Who Will Speak for Me? Disparities in Palliative Care Research with “Unbefriended” Adolescents Living with HIV/AIDS

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Abstract

Objective: To report a finding of a severe lack of social support with potential for serious harm during the course of a pediatric advanced care planning study.

Method: A longitudinal, single-blinded, multisite randomized controlled trial, conducted in six pediatric hospital-based HIV-clinics, located in high HIV mortality cities.

Results: Between July 2010 and June 2014, 366 adolescents aged 14 to 21 years with HIV/AIDS were approached for participation. From among 125 ineligible adolescents living with HIV/AIDS, 62 (50%) were ineligible because they could not identify a surrogate decision-maker they trusted enough to make end-of-life decisions for them, if they were unable to do so for themselves.

Conclusion: Healthy People 2020’s goal of increasing the proportion of adolescents connected to a trusted adult with whom they can talk about serious problems is unmet among adolescents living with a serious illness.

Discussion: Ethical concerns for justice, dignity, and access to health services are raised as adolescents who most need support in future medical decision making are least likely to have this support.

Keywords: HIV; pediatric advanced care planning; stigma

Introduction

ADVANCED CARE PLANNING (ACP), one dimension of palliative care, focuses on improving quality of life for persons of any age who are living with any serious illness and their families by using advanced communication skills to establish goals of care.¹ A pediatric ACP (pACP) process seeks to help adolescents with chronic or life-limiting illnesses identify a surrogate decision-maker who would speak for them if they could not speak for themselves; and to engage in facilitated goals of care conversation with their surrogate decision-maker about their treatment preferences, if there were to be a bad outcome situation. The process of pACP offers the hope of a higher quality of life, improved commu-

nication, spiritual and emotional support, increased well-being, dignity, a reduction in symptoms, and increased medication adherence.^{2,3}

The Centers for Disease Control and Prevention estimates 1,218,400 persons aged 13 years and older are living with HIV infection in the United States⁴ with significant racial disparities in morbidity and mortality.^{5–7} In 2013, 109 youth aged 15 to 24 years died of HIV or AIDS in the United States.⁸ These deaths are geographically clustered in the DC/Baltimore metropolitan area and in southern states.^{4,5,9,10} Treatment failure makes pACP especially relevant in this already disadvantaged population.^{11,12} In this article we report on a finding of a severe lack of social support during the course of a longitudinal multisite randomized clinical trial of pACP.

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Methods

Between July 2010 and June 2014, 366 potentially eligible adolescents living with HIV were approached in six hospital-based outpatient HIV specialty clinics to participate in a pACP intervention. English-speaking adolescents ≥ 14 to < 21 years of age were eligible if they had been diagnosed with HIV, and their legal guardian(s), (for youth under age 18), or their chosen surrogate decision-maker (for youth age 18 or older) agreed to participate with them. Legal guardians or surrogates were 18 years of age or older. To be eligible, all adolescents in this study had to identify a legal guardian or a surrogate decision-maker whom they trusted enough to make end-of-life decisions for them, if they could not speak for themselves. The protocol was approved by the study sites' Institutional Review Boards (IRB). The results reported here are from the recruitment and enrollment phase of the pACP randomized controlled clinical trial.¹³

Patients were recruited by trained research assistants (RAs) who approached participants face-to-face in a private clinic room, after confirming initial eligibility and appropriateness with the treating physician. The RA told potential participants that other adolescents had told us they wanted to have a voice in their future medical care, if they could not speak for themselves.³ The RA then asked if this was something that interested them. If yes, an IRB-approved Information Sheet was used to describe the study. The RA then let the adolescent know that if they were under the age of 18 their legal guardian would also need to participate; or if ages 18 up to 21 years that they could choose the person they wanted to speak for them, if they could not speak for themselves. The RAs also offered to speak to the surrogate directly, if the adolescent preferred. Guidelines from the Disease Specific ACP^{®14} and from the Washington, D.C., Family Ties Project for choosing a surrogate decision-maker were used. We asked them to consider these criteria in choosing a surrogate: (1) Is the person willing to be a surrogate? Sometimes even the most trusted and loving people would find this role very difficult. (2) Do you trust the person to know your views and be willing to talk with you? (3) Is the person able to follow through and honor your wishes, even if they might not agree with your choices? (4) Can the person make decisions under sometimes stressful and difficult situations?

Results

Of the 326 individuals screened for participation between July 2011 and June 2014, 218 were excluded. Of those excluded, 93 patients declined, 35 were interested but not ready to participate, and 90 did not meet the inclusion criteria. Of those who were excluded for reasons other than declining (e.g., screening failure), 50% (62/125) were ineligible due to failure to identify a surrogate decision-maker whom they trusted enough to make medical decisions for them.

