

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



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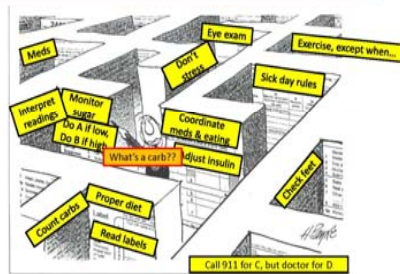
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THE PROBLEM

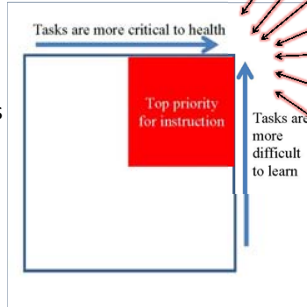
Individuals with disabilities have especially high rates of diabetes. In Delaware, the rate is three times higher than for adults without disabilities: 15.5% vs. 5.3% (CDC, 2009). Although among the most vulnerable and costly of patients, few if any programs consider the special hurdles that a cognitive 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.

Diabetes self-management from patient's perspective



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.

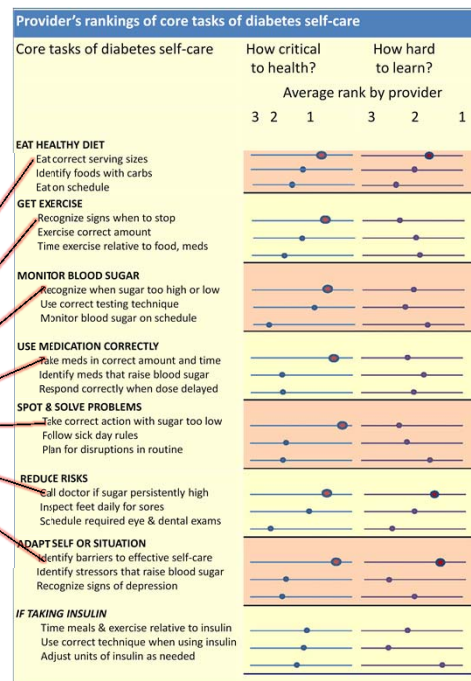


PROVIDER CHARACTERISTICS

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).

PROVIDERS IDENTIFIED THE TASKS MOST CRITICAL TO HEALTH & DIFFICULT TO LEARN



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 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

- Centers for Disease Control and Prevention (CDC) (2009). Behavioral Risk Factor Surveillance System Survey Data [Data File]. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.
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