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Pediatric advance care planning linked to better understanding of child's end-of-life care choices

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Maureen E. Lyon, Ph.D., ABPP, a clinical health psychologist at Children's National Health System and the study's lead author. Credit: Children's National

Health System

WASHINGTON-The more that families understand the end-of-life treatment preferences expressed by adolescents living with human immunodeficiency virus (HIV), the less likely these youth are to suffer HIV-related symptoms compared with youths whose families do not understand their end-of-life care goals, according to a single-blinded, randomized study published online Oct. 19, 2018, in *Pediatrics*. And when families struggle to understand their child's end-of-life care choices, that is associated with a higher likelihood of HIV-positive adolescents suffering physical symptoms, including pain.

While overall new HIV infections dropped in Washington from 2013 to 2017, there was an increase in new HIV diagnoses among young people aged 13 to 29, according to DC Health. And despite the advent of highly effective medications, U.S. youth living with HIV/AIDS are six to 12 times more likely to die than the general public, the new research paper notes.

In that study, a multi-institutional research team spent five years quantifying the relationship between FAmily CEntered (FACE) pediatric advance care planning and HIV-specific symptoms experienced by youths, building on earlier results from a small randomized trial. From July 2011 to June 2014, they enrolled 105 HIV-positive youth receiving treatment at HIV clinics based at six U.S. hospitals and their families.

The patients' mean age was 17.8 years (range 14 to 21 years). Fifty-four percent were male; 93 percent were African American; 55 percent had viral suppression. Family member's mean age was 45. Eighty-two percent were female, and 90 percent were African American. One-third of family participants reported being HIV-positive themselves.

The patients and families received three, 60-minute FACE sessions weekly that included completing an advance care planning survey, having conversations about care goals in order to create advance care plans using the adapted "Next Steps: Respecting Choices" interview and by discussing the "Five Wishes" document.

End-of-life treatment preferences included:

- Continuing all treatment to live as long as possible (e.g., staying alive is most important to me, no matter what)
- Stopping efforts to keep the individual alive (e.g., living well is more important than life span) and
- Unsure.

"Controlling for age, parental education, family income and other variables, family members who participated in FACE were more likely to understand their child's end-of-life care goals, which significantly reduced the adolescents' physical symptoms, like pain, up to 12 months later," says Maureen E. Lyon, Ph.D., ABPP, a clinical health psychologist at Children's National Health System and the study's lead author. "A greater degree of familial understanding suggests good communication and social support, which already has been demonstrated to decrease HIV-specific symptoms in adults."

According to the research team, participating in pediatric advance care planning conferred a sense of control for youths living with HIV, which is associated with reduced physical symptoms, especially pain. Two mechanisms exerted a particularly powerful effect, Lyon adds: Satisfying social support by way of respectful and authentic conversations and making choices about treatments with parental support when outcomes were poor, such as facing the prospect of lengthy hospitalization, multiple procedures and a slim chance of survival.

"Our results underscore the potential to improve patients' quality of life by offering pediatric advance care planning in HIV clinics based at pediatric hospitals," Lyon says. "In addition, these findings could inform best practices for caring for pediatric patients who are contending with other serious, life-threatening illnesses."

In future research, the team will explore why families who were highly religious correlates with a higher likelihood of youths experiencing more HIV-specific symptoms. They assessed the health-relevant domains of religiousness/spirituality by using a validated tool to ask such questions as whether the family member feels "God's presence," how often they prayed privately or attended religious services, and whether they considered themselves to be a religious or spiritual person.

Provided by Children's National Medical Center

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