

RESEARCH HIGHLIGHT-2

Advocating for Care Coordination

Stille, C. J., Primack, W. A., McLaughlin, T.J., Wasserman, R. C. (2007). Parents as information intermediaries between primary care and specialty physicians. *Pediatrics*, 120, 1238-1246.

BOTTOM LINE

This research study examined parents' and physicians' perceptions of parents as communicators of medical information between general care physicians and specialty physicians. The role of parents as communicators was not explicitly defined, but it appears that parents either played an active role (e.g., taking an active role in communicating about their child's condition between physicians) or primary role (e.g., being the primary way their child's physicians communicated with one another). In terms of the active role, parents reported that they perceived this role as more important than primary care and specialty physicians perceived parents' role as active communicators; specialty physicians rated parents' active role as the least important among the three respondents. While parents usually felt comfortable in the active role, they were less comfortable being the *primary* communicator of information. Both primary care physicians and specialty physicians were less comfortable with parents as the primary communicator of medical information. Parents' comfort level was related to the number of visits to their child's specialty doctor. Consistent with family-centered practice, these authors recognize the importance of shared partnerships between physicians and families, and that families should not be expected to be the primary communicator of information among their child's physicians.

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ACTION STEPS

- Have a conversation with your child's primary care or specialty doctor about how medical information about their patients is typically shared with other physicians.
- If asked as a parent to share medical information with other physicians, state your preferences about the types of information you feel comfortable relaying to other physicians.
- If you are not comfortable being the primary communicator of information or have a hesitation about relaying technical information, ask who can assist with the information transfer.
- Ask if a nurse is available to help transmit medical information either by telephone or fax.
- Recognize that you can request copies of the doctor's medical notes, copies of referral/consultation letters, and copies of all tests/lab information so you may include this information in your child's care notebook.

To be sure you understand the medical information, it can be helpful to summarize the medical findings with the doctor at the end of each visit.

KEY FINDINGS

- A little over 80% of parents believed it was very important for them to play an active role in the communication process between primary care and specialty doctors, but only 56% of primary care doctors and 30% of specialty doctors felt it was important for parents to assume this role.
- On a 4-point rating scale of importance, parents rated their role as an information communicator (3.7) significantly higher than primary care physicians (3.3) and higher than specialty physicians (2.7) rated parents in this role.
- When parents were regarded as the *primary* communicator of information between primary care doctors and specialty doctors, 57% of families felt very or somewhat uncomfortable in this role. By contrast, 71% of primary care physicians and 61% of specialty physicians felt very or somewhat uncomfortable with parents serving in this role.
- Using a 4-point scale, parents rated their comfort level as the primary communicator significantly higher (2.4) than primary care physicians' ratings of parents assuming the primary communicator role. (2.1). There was no significant difference between primary care physicians' (2.1) and specialty physicians' (2.2) ratings of parents as the primary communicator.
- Familiarity with the specialist physician was a stronger predictor of parent comfort in this role than were demographic factors or parents' experience with the health care system.

METHOD

- This study represents a smaller component of a larger studying examining communication between primary care pediatricians and pediatric medical specialists.
- Participants in this study included parents of children with special health care needs whose child was referred to a university-based multi-specialty group practice. Parents were recruited from a pool of child patients who were referred from 30 local primary care practices to one of five university specialty clinics.
- Completed surveys were only returned from 173 primary care physicians, 157 specialists, and 121 parents.
- To ensure an adequate relationship was developed between the parents and the specialty doctor, the survey was mailed 6 months after their initial visit with the specialty physician.
- Survey questions presented to physicians and parents addressed three topics: (a) the importance of playing an active role in helping their child's doctors communicate with one another, (b) comfort with the scenario in which they might be the primary way for their child's doctors to communicate with one another, (c) whether they actually serve as the primary way for their child's doctors to communicate with one another (p. 1239-1240).

NEXT STEPS IN RESEARCH

- This research raises important issues regarding family-physician partnerships. It seems to suggest less faith in families' ability to effectively transmit medical information among providers. More research is needed to understand how families and physicians can build stronger partnerships.
- Given that nearly 60% of families felt uncomfortable as the primary communicator of information, it is imperative to understand the efficacy of care coordinators assuming the role of information intermediaries and how this position can be integrated and funded within the doctor's office.
- A follow-up study might examine interventions aimed to increase parents efficacy and empowerment as information intermediaries among medical professionals.

RELATED PUBLICATIONS

- Denboba, D., McPherson, M. G., Kenney, M. K., Strickland, B., & Newacheck, P. W. (2006). *Achieving family and provider partnerships for children with special health care needs. Pediatrics, 118, (4), 1607-1616.*
- MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals' perspectives on family-centered care. *Health expectations: an international journal of public participation in health care and health policy, 8(1), 74-85.*

Stille, C. J., Primack, W. A., & Savageau, J. A. (2003). Generalist-subspecialist communication for children with chronic conditions: A regional physician survey. *Pediatrics*, 112 (6), 1314-1321.

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