

Family Perspectives on High-Quality Pediatric Subspecialty Referrals



Kristin N. Ray, MD, MS; Laura Ellen Ashcraft, MSW; Jeremy M. Kahn, MD, MS; Ateev Mehrotra, MD, MPH; Elizabeth Miller, MD, PhD

From the Departments of Pediatrics (Drs Ray and Miller), Critical Care Medicine (Ms Ashcraft and Dr Kahn), University of Pittsburgh School of Medicine, Children's Hospital of Pittsburgh (Drs Ray and Miller), Department of Health Policy and Management (Dr Kahn), University of Pittsburgh Graduate School of Public Health, Pittsburgh, Pa; and Department of Health Care Policy and Medicine (Dr Mehrotra), Harvard Medical School and RAND Corporation, Boston, Mass

The authors have no conflicts of interest to disclose.

Address correspondence to Kristin N. Ray, MD, MS, Children's Hospital of Pittsburgh, 3414 Fifth Ave, CHOB, 3rd Floor, Pittsburgh, PA 15213 (e-mail: Kristin.Ray@chp.edu).

Received for publication January 29, 2016; accepted May 20, 2016.

ABSTRACT

OBJECTIVE: Although children are frequently referred to subspecialist physicians, many inadequacies in referral processes have been identified from physician and system perspectives. Little is known, however, about how to comprehensively measure or improve the quality of the referral systems from a family-centered perspective. To foster family-centered improvements to pediatric subspecialty referrals, we sought to develop a framework for high-quality, patient-centered referrals from the perspectives of patients and their families.

METHODS: We used stakeholder-informed qualitative analysis of parent, caregiver, and patient interviews to identify outcomes, processes, and structures of high-quality pediatric subspecialty referrals as perceived by patients and their family members.

RESULTS: We interviewed 21 informants. Informants identified 5 desired outcomes of subspecialty referrals: improved functional status or symptoms; improved long-term outcomes; improved knowledge of their disease; informed expectations; and reduced anxiety about the child's health status. Processes

that informants identified as supporting these outcomes centered around 6 key steps in subspecialty referrals, including the referral decision, previsit information transfer, appointment scheduling, subspecialist visit, postvisit information transfer, and ongoing care integration and communication. Health care delivery structures identified by informants as supporting these processes included physical infrastructure, human resources, and information technology systems.

CONCLUSIONS: We identified family-centered outcomes, processes, and structures of high-quality pediatric subspecialty referrals. These domains can be used not only to improve measurement of the quality of existing referral systems but also to inform future interventions to improve patient-centered outcomes for children in need of specialty care.

KEYWORDS: consultation; family-centered; outcomes; patient-centered; pediatric; quality; referral; specialty; subspecialty

ACADEMIC PEDIATRICS 2016;16:594–600

WHAT'S NEW

Little is known about family-centered perspectives on pediatric subspecialty referral systems. Through stakeholder-guided, qualitative analysis of parent, caregiver, and patient interviews, we identified family-centered outcomes, processes, and structures of high-quality pediatric subspecialty referrals.

SUBSPECIALTY CARE IS crucial to the health and well-being of many children, especially because of rising rates of chronic illness in the pediatric population.¹ Despite the importance of subspecialty consultation, primary care providers (PCPs) and subspecialists identify numerous frustrations and inefficiencies with subspecialty referrals.² Multiple studies show inadequate transfer of information between PCP and subspecialist, lack of coordination of care between PCP and subspecialist, and conflicting expectations regarding patient comanagement.^{2–5}

Although such previous work identified clear targets for improvement in subspecialty referrals from the viewpoint of PCPs and subspecialists, less is known about the viewpoint of patients and families, particularly regarding the overall experience of subspecialty care. Previous studies have focused on parent perspectives of specific aspects of subspecialty referrals, such as information exchange, shared decision-making, and continuity of care,^{6–8} but have not examined the broader experiences and preferences of families receiving subspecialty care. Related to this, in a recent systematic review it was reported that most measures in studies of subspecialty referrals focused on referral initiation, subspecialist accessibility, and appointment attendance rather than patient experiences, patient satisfaction, or health outcomes,⁹ indicating that family perspectives also received little weight in previous evaluations of subspecialty referrals. The Patient Centered Outcomes Research Institute and others have emphasized the importance of

family perspectives in identifying appropriate patient and family-centered measures and defining value in pediatric health care systems.^{10–13} To ensure future health care system interventions lead to patient-centered improvements, it is important to understand referral quality from the perspectives of patients and their families, who are uniquely positioned to benefit from, or be harmed by, the referral experience.^{10–13} Without such knowledge, health care systems seeking to improve the quality of subspecialty referral systems risk developing interventions that are poorly informed and targeting end points that are not maximally relevant to patients and families.

