ARTICLE

Parents' Perspectives on Shared Decision Making for Children With Solid Organ Transplants

Stacee M. Lerret, PhD, RN, CPNP, Kristin A. Haglund, PhD, RN, PNP, BC, & Norah L. Johnson, PhD, RN, CPNP

ABSTRACT

Introduction: The Institute of Medicine prioritizes active family and clinician participation in treatment decisions, known as shared decision making (SDM). In this article we report the decision-making experiences for parents of children who had a solid organ transplant.

Method: We performed a prospective longitudinal mixed methods study at five major U.S. children's medical centers. Qualitative interview data were obtained at 3 weeks, 3 months, and 6 months after hospital discharge following the child's transplant.

Results: Forty-eight parents participated in the study. Three themes were identified: (a) Parents expect to participate in SDM; (b) parents seek information to support their participation in SDM; and (c) attributes of providers' professional practice facilitates SDM. SDM was facilitated when providers were knowledgeable, transparent, approachable, accessible, dependable, and supportive.

Conclusions: Parents expect to participate in SDM with their transplant team. Health care providers can intentionally use the six key attributes to engage parents in SDM. The results provide a framework to consider enhancing SDM in other chronic illness populations. J Pediatr Health Care. (2016) *30*, 374-380.

KEY WORDS

Shared decision making, chronic illness, solid organ transplant, qualitative

Stacee M. Lerret, Assistant Professor, Division of Pediatric Gastroenterology and Transplant Surgery, Medical College of Wisconsin, Milwaukee, WI.

Kristin A. Haglund, Associate Professor, Marquette University, College of Nursing, Milwaukee, WI.

Norah L. Johnson, Assistant Professor, Marquette University, College of Nursing, Milwaukee, WI.

Supported by a grant from Children's Research Institute Pilot Innovative Research Award and by the National Center for Research Resources and the National Center for Advancing Translational Sciences, National Institutes of Health, grant 8UL1TR000055.

Conflicts of interest: None to report.

Correspondence: Stacee M. Lerret, PhD, RN, CPNP, Division of Pediatric Gastroenterology and Transplant Surgery, Medical College of Wisconsin, 8701 Watertown Plank Rd, Milwaukee, WI 53226; e-mail: slerret@chw.org.

0891-5245/$36.00

http://dx.doi.org/10.1016/j.pedhc.2015.10.001

Pediatric solid organ transplant (SOT) recipients are medically fragile and have complex home management regimens. Parents of transplant recipients typically experience uncertainty during the transplant process (Shellmer, Brosig, & Wray, 2014). They have reported stress (Aldridge, 2008) and difficulty with coping, managing life at home, and adhering to complex care regimens (Lerret et al., 2015; Lerret & Weiss, 2011), which may result in posttransplant complications. Collaboration between patients, families, and health care professionals improves health outcomes and decreases rates of readmission and complications in populations of persons with complex chronic conditions (Committee on Hospital Care and Institute for Patient and Family Centered Care, 2012). Engaging patients and families in collaboration is referred to as shared decision making (SDM) in current health care policies, including the Affordable Care Act (Informed Medical Decisions Foundation, 2015).

The Institute of Medicine encourages SDM as a method of fostering improved patient satisfaction with health care (Institute of Medicine [IOM], 2001). SDM has been recognized for years as a process of four components: (a) active participation of both clinicians and families in treatment decisions, (b) exchange of information, (c) discussion of preferences, and (c) joint determination of treatment plans (Charles, Gafni, & Whelan, 1997). With SDM both the provider and patient are involved in the decision-making process, express treatment preferences, and mutually agree on a treatment plan (Fiks, Localio, Alessandrini, Asch, & Guevara, 2010), focusing on the aspects of care that matter most to the child and parent (Barr et al., 2014; IOM, 2015). Parents see themselves as the expert for their child and report SDM as a partnership with their provider (Fiks, Hughes, Gafen, Guevara, & Barg, 2011).

SDM may be an intermediary step to patient activation. Patient activation refers to the skills and confidence that equip patients to become actively engaged in their health care (Hibbard & Greene, 2013). Patient activation has been shown to contribute to better health outcomes and health care experiences (Hibbard & Greene, 2013). Intentional use of patient-empowering provider behaviors could lead to improved patient activation and functional health status (Jerofke, Weiss, & Yakusheva, 2014).

SDM is a process advocated by professionals and most often studied from the perspectives of professionals. Researchers have measured parents' decision-making behaviors quantitatively, but few qualitative studies have been performed in which parents expressed their perspectives on making health care decisions on behalf of their children (Coyne, O'Mathuna, Gibson, Shields, & Sheaf, 2013; Kavanaugh, Savage, Kilpatrick, Kimura, & Hershberger, 2005; Pentz et al., 2012). Further, SDM has not been explored among parents of children facing SOT. The data reported in this article were part of a larger study designed to explore discharge preparation and the effects of that preparation on postdischarge care (Lerret et al., 2015). Parents in this study responded to questions about medical decision making; their responses reflected the components of SDM previously identified in the literature. The purpose of this article is to report the experiences of medical decision making among parents of children who had an SOT. The results have implications for health care providers in acute and primary care settings.

METHODS

Study Setting and Recruitment of Participants

This prospective, qualitative, longitudinal study was conducted at five major children's medical centers in the United States after Institutional Review Board approval was obtained at each site. Recruitment via convenience sampling took place from July 2010 to January 2012 among parents identified as the primary caregiver of a child who had received a heart, kidney, liver, lung, or multivisceral transplant. The inclusion criteria included being 18 years or older, speaking English, and having access to a telephone to complete the postdischarge telephone interviews. Parents of children who had a previous transplant or a serious co-morbid condition were excluded because these circumstances would have changed the families' discharge preparation, which was the focus of the original study.

Near the time of hospital discharge, the transplant coordinator or research assistant identified eligible parents and explained the study. Fifty-nine eligible parents were invited to participate in the study, and 51 were enrolled on the day of hospital discharge. High retention was achieved during the 6-month time frame of the study, with 48 participants at 3 weeks, 46 participants at 3 months, and 44 participants at 6 months (see the Figure). Data for the study reported in this article were collected via semi-structured telephone interviews completed at 3 weeks, 3 months, and 6 months after hospital discharge by the research assistant and principal investigator (SL). Participants were asked about their perspectives and experiences regarding caring for their children after discharge, participation in medical decision making, and interactions with the transplant team (see Table 1). Parents' responses were audio recorded and transcribed verbatim by one of the researchers.

Transcriptions were entered into NVivo (QSR International, Melbourne, Australia), a software program for qualitative data analysis. Data were coded by one researcher (KH). The coded data were discussed in multiple research team meetings and codes were revised until consensus was reached regarding the names of the codes and how they were applied to the data. After coding was complete, data were examined within each main and subcode to generate descriptions of participants' experiences and perspectives. The research team discussed the coded data and descriptions to identify themes. Themes were refined until they concisely reflected the participants' points of view regarding participation in decision making and their expectations of their health care providers.

RESULTS

Characteristics of Participants

The majority of parents (median age, 34 years; range, 19-55 years) were female (*n* = 41; 85%), white (*n* = 39; 81%), and married (*n* = 34; 71%). The children (median age, 2.8 years; range, 3 weeks to 17.5 years), received a liver (*n* = 20; 41%), heart (*n* = 15; 31%), kidney (*n* = 8;