Identifying the special difficulties in diabetes self-management among individuals with cognitive disabilities

**THE PROBLEM**

Individuals with disabilities have especially high rates of diabetes. In Delaware, the rate is three times higher than for adults without disabilities: 15.5% vs. 5.3% (CDC, 2009). Although among the most vulnerable and costly of patients, few if any programs consider the special hurdles that a cognitive disability erects in learning and implementing an effective self-management regimen. Few if any programs consider just how complex the job of diabetes self-care is for anyone.

**PROVIDER CHARACTERISTICS**

Twenty three health care professionals completed the survey in the Fall of 2011. The respondents represented a range of clinical roles: physicians (9), certified diabetes educators (8), nursing professionals (12) and registered dietitians (1).

Respondents reported caring for an average of 37 diabetes patients each week (range of 4-100 patients per week).

**PATIENT CHARACTERISTICS**

**Prevalence of cognitive limitation among patients**

Providers were asked about whether their patients had cognitive limitations. Ninety six percent (96%) reported that some (82%) or most (14%) of their patients have an intellectual disability related to one of the following conditions: traumatic brain injury, dementia, drug- or alcohol-induced impairment, mental retardation, schizophrenia, autism or PTSD.

**Prevalence of inadequate health literacy**

Providers were asked how many of their patients “often or always” needed help reading instructions. Nearly all (91%) indicated that some (64%), most (18%) or virtually all (9%) of their patients met this definition of “inadequate” health literacy.

**CONCLUSIONS & NEXT STEPS**

- Providers tended to agree on which tasks are most critical, but seemed less able to rank tasks by learning demands.
- Nearly all providers reported that they serve patients with intellectual disabilities or inadequate health literacy.

**Phase 1: Provider Reports of Most Common and Critical Episodes of Non-Adherence**

Project investigators conducted an online survey of health care professionals who help patients manage their diabetes. The aim was to solicit their judgments about which tasks in diabetes self-management are most critical to patient health and most difficult for patients to learn.

**Phase 2: Patient Reports of Special Difficulties**

Small focus groups will be conducted to capture the most common and serious mistakes patients make in-self care.

**Phase 3: Design More Effective Tools**

Modify diabetes instruction and monitoring to focus on the most critical and error-prone self-management tasks.

**REFERENCES AND ACKNOWLEDGEMENTS**

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