Discussion

Half of potentially eligible adolescents were unable to identify a surrogate decision-maker; that is, a trusted person who will be called upon to make healthcare choices for them if unable to speak for himself or herself in a medical crisis.

This incidental, but important, finding indicates a significant health disparity with access to pACP. This health disparity was not found in a similar pACP study of adolescents living with cancer, in which not a single adolescent was excluded for failure to identify an adult who could make end-of-life decisions for them.¹⁵ Because this finding surfaced in the middle of our research, we did not collect demographic data on these unsupported adolescents. We can simply document the existence of a disparity without knowing why.

Why are these adolescents unable to identify surrogate decision-makers? Possible explanations include HIV stigma and the associated failure to disclose HIV status to people who might be able to support them. For those adolescents who did participate in this study's pACP intervention, the question from the structured interview, "How has HIV changed your life?" often triggered the response that they never really have a best friend, because of keeping their HIV diagnosis a secret. No cancer patient responded in this way to the same question. Stigma associated with HIV leads to social isolation,¹⁶ narrowing the pool of potential surrogate decision-makers. An additional contribution to this sense of being alone may be the product of the increased social challenges our adolescent HIV-infected patients often face: sexual abuse, violence exposure, and neglect.¹⁷ Research is needed to determine whether for these youth, traumatic childhood experiences makes it difficult to trust people in general, and sex partners in particular, which in turn may be associated with earlier death, as has been found with adults.¹⁸

The impact of this isolation can be significant. For instance, parental absence from clinic visits predicts HIV treatment failure in adolescence,¹⁹ consistent with research on the link between strong social support for patients and the receipt of high quality reliable healthcare for chronic diseases.^{20,21} We do not know, however, if this "unbefriended" group represents youth who did not have supportive family relationships. Further research is needed.

The Institute of Medicine 2015 report, *Dying in America*, emphasizes the need for physicians and institutions to have clear guidance on how to handle the care of "unbefriended" patients; patients lacking a surrogate decision-maker. Furthermore, the report clearly states that having a health professional make decisions about their healthcare for an "unbefriended" patient is ethically unsatisfactory in terms of protecting patient autonomy and establishing transparency.²² Additionally, The Palliative and End of Life Care Expert Panel of the American Academy of Nursing has declared developmentally appropriate end-of-life conversations an essential element in the care of pediatric patients, especially those who are adolescents.² Without these conversations patient care is compromised and the opportunity to have thorough and thoughtful consideration of the patient's preferences is prevented.²³ Collaboration is needed in the healthcare community to close this health disparity gap.²⁴ Access to a trusted and capable surrogate in order engage in pACP is most crucial in high need and vulnerable populations.^{25,26}

Healthy People 2020 has set a goal of increasing to above 80% the proportion of adolescents who are connected to a trusted adult with whom they can talk about serious problems.²⁷ Closing this disparity in the pACP process, when no trusted surrogate decision-maker or legal guardian is identified by an adolescent interested in participating in pACP, would be relevant to achieving this goal. So that this health

disparity does not persist as the Healthy People 2020 goal is achieved, we recommend pACP research opportunities and programs be used to: (1) market pACAs public health efforts to promote the value of pACP in vulnerable populations; (2) implement evidence-based pACP intervention models to reach vulnerable populations; (3) de-stigmatize HIV and commitment to civil rights enforcement²⁸; and (4) identify ways, such as “a treatment buddy” or the appointment of a “guardian ad litem” (a person the court appoints to investigate what solutions would be in the “best interests of a child”) or care managers, to support “unsupported” adolescent patients, so we can expand access to pACP and remove barriers to quality healthcare for adolescents who are HIV positive. In conclusion, pACP for adolescents living with HIV and other serious illnesses is a public health issue given its potential to prevent unnecessary suffering, as well as to support an individual’s decisions and preferences related to medical treatment preferences and end-of-life care. The Centers for Disease Control and Prevention recognize the public health opportunity to educate the American population about pACP and to improve their quality of life at the end of life.^{29–32} Unsupported adolescents living with HIV are deprived of this opportunity—an issue of justice and a health disparity.

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Clinical Trial Registration

Trial name-Longitudinal Pediatric Palliative Care: Quality of Life & Spiritual Struggle. Registered at www.clinicaltrials.gov Identifier # NCT01289444.

Author Disclosure Statement

No competing financial interests exist.

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