

Original article

# Psychologists and the Transition From Pediatrics to Adult Health Care



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Wendy N. Gray, Ph.D.<sup>a</sup>, Maureen C. Monaghan, Ph.D.<sup>b</sup>, Jordan Gilleland Marchak, Ph.D.<sup>c</sup>, Kimberly A. Driscoll, Ph.D.<sup>d</sup>, and Marisa E. Hilliard, Ph.D.<sup>e,\*</sup>

<sup>a</sup> Department of Psychology, Auburn University, Auburn, Alabama

<sup>b</sup> Center for Translational Science, Children's National Health System, Washington, District of Columbia

<sup>c</sup> Department of Pediatrics, Emory University School of Medicine, Atlanta, Georgia

<sup>d</sup> Department of Behavioral Sciences and Social Medicine, Florida State University College of Medicine, Tallahassee, Florida

<sup>e</sup> Department of Pediatrics, Baylor College of Medicine, Houston, Texas

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# ABSTRACT

**Purpose:** Guidelines for optimal transition call for multidisciplinary teams, including psychologists, to address youth and young adults' multifactorial needs. This study aimed to characterize psychologists' roles in and barriers to involvement in transition from pediatric to adult health care. **Methods:** Psychologists were invited via professional listservs to complete an online survey about practice settings, roles in transition programming, barriers to involvement, and funding sources. Participants also responded to open-ended questions about their experiences in transition programs.

**Results:** One hundred participants responded to the survey. Involvement in transition was reported at multiple levels from individual patient care to institutional transition programming, and 65% reported more than one level of involvement. Direct clinical care (88%), transition-related research (50%), and/or leadership (44%) involvement were reported, with 59% reporting more than one role. Respondents often described advocating for their involvement on transition teams. Various sources of funding were reported, yet, 23% reported no funding for their work. Barriers to work in transition were common and included health care systems issues such as poor coordination among providers or lack of a clear transition plan within the clinic/institution.

**Conclusions:** Psychologists assume numerous roles in the transition of adolescents from pediatric to adult health care. With training in health care transition-related issues, psychologists are ideally positioned to partner with other health professionals to develop and implement transition programs in multidisciplinary settings, provided health care system barriers can be overcome. © 2015 Society for Adolescent Health and Medicine. All rights reserved.

#### IMPLICATIONS AND CONTRIBUTION

Psychologists contribute to the process of transitioning adolescents with chronic health or mental health needs from pediatric to health adult care in numerous ways via clinical, research, and leadership roles. Findings highlight the diverse contributions, funding strategies, and experienced by barriers psychologists in supporting transition efforts.

The process of transitioning from pediatric to adult health care has garnered increasing attention as a result of the growing number of children with chronic conditions who now exceed previous shortened life expectancy estimates. Given

E-mail address: marisa.hilliard@bcm.edu (M.E. Hilliard).

recommendations that transition processes should be purposeful and planned [1], the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians [2] issued a joint clinical report summarizing expert and consensus opinions about transition including an algorithm and steps that are critical to transition success: creating a clear timeline for transition with discussions beginning in early adolescence, discussing the medical home transition policy, initiating the transition plan developed, reviewing/updating

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

<sup>\*</sup> Address correspondence to: Marisa E. Hilliard, Ph.D., Department of Pediatrics, Baylor College of Medicine, Feigin Center, 1102 Bates Avenue, Suite 940, Houston, TX 77030.

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the transition plan as needed, and implementing an adult-care model. The development and implementation of transition plans are essential to continuity of care, particularly because adolescents and young adults are extremely vulnerable during this time and declines in health outcomes are extremely common [3]. Ideal models of transition support include a multidisciplinary team comprised of pediatric and adult physicians and nurses, psychologists, and other essential team members such as educators and dieticians [4], occuring in the context of health care systems that support and promote transition [5].

