Transcript Details

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Understanding the Caregiver Burden in TK2 Deficiency: New Insights from a Study

Announcer:
You're listening to *Clinician's Roundtable* on ReachMD, and this episode is supported by UCB. Here's your host, Dr. Charles Turck.

Dr. Turck:
This is *Clinician's Roundtable* on ReachMD, and I'm Dr. Charles Turck. Here with me today to share the key findings from his study examining the impacts of caring for those with thymidine kinase 2 deficiency, or TK2d for short, is Dr. Philip Yeske. He's the United Mitochondrial Disease Foundation Science and Alliance Officer. Dr. Yeske, welcome to the program.

Dr. Yeske:
Great to be with you today, Dr. Turck.

Dr. Turck:
Well, why don't we get started by taking a high-level look at TK2d. Would you give us a little bit of background on this rare disease and what clinicians should know to lay the groundwork for discussing the study you conducted?

Dr. Yeske:
Yeah, sure. TK2 deficiency is one of hundreds of types of mitochondrial disease. It happens to be a mitochondrial DNA depletion syndrome. Phenotypically, we would generally describe it as a relentlessly progressive form of mitochondrial disease that impacts the patient's ability to walk, eat, talk, and breathe. Onset can occur very early in life or even later in life, into adolescence or adulthood. And the forms of the disease are quite different depending on age of onset.

So when we started this, it was based on the desire as a patient advocacy group to really understand the caregiver perspective as much as the patient perspective when it comes to TK2 deficiency.

Dr. Turck:
So now getting to the topic at hand, Dr. Yeske, what was the primary objective of this research, and how did your study's design reflect that?

Dr. Yeske:
Ultimately, the study aimed to explore the lived experience of caregivers for individuals with TK2 deficiency, a population that previously was underrepresented in the literature. So we saw an opportunity to really fill this gap in understanding the caregiver perspective as much as the patient perspective.

And to do that effectively, we knew that as patient advocates, we needed to partner with clinicians to ensure the rigor of the study. So in close collaboration with clinicians taking care of mitochondrial disease patients, we developed a mixed methods online survey, collecting both quantitative and qualitative data. And ultimately, we stratified the results based on age of onset of the symptoms and developmental age group.

Dr. Turck:
And with that background in mind, let's jump to the results. When it comes to the intensity of caregiving, how extensive were the time-related and physical demands that participants reported?

Dr. Yeske:
Yeah, these data really jumped out at us right away. Nearly 70 percent of the respondents to the surveys reported spending 75 hours or

more per week providing care for the patient in their household. Nearly 1/2 of them spent more than 100 hours per week. So I think immediately, you get a sense of the degree of burden associated with taking care of a patient with TK2 deficiency.

Not surprisingly, the support was especially intensive for those patients that had the most severe symptoms associated with it. And if they had medical equipment that they required as part of, perhaps, a breathing perspective, this added to the level of support required. And then care coordination, right? The need to coordinate with multiple specialists, healthcare providers, etc., adds hours on top of what we captured just under providing care.

Dr. Turck:
Now, when caregivers were asked to rate how caregiving affected their quality of life, they reported negative effects across all domains. So if we zero in on each one individually and start with physical health, what notable patterns did you see in caregiver health outcomes?

Dr. Yeske:
Again, the data really jumped out at us when we sat down to analyze it. 63 percent reported negative physical impacts that could range from reduced self-care, sleep deprivation, low energy, and even injuries from caregiving tasks. So this—when tied together with the time involved with it—really paints a picture of a high degree of burden for these caregivers.

Dr. Turck:
For those just tuning in, you're listening to *Clinician's Roundtable* on ReachMD. I'm Dr. Charles Turck, and I'm speaking with Dr. Philip Yeske about his research on the challenges of caring for those with thymidine kinase 2 deficiency, or TK2d.

So let's continue parsing through these findings, Dr. Yeske, and talk about how caregiving can affect personal relationships and emotional well-being. What did the study reveal there?

Dr. Yeske:
It could have been a number of findings inside of this. First off, relationship strain—more than 1/2 of the caregivers who participated in the study reported relationship strain with friends and over 40 percent with family and spouses. So it's not just between the patient and the caregiver; it clearly moves out to that next ring of direct family and then out to friends as well.

Mood was definitely impacted as a result of the burden, chronic stress, burnout, helplessness, and feeling of exhaustion all reported by these caregivers. It was especially high for caregivers who unfortunately had to witness their loved one declining in front of them.

Dr. Turck:
Now, another area that stood out in this study was financial and employment impact. So how did caregiving affect those domains?

Dr. Yeske:
Yeah, 75 percent of the participants in the study reported financial hardship at some level. That could range from reduced work capacity to high care-related expenses, but the financial burden definitely came through in the data. Half of the caregivers had to reduce their hours of work, change jobs, or even stop working entirely in order to meet the care demands of the loved one that they're helping to take care of.

Dr. Turck:
Were there any recurring concerns from caregivers about unmet needs, either in day-to-day care or looking ahead to the future?

Dr. Yeske:
Yeah, not surprisingly, right? First and foremost, there were concerns around their loved one, the disease progression, and seeing their loved one regressing right in front of them—so uncertainty about the future for their loved one, uncertainty about the future care and what it might require if the disease becomes worse, and lack of access to equipment and resources. As I mentioned, it's a huge financial burden as well.

About 70 percent of the caregivers reported worrying about the future in some way, especially regarding access to treatment, funding, or even transitioning from pediatric to adult care. These were all aspects that were reported by the caregivers. Some of these caregivers relied on personal networks and donations just to meet basic care needs. So it really paints a picture of a family under stress.

Dr. Turck:
And lastly, Dr. Yeske, given all these findings, what were the key takeaways for clinicians and rare disease stakeholders who support families affected by TK2d?

Dr. Yeske:
Yeah, I think ultimately, this study highlights that caregiver support isn't ancillary or secondary in any way; it's really central to rare

disease care. That's an important finding, and one we absolutely intend to extend across other forms of mitochondrial disease. But within the TK2d community, central to the care was caregiver burden and caregiver support.

We definitely were able to identify the need for comprehensive and family-centered interventions that address both clinical and psychosocial needs. That came out very clearly in the data. And ultimately, I would say it just represents a clear opportunity for earlier diagnosis, coordinated care models, and the development of resources tailored to caregiving realities.

So it was an important study with important findings, and we're thrilled to be able to participate in it.

Dr. Turck:
Well, with those parting thoughts in mind, I want to thank my guest, Dr. Philip Yeske, for joining me to discuss how supporting those with thymidine kinase 2 deficiency can impact caregivers. Dr. Yeske, it was great having you on the program.

Dr. Yeske:
Thank you. My pleasure.

Announcer:
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