

Disclosure of a Dementia Diagnosis:

Minimizing Medical Trauma

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Case Report

Ms. D., a retired secretary, was 65 years old when she sought assessment for "memory impairment" in a memory disorders clinic. She and her husband attributed recent memory lapses to the low dose lithium carbonate she had taken for many years following a manic episode in her 30's. Her neurological and physical examinations and laboratory studies—including lithium level—were unremarkable. Although she scored 27/30 on the Mini Mental Status examination,¹ her behavior suggested more significant cognitive compromise. She was repeating questions and she displayed difficulty recalling recent events. She acknowledged some confusion about directions when driving. Although advised to have an MRI and neuropsychological testing, she declined these tests for fear they would show her "in a bad light." Her cognitive symptoms were provisionally ascribed to lithium toxicity.

Lithium discontinuation was followed by increasing difficulty performing customary household tasks and engaging in her usual activities. Two years after her initial assessment, she agreed to further evaluation. At age 67, her Montreal Cognitive Assessment² score was 7/30 and neuropsychological testing demonstrated significant cognitive impairment. Her brain MRI showed involuntional changes including parenchymal volume loss and chronic white matter microvascular ischemic changes. FDG-PET scan demonstrated regional hypometabolic changes consistent with a diagnosis of Alzheimer's Disease.

When told that her cognitive symptoms most likely represented Alzheimer's dementia, Ms. D. reacted with immediate shock and terror. Over several days she slipped into a deep depression accompanied by delusions of persecution, which necessitated inpatient psychiatric care. In lucid moments, she was able to discuss how traumatized she felt by the disclosure of her Alzheimer's disease diagnosis, a condition she could not name without bursting into tears. Her impaired memory limited the value of psychotherapy, but her depressive symptoms resolved gradually when she was treated with antidepressant and antipsychotic medications. Subsequently, having observed her devastated response to the discussion of her diagnosis, her family and care providers learned to avoid mention of dementia or Alzheimer's disease in her presence. Her husband, designated as decision-maker, was able to discuss the management of her Major Neurocognitive Disorder with her clinicians in order to facilitate appropriate treatment interventions.

Discussion

While symptoms such as pain, fever, vomiting, or bleeding often prompt a quick search for evaluation and treatment, many people react differently to cognitive symptoms. