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

College of Education & LAWARE. Human Development SCHOOL OF EDUCATION





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 selfmanagement are most critical to patient health and most difficult for patients to learn.



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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

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			1.1000000000		How hard to learn?		
	32	-	rank by provider				
CAT USALTUN DIST		1	3	2	1		
EAT HEALTHY DIET							
Eat correct serving sizes	-		-	•	-		
Identify foods with carbs		•	-	•	-		
Eat on schedule					-		
GET EXERCISE							
Recognize signs when to stop					_		
Exercise correct amount	-		-				
Time exercise relative to food, meds				•	_		
MONITOR BLOOD SUGAR							
Recognize when sugar too high or low				•	-		
Use correct testing technique	4	•			1		
Monitor blood sugar on schedule				•	_		
USE MEDICATION CORRECTLY							
Take meds in correct amount and time	0	-		•	-		
Identify meds that raise blood sugar				-	_		
Respond correctly when dose delayed					_		
SPOT & SOLVE PROBLEMS	-						
Take correct action with sugar too low		-					
Follow sick day rules	144		_				
Plan for disruptions in routine							
				•	_		
REDUCE RISKS							
Call doctor if sugar persistently high			-		-		
Inspect feet daily for sores		•		•	_		
Schedule required eye & dental exams							
ADAPT SELF OR SITUATION					_		
dentify barriers to effective self-care	_		_				
Identify stressors that raise blood sugar							
Recognize signs of depression					_		
IF TAKING INSULIN	-		Dk		-		
Time meals & exercise relative to insulin		-					
Use correct technique when using insulin	-	•		•	-		
Adjust units of insulin as needed		•		-	-		

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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 alcoholinduced 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. AADE7 reproduced with permission of the American Association of Diabetes Educators. All rights reserved. May not be reproduced or distributed without the written approval of AADE.