Testing a Program to Support Decision Making among Parents of Children in the PICU

Principal investigator

Kelly N. Michelson, BA, MD, MPH

Organization

Ann & Robert H. Lurie Children's Hospital of Chicago

What was the research about?

The pediatric intensive care unit, or PICU, takes care of children who are seriously ill. These children may be recovering from surgery or have an infection or a life-threatening illness. Their parents may have to make hard choices about health care, life support, or end-of-life care.

In this study, the research team created and tested a program for parents in the PICU, called PICU Supports. In this program, trained counselors offered parents help and support when making choices about care. The team wanted to learn if parents in the program felt more satisfied with the process of making decisions than parents who received a brochure about the PICU.

What were the results?

Parents in PICU Supports and parents who received the brochure didn't differ in how satisfied they were with the process of making decisions. In addition, parents in the two groups didn't report differences in

- Amount of regret about choices they made for their child's care in the PICU
- Worry, sadness, or stress
- Quality of life
- Perceptions of how well PICU staff worked together and communicated with families
- Satisfaction with care

Who was in the study?

The study included 442 parents of 382 children in the PICU. All children received care at two children's hospitals in Chicago, Illinois. Of the parents, 54 percent were white, 18 percent were black, 3 percent were Asian, 13 percent were other races, and 11 percent didn't report a race. The average parent age was 35, 71 percent were women, and 9 percent didn't report their gender. The average patient age was 5. The most common reasons for children being in the PICU were breathing problems and care after surgery. All children received PICU care for more than one day.

What did the research team do?

The research team worked with parents of children in the PICU and people who work in the PICU to design PICU Supports.

The research team then assigned families to one of two groups by chance: PICU Supports or the PICU brochure. For those in PICU Supports, a trained counselor met with families each weekday. The counselor also offered to hold weekly meetings for parents with PICU staff. They gave parents other resources as needed, such as a list of common questions for the doctor and a PICU handbook.

The second group received a brochure about the PICU. It had information about PICU staff, how to visit the PICU, a list of terms often used in the PICU, and ways parents could be involved in their child's care.

The research team asked parents in both groups to fill out a survey three to five weeks after leaving the PICU.

Parents of children who had been in the PICU and healthcare professionals helped plan the study.

What were the limits of the study?

The study enrolled fewer families than planned. Fewer than 60 percent of parents filled out the survey three to five weeks after leaving the PICU. Parents who filled out surveys differed from those who didn't in terms of education, race, ethnicity, age, marriage status, and gender. Also, PICU staff were aware of PICU Supports, which may have changed the way they talked with all

parents in the study. As a result, it may have been hard to detect differences between the PICU Supports group and the brochure group.

Future research could compare other ways of supporting parents in the PICU as they make choices about their child's care.

How can people use the results?

Hospitals can use the results when considering ways to support parents of children in the PICU.

To learn more about this project, visit www.pcori.org/Michelson248.