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Measuring Youth Health Engagement: Development of the Youth Engagement With Health Services Survey

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A B S T R A C T

Purpose: The purpose of this study was to create and validate a survey instrument designed to measure Youth Engagement with Health Services (YEHS!).
Methods: A 61-item YEHS! survey was created through a multistaged process, which included literature review, subject matter expert opinion, review of existing validated measures, and cognitive interviewing with 41 adolescents in Colorado and New Mexico. The YEHS! was then pilot tested with a diverse group of high school students (n = 354) accessing health services at one of eight school-based health centers in Colorado and New Mexico. We conducted psychometric analyses and examined correlations between the youth health engagement scales and measures of quality of care.
Results: We created scales to measure two domains of youth health engagement: health access literacy and health self-efficacy. The youth health engagement scales demonstrated strong reliability (Cronbach's α .76 and .82) and construct validity (mean factor loading .71 and .76). Youth health engagement scores predicted higher experiences of care scores ($p < .001$) and receipt of more anticipatory guidance ($p < .01$).
Conclusions: This study supports the YEHS! as a valid and reliable measure of youth health engagement among adolescents using school-based health centers. We demonstrate an association between youth health engagement and two quality of care measures. Additional testing is needed to ensure the reliability and validity of the instrument in diverse adolescent populations.

IMPLICATIONS AND CONTRIBUTION

This article presents the development and validation of a new survey instrument that measures youth health engagement. We report the association between youth health engagement and measures of adolescent health care quality. This survey may be useful in studies evaluating adolescent health care experiences.

Changes in the health care delivery system, including an emphasis on cost-effective and high-quality outpatient care and patient-centered options for the treatment of chronic conditions, have resulted in increasing expectations that patients be engaged with their own health care [1–4]. Patients who are more involved in their care are more satisfied with the care they receive and have better outcomes [3,5–7]. Patients with more health knowledge (health literacy) and who are involved in the decision-making about their treatment options are more likely to adhere to medication and treatment plans, resulting in better management of health conditions [1,7–9].

Conflicts of Interest: The authors have no conflicts of interest to disclose.

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However, the field of patient engagement is relatively new, and research to date has centered on adults, more specifically those with chronic conditions [5,7,9,10]. Even for adults, relatively few studies exist dealing with key aspects of engagement, including its conceptualization and measurement [1,2,11,12], implementation of engagement strategies [7,9,13–15], and the connection between engagement and health outcomes [3,5,8,16,17]. There is a growing interest in expanding these concepts to youth, including provision of youth-friendly services [18–20] and engaging youth productively in their own care [10,21–23]. To support this direction in the provision of services to youth, we need a tool to measure youth engagement with their health care.

To fill this gap, we developed a scale to measure levels of engagement of adolescents with their health care. This scale is included in a survey that also includes measures of health care utilization, experiences with care, health risks, and receipt of anticipatory guidance. The intent was that the resulting instrument could be used not only to assess engagement with services but also to relate this engagement to other aspects of care. This was done as part of the school-based health center (SBHC) improvement project in Colorado and New Mexico, which is 1 of the 10 national demonstration projects funded through the Children's Health Insurance Program Reauthorization [24].

The purpose of this article is to describe the development of the youth health engagement scale. The results indicate that the items developed to measure youth health engagement are valid and reliable measures of this construct within the adolescent populations in which it was tested.

Methods

Ethical review

The study was approved by the Human Research Protections Office of The University of New Mexico Health Sciences Center and Cincinnati Children's Hospital Medical Center.

Conceptualizing patient engagement for adolescents

Patient engagement has been defined as "actions individuals must take to obtain the greatest benefit from the health care services available to them" and focuses on the behaviors of individuals, rather than the actions of professionals or policies of institutions [1]. The most well-known measurement of patient engagement is Hibbard's *patient activation measure* [12], which identifies and measures four components of patient activation: locus of control (or the belief that the patient is responsible for and can affect their own health); knowledge (of health and health problems); confidence (in the patient's own ability to manage their health, interact effectively with providers, and adhere to treatment plans); and action (the extent to which the patient is adhering to treatment plans). These four components were later used as the basis for Gruman et al.'s [1] comprehensive list of engagement behaviors. Central to both of these conceptualizations of engagement are elements of seeking health care and health information, working in partnership with providers, managing one's own health care (i.e., keeping appointments and making lists of questions), and health-promoting behaviors (including treatment adherence, preventive care, and adoption of healthy habits). Measuring the health engagement of *adolescents* requires a conceptualization of the health-engaged young person, which takes into account adolescents' developmental stage and recognizes adolescents' growing knowledge base and emerging abilities to communicate and advocate for their own needs.

A similar construct that has been discussed in the literature is that of transition readiness, which focuses on the ability of adolescents with special health care needs to effectively make the transition from pediatric to adult care and from care managed by a parent or caregiver to management of their own care [25,26]. Measures of self-efficacy and disease-specific literacy have been included in tools developed to measure transition readiness [25,26]. However, similar to other tools measuring aspects of engagement, these tools have been developed for patients with chronic conditions or special health care needs. Presumably, adolescents without special health care needs also struggle with the transition from pediatric to adult care, and many of the same skills and knowledge to effectively do so are required.

Based on the components of patient engagement found in the literature, we conceptualized *youth health engagement* as being composed of health access literacy (knowledge) and health self-efficacy (incorporating elements of self-advocacy, effective communication with providers, and ability to follow through on plans made with providers). We developed items intended to measure these two components of youth health engagement and hypothesized that these components would correlate with one another, as measures of one underlying construct (youth health engagement), and with measures of quality of care, including adolescents' ratings of their experience of care and reported receipt of anticipatory guidance.

Instrument development

The Youth Engagement with Health Services (YEHS!) survey instrument includes several components, including the youth health engagement scale as well as measures of experiences with health care, reported receipt of anticipatory guidance, and demographic information. To measure experiences of care, we included five items from the Experiences of Care Scale, developed for the Consumer Assessment of Healthcare Providers and Systems survey [27]. To measure the receipt of recommended anticipatory guidance, we created survey items that were based (with permission) on the American Academy of Pediatrics Bright Futures Guidelines and the Young Adult Health Care Survey [28,29]. We included four topical domains from Bright Futures Guidelines: physical growth and development; academic and social competence; emotional well-being; and sexual health risk reduction, as these domains corresponded to our Children's Health Insurance Program Reauthorization grant improvement areas [24].

Developing the youth health engagement scale items for the YEHS! survey involved multiple steps to operationalize the constructs, including a review of existing literature on health literacy, health self-efficacy, and patient engagement; subject matter expert opinion; focus groups with youth to assess face and content validity; and analysis of data from the pilot administration of the survey.

Survey items measuring health access literacy include items related to knowledge of where to get care, health insurance, and confidential services. Items measuring health self-efficacy include those related to accessing care, working in partnership with health care providers, and carrying out plans made with a provider.

Cognitive testing

In the winter of 2012, a draft of the survey was administered with five groups of adolescents in Colorado and New Mexico. All