Chronic Diseases as Cognitively Demanding Careers for Patients & Families: Diabetes, Parkinsons, Alzheimers, & Breast Cancer

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Chronic Disease as Life-Long Career

Chronic illnesses:

 "Slow-acting, long-term killers that can be treated but not cured." "Self-care is often as important as health care."

Like jobs:

- Evolving set of duties
- Specialized knowledge
- Independent judgment
- Good performance matters

Not like jobs:

- Sudden, unexpected, involuntary
- Threat to well-being, no vacations

Past Job Analyses of Occupations

React quickly to unexpected

problems

Job attributes that correlate highly with job complexity:

Behavioral requirements	Working conditions	Task characteristics		
Compile info	Ambiguity, change	Abstractness of info		
Combine info	Uncertainty, unpredictability	Incomplete info		
Transmit info in writing & orally	Distractions	Amount of irrelevant info		
	Time pressure	Inferences required		
Learn & recall relevant info	Lack of structure	Unclear means-ends		
Reason, analyze	No set procedures			
Make decisions	Little feedback			
Evaluate, judge	Lack of supervision			
Advise, persuade				
Plan, schedule, coordinate				
Update knowledge	Similarity to	general intelligence		
Spot problems quickly	* "Ability to reason, plan, spot & sol			
	1			

intelligence (g):

n, spot & solve problems, think abstractly, comprehend complex ideas, learn quickly & from experience." "Ability to deal with complexity."

Diabetes

- Goals: Prevent cumulating, hidden damage to organ systems (high sugar); Avoid life-threatening emergencies (very low sugar); Integrate adherence into life style
- * Tasks: Learn about the disease & its control; Monitor signs & symptoms closely during the day; Keep blood sugar within healthy limits at all times; Schedule life and work activities to achieve that; Communicate needs to family & friends so they support rather than impede efforts; Get regular check-ups; Control co-morbidities (blood pressure, etc.)
- ❖ Cognitive hurdles (patient): Use independent judgment to coordinate three interacting factors that affect blood sugar (diet, exercise, meds); Understand abstract concepts (carbohydrate, etc.); Plan ahead for unforeseen circumstances that jeopardize control (late meals, etc.); Conceptualize unseen bodily damage caused by sloppy control; Recognize subtle signs & react quickly before sugar veers far out of control; Estimate lag times in losing & regaining control
- Cognitive impairments caused by disease (when sugar low): Confusion, poor judgment, & slurred speech (temporary)



Parkinsons Disease (PD)

- Goals: Slow the inevitable physical decline; Retain functional capabilities for maximum time; Create safe work & home environments; Maintain personal ties & interests
- Tasks: Inform self about course of PD, symptoms (rigidity, tremors, etc.), & amelioration (medication, exercises, etc.). Monitor changes in symptoms & reactions to meds; Modify physical environments to prevent accidents; Seek & adhere to treatment (diet, timing of medications, exercises); Update evaluations by specialists; Plan for long-term care, powers-of-attorney, etc.
- Cognitive hurdles (patient & caregivers): Conceptualize how once-safe environs become hazardous with PD; Grasp peculiar changes in perception of light, space, and patterns that interfere with locomotion, proprioception, and safety. Develop ways to communicate effectively in person & on telephone despite speech impairments, and to eat/take meds safely with swallowing impairment; Anticipate misconstrual of speech & facial impairments as cognitive impairments
- Cognitive impairment caused by disease: Dementia in late stages (sometimes).



Alzheimers Disease (AD)

- Goals: Slow the inevitable mental decline; Create safe, secure, & caring environment for years ahead; Maintain personal ties & dignity
- Tasks (gradually assumed by caregivers): Review finances, powers of attorney, will; Develop support system; Manage stress; Prevent accidental injury; Set predictable schedule; Monitor progression of symptoms; Compensate for worsening memory, communication, mood, self-care; Adhere to treatment; Find enjoyment
- ❖ Cognitive hurdles (patient in early stages): Conceptualize progress of AD and life; Anticipate needs and solutions; Monitor symptoms and adjust behavior (Caregiver): Infer emotional experience & increasingly elusive thought processes in AD; Spot slow & subtle evolution of symptoms and functional capabilities; Recognize where old environs are new hazards, old activities are new stressors; Update knowledge; Identify new resources; Learn own needs & limits
- Cognitive impairment caused by disease (patient): Inexorable & devastating (Caregiver in later stages): Extreme stress & fatigue



Breast Cancer

- Goals: Get proper treatment; Prevent recurrence; Find the "new normal" living with cancer
- Tasks: Inform self about treatment & reconstruction options, facilities available, costs entailed; Select and schedule treatment; Mobilize support/delegate tasks during treatment; Cope with long-term side-effects; Adhere to long-term regimen of self-care, self-monitoring, medication, & health-care follow-up; Reestablish normalcy in life, work, & self-image
- Cognitive hurdles (patient & family): Quickly & independently locate, evaluate, integrate large body of technical information about cancer & treatments; Identify treatments later foreclosed by treatments chosen today; Weigh probabilistic survival data when deciding treatment; Communicate effectively with health providers; Make life-changing choices under time pressure and emotional stress; Develop strategies to deal with lasting side-effects of treatment
- Cognitive impairment caused by treatment: Chemo-brain, extreme fatigue from chemo/radiation/surgery (usually temporary)

Hypotheses Generated - 1

- Similarities in cognitive hurdles:
 - Cognitive overload at diagnosis
 - Higher g lowers the hurdles
 - External cognitive resources required, at times

Hypotheses Generated - 2

Differences in cognitive hurdles:

	Diabetes	Parkinsons	Alzheimers	Breast cancer	
Cognitive Demands					
Timing	sustained	risk creep	risk creep	spiked	
Cognitive Supply					
Impaired by disease	Mild-Mod Oscillates	Mild-Mod Permanent	Severe Permanent	Mod-Severe Episodic	
Cognitive Sufficiency					
Depends on pre- morbid g:					
physical functioning	Highly	Mod	Highly	Lo	
emotional adjustment	Lo	Lo	Lo	Lo	

Recommendations

- ✓ Formal job analyses from patient's view
 - Esp., job complexity (constellation & sequencing of tasks in self-care; unseen processes; inferences required; etc.)
- ✓ Greater attention by providers to individual differences in g
- ✓ More targeted, timely cognitive supplementation