

Exceptional care requires patient-driven education

December 17 2015, by Michele Berger

We've all been there: Sitting in a consultation with a doctor or nurse, jargon gets thrown around, time with the health-care provider is short and, soon after the conversation concludes, you forget half of what you were told. This can happen whether you're "health literate," meaning you comprehend and feel comfortable with medical terms and concepts, or not, and whether you're a parent dealing with your child's acute sickness or chronic disorder.

New research from the University of Pennsylvania, Texas Christian University and the University of Texas at Arlington reveals that for parents in the latter group, whose offspring have a condition like Type 1 diabetes, education and communication must be learner-driven, not instructor-driven. This follows for parents with low and adequate health literacy alike, opposite ends of this communication spectrum.

The researchers published their findings in the November issue of the *Journal of Health Communication*.

"Literacy implies the ability to read. That's not really what health literacy is," said Terri Lipman, assistant dean for community engagement and a professor of nursing of children at Penn's School of Nursing. "It's the capacity to obtain, process and understand basic health information."

For parents trying to keep their children healthy, particularly those dealing with a chronic, complex ailment like Type 1 diabetes, understanding the health-care provider is key. In the clinical setting,

these parents often work with diabetes educators, so Lipman and colleagues felt those parents offered an appropriate study cohort.

The researchers recruited 162, all of whom had a child with Type 1 diabetes and had seen a diabetes educator at least once during the previous year. Participants completed a survey that looked at measures including general clarity and explanation of conditions and care, as well as parent concerns. A smaller group then agreed to be interviewed, answering questions about their perceptions of, and needs around, diabetes education.

"One of the themes that emerged was, 'Teach me at my pace.'" Lipman said. "Parents with low health literacy said, 'I need to be told the same thing many times. Don't rush me.' Parents with adequate health literacy said, 'You need to be flexible, you need to teach at my pace. The conversation needs to move more quickly.'"

Interestingly, Lipman added, "both sets of [parents](#) were dissatisfied and frustrated." The results surprised the researchers.

Lipman said that, generally, health-care providers tend to believe they speak too quickly or use too much medical jargon, so they aim somewhere in the middle, trying to deliver their message at an average pace and a basic but not oversimplified level. "We think that we'll do our best educating most people," she said, "but we really satisfy few."

To Lipman, this research reaffirmed that providers need to assess the health literacy of each family and parent (though this is controversial because some believe it fosters unfair treatment based on preconceived biases) and then get creative in their communication methods.

She notes as an example e-learning tools that a patient or parent could watch at home, during free time, when the children are asleep, and speed

it up, slow it down or re-watch it as many times as necessary. "Maybe it's a combination," she said. "There is face-to-face teaching and then families are able to go home with an e-learning tool that is very visual and has a lot of demonstrations. There's a need for creativity and the bottom line is that it has to be patient-driven."

Next up for this research, Lipman and colleagues plan to replicate the study with a much larger, more diverse group to confirm their results.

"This is really about interpersonal communication," she said. "If you want to look beyond [health literacy](#) and education, it is about the provider-patient-family dance. How is it that we relate to one another and how it is that we collaborate in moving forward together to improve health?"

Provided by University of Pennsylvania

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