A wealth of publications has addressed communication within the patient-physician relationship, yet the question of how to best communicate with persons with disabilities remains notably absent from the literature. This is cause for concern when one considers that this communication gap may affect the quality of care provided.

In a 2005 Call to Action, the US Surgeon General underscored the use of “people first” language, which focuses attention on individuals rather than their limitations. The document urged the health care community to regard the whole person with a disability with dignity. The Arc of Massachusetts (2008) identified that health care professionals have biases about people with intellectual and developmental disabilities and are more often insensitive to these patients’ needs. Further evidence shows that physicians’ attitudes directly affect the treatment they provide patients with complex needs.

Barriers to care can be overcome through education of medical students and residents. A variety of teaching strategies about disability and related approaches to care have been used by medical schools and training programs. The use of standardized patients with disabilities is a growing trend within medical education, and many programs in the United States and the United Kingdom have engaged patients to take more active roles. It has been shown that when patients are given adequate support, training, and remuneration they can become colleagues in medical training.

In view of the above findings and with the help of a 2-year grant from the Kenneth B. Schwartz Center, the Lehigh Valley Health Network (LVHN) Family Medicine Residency Program designed the Patients With Disabilities as Teachers (P-DAT) program in 2008. The program follows the philosophies of relationship-centered care and the patient-centered medical home.

**Methods**

**The P-DAT Program**

Third- and fourth-year medical students in family medicine are required to participate in a monthly training session on “Disability Etiquette.” The sessions address the Accreditation Council for Graduate

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Medical Education (ACGME) competencies of patient care, medical knowledge, interpersonal and communication skills, professionalism, and systems-based practice. The class size is kept small, between four and eight students, to allow for uninhibited discussions. The training is provided by two of the practice’s patients, both of whom are in their late 20s and use wheelchairs. One of them has spinal muscular atrophy, and the other has cerebral palsy. Both patients live independently and have no evident intellectual disabilities.

Selection of the patient educators was made with the help of criteria available for patient advisors in different programs.9 The P-DAT educators were trained by a communication specialist, a parent advocate, and a theatre director who has developed a play performed by individuals with disabilities. The training session was composed of a structured reflective process through which the educators discussed their life experiences and learned the skills of effectively sharing their stories with an audience.

P-DAT Program Format

The 1-hour P-DAT sessions are primarily run by the patient educators, who are paid a stipend, and are facilitated by a family medicine faculty member. An introductory letter that emphasized the importance of learning “Disability Etiquette” and publications regarding care of patients with disabilities are given to the students as an orientation package.10,11

The educators tell students about their lives, emphasizing their living arrangements, daily schedules, and volunteer activities. This introduction is intended to emphasize for the students the “abilities” rather than the “disabilities” of the educators. To encourage interaction, the students are encouraged to describe any experiences they have had with people with disabilities.

The educators ask the students about their discomfort, if any, with patients who have disabilities. The educators then share their own experiences within the health care community and discuss their expectations of a visit to the doctor’s office. This is followed by viewing the video “The Ten Commandments of Disability Etiquette.”12 Another round of interactive discussion follows. The students are invited to ask any additional questions they may have, and in closing, they complete an evaluation form included in the orientation package. This project did not qualify for IRB review as determined by LVHN’s Research Participant Protection Office, as it did not constitute research on human subjects as defined by the US Department of Health and Human Services or the federal Food and Drug Administration.

Results

The program evaluation form (available from the first author on request) that was completed by medical students at the end of each training session consists of three Likert-scale questions and four open-ended questions. In the first phase of the P-DAT program described here, 44 students completed the training, and the evaluation results were as follows: On the Likert-scale items, all three components of the training (the trainers/educators, the video, and the interactive discussion) received high scores, with averages of 4.83 for the trainers, 4.65 for the video, and 4.73 for the discussion out of a possible 5.00 points (Table 1).

Open-ended evaluation questions were analyzed manually using grounded theory.13 Response data were coded and emergent core categories identified. Findings were very encouraging regarding the need, effectiveness, and receptivity of the training program. In Question #1 regarding discomfort around interaction with patients with disabilities, 89% of the students stated that prior to the training program they felt uncomfortable. Of those responses, 73% indicated their primary concern was treating the person with a disability differently and insulting them. Emergent themes from Question #2 demonstrated a clear preference for learning etiquette by focusing on practical tips (52%) and instruction by a person with a disability (39%) over other delivery methods. When asked what they would like to see modified in the training (Question #3), the two most frequently cited suggestions were: (1) more time for discussion and interaction with the educator (30%) and (2) opportunities to role play health care interactions (16%). Question #4 asked about potential influence of the training on their future interactions involving patients with special needs. Among the responses, 98% stated the program was beneficial, either by increasing overall awareness and sensitivity (52%) or by increasing competency for future communication with patients with disabilities (46%).

Discussion

Although the evaluation results presented in this article demonstrate the early stage of implementation, the feedback from medical student participants is encouraging. The suggestions for improvements indicate that the students are interested in a fully engaged process in which they can demonstrably improve their attitudes and skills of communicating with persons with disabilities. Initially, the training was attended by students rotating through family medicine, but upon request, the program was opened up to students from other rotations.

Based on the positive feedback received from students, the P-DAT program was expanded to 3-hour sessions. In the new format, the training incorporates parents of children with disabilities who share their perspectives with the learners. An expanded section on “abilities of people with disabilities” has been added to further embed the “person first” aspect into care of these patients. Students rotating in the four
primary care specialties at LVHN—internal medicine, family medicine, pediatrics, and obstetrics and gynecology—attend the program, which is now funded in full by the Department of Family Medicine.

Conclusions
Communication and basic etiquette are essential tenets of any patient-doctor relationship. To provide “relationship centered” care, it is important that both the physician and the patient feel comfortable in their interactions with each other. A program such as P-DAT helps develop this rapport, especially since it is primarily taught by the patients themselves and is based on real-life experiences of the patients.

Our hope is to disseminate information about the P-DAT program to all academic medical institutions in anticipation that it will pave a smoother path toward a medical home for every patient with a disability.

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References