Pediatric oncology provides one model for the integration of psychologists into multidisciplinary pediatric medical teams. However, even in this subspecialty where pediatric psychologists have made remarkable contributions in a variety of areas (e.g., coping; treatment adherence; managing procedural pain, nausea, and other symptoms; understanding and reducing neuropsychological effects), their focus in the area of transition has traditionally been the transition to palliative care and bereavement, with less focus on the transition from pediatric to adult medical care [6]. Indeed, across many medical and psychiatric conditions affecting youth, very little is known about the roles that psychologists play in the transition process as most of the extant literature has focused on describing models and strategies of care [3,7], creating standardized measures of transition [8,9], and assessing patient readiness to transition within specific diseases [4,10,11].

Psychologists have expertise in developmental and behavioral issues highly relevant to transition of care, such as adherence and health behavior change, patient—provider communication, patient self-advocacy skills, and developmental considerations relevant to the adolescent and young adult period [12]. In fact, psychologists conduct much research, clinical, and policy work related to transition readiness and transition programs across a number of health and mental health conditions [13–21]. Despite these qualifications, to our knowledge, there are no studies documenting or describing the roles that psychologists have in the planning and implementation of transition models.

Therefore, the purpose of this study was to characterize psychologists' various roles and types of involvement in transition care, including roles and responsibilities in transition care, levels of involvement from individual care to high-level transition programming, collaboration with other disciplines on transition teams, the health and mental health populations with the greatest involvement of psychologists in transition, and barriers to involvement in transition efforts.

## Method

#### Procedure

The present study was approved by the governing institutional review board at the institution hosting the survey; institutional review board approval was also obtained from each of the authors' institutions, when required. To capture a broad cross-section of psychologists involved in transition care, a brief description of the study and an invitation to participate were distributed via listservs whose membership included primarily U.S.-based adult or child psychologists who were most likely to be involved in transition-related work. This included select divisions of the American Psychological Association (Society of Pediatric Psychology, Health Psychology, and Association of Psychologists in Academic Health Centers) and the Society of Behavioral Medicine. All psychology professionals, including masters- and doctoral-level trainees, were eligible for participation. Interested participants were invited to click a link within the e-mail, which provided a brief description of the study and requested their voluntary participation. As this was online work, completion of the survey was considered implied consent. Those who were willing to participate were directed to a brief online anonymous survey hosted via a secure, Web-based application designed to support data capture for research studies (Research Electronic Data Capture; REDCap, http://project-redcap.org/) [22]. Two self-report screening questions, which confirmed the respondent's identity as psychologist or psychology trainee and their involvement in transition work, were used to determine eligibility. No compensation was provided.

# Measures

An 18-item survey assessing psychologists' involvement in transition care was developed for this study by the study investigators; all of whom have a background in transition research and/or clinical care (Supplementary Material for a copy of the full survey). Survey questions were guided by the existing transition literature and authors' expertise, and focused on characterizing the participants' involvement in transition care, including practice settings (e.g., children's hospital), roles and responsibilities in transition care (e.g., clinical, research, and leadership), involvement of other medical disciplines in transition (e.g., physicians), patient populations worked with (e.g., ages, medical, and/or psychiatric conditions), and barriers to their involvement in transition efforts. In addition, participants were asked to rate their institutional culture with regard to transition using a 1 (not a focus, no investment) to 100 (full investment) scale. Sociodemographic information was also collected. Participants reporting direct involvement in transition programs in clinical, research, and/or leadership roles were invited to complete the full survey. Those not reporting current involvement completed an abbreviated version of the survey, which assessed barriers experienced to participation in transition efforts and demographic information.

#### Data analytic plan

Descriptive statistics were used to characterize the study sample and survey responses. When appropriate, data were analyzed separately for participants actively involved in transition work compared with those who were not involved. The criterion level of significance was set to p < .05. Free-text responses provided by participants were extracted and coded using conventional thematic content analyses [23]. Two of the study authors independently reviewed, analyzed, and coded all responses to identify key themes and create labels that reflected the thematic content. Any coding discrepancies were discussed, and a final code was agreed on by both coders and the full study team.

## Results

#### Sample characteristics

One hundred five surveys were initiated. Five were excluded (one ineligible, four incomplete data), resulting in a sample of 100. Seventy-seven were directly involved in tasks related to transition and completed the full survey. Those not directly Download English Version:

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