To address this knowledge gap, we sought to identify the aspects of subspecialty referral systems that define a high-quality referral experience from the perspective of patients and families. Using stakeholder-guided semistructured interviews, we elicited family experiences of successful and unsuccessful subspecialty referrals. On the basis of qualitative analysis of the interview transcripts, we identified family-centered outcomes, processes, and structures associated with high-quality pediatric subspecialty referrals and developed a family-centered conceptual model for use in future quality improvement and research initiatives.

METHODS

We examined family experiences of subspecialty referrals through qualitative analysis of family member interviews (including parents, caregivers, and patients) informed by a stakeholder advisory group. Using recommended best practices for engaging stakeholders as research collaborators,^{14,15} we assembled a group of 6 individuals representing patients, parents/caregivers, providers, and payers, including individuals who self-identified as living in communities with poor access to pediatric subspecialty care. The purpose of this group was to optimize the relevance and interpretability of this work for a range of stakeholders. Stakeholders were consulted throughout the research process, guiding development of the interview guide, recruitment of participants, interpretation of results, and dissemination of findings.

We developed the interview guide through an iterative process informed by previous models of subspecialty care^{2,9,16} and refined through multiple discussions with our stakeholder advisory group and through pilot interviews. Interview guide domains included positive and negative experiences with subspecialty referrals, perceived benefits and costs of subspecialty referrals as well as patient and parent/caregiver decision-making around subspecialty referrals. The interview guide was targeted to an interview length of between 30 and 60 minutes. A copy of the parent interview guide, which was modified for adolescents and young adults, is provided in [Supplementary Appendix 1](#). Individual interviews were conducted by telephone from March 2015 to September 2015.

Subjects were recruited through an existing practice-based research network, Pediatric PittNet, which consists

of 24 pediatric and adolescent primary care sites in 6 counties across Western Pennsylvania, including practices near to and far from subspecialty referral centers. Parents or other caregivers (with children aged 0–21 years), young adults (aged 18–21 years), and adolescents (aged 14–17 years) who had ever been referred to a subspecialist were eligible for participation. Eligible parents/caregivers and young adults who presented for primary care visits at participating practices were notified of the study by practice physicians or care coordinators during their visits. For additional caregiver recruitment, we performed snowball sampling with caregiver interviewees. To recruit adolescents, we obtained caregiver permission to contact adolescents at the time of caregiver interviews and subsequently obtained assent from the adolescent. Throughout the recruitment process, we used purposeful sampling at the practice level to ensure diverse representation, including interviewees living near to and far from subspecialty care (according to interviewee-reported travel time) as well as interviewees with high and low subspecialty utilization (according to self-reported number of visits). Participation was incentivized using a \$25 gift card which was mailed to participants after interview completion.

All interviews were conducted by a trained investigator with experience in qualitative data collection (L.E.A.). This individual obtained verbal consent before each interview. Interviews were recorded and transcribed with identifiers removed. Interview transcripts were analyzed using thematic content analysis,¹⁷ first identifying broad themes and subsequently differentiating subthemes. Two investigators (K.N.R. and L.E.A.), trained in qualitative methods, coded all interviews. A preliminary codebook was developed on the basis of the first 5 interviews. This codebook was reviewed by our stakeholder group to enhance reliability. Interviews were then coded by the 2 investigators, compared for agreement, and finalized through consensus. Coding was performed using NVIVO 10 (QSR, Melbourne, Australia).

We continued interviews until we reached thematic saturation.¹⁸ To increase the trustworthiness of our results, we performed 2 additional member-checking steps. First, for parent/caregiver interviews in which the child in question was 14–21 years old, we also sought parental permission and child assent to interview the child to gain their complementary perspective as discussed previously. Second, at the conclusion of coding, themes were again reviewed with our stakeholder group and refined on the basis of their feedback.

We then categorized themes and subthemes into 3 domains on the basis of the Donabedian model of health care quality: outcomes, processes, and structures.¹⁹ Using this model, outcomes are the changes to knowledge, behavior, satisfaction, or health that occur due to health care. Processes are the activities carried out by professionals or families in the delivery of health care. Structures are the characteristics of the setting where care occurs, including material resources, human resources, and organizational characteristics. We further organized the identified processes using sequential steps of subspecialty referrals

Download English Version:

<https://daneshyari.com/en/article/4138869>

Download Persian Version:

<https://daneshyari.com/article/4138869>

[Daneshyari.com](https://daneshyari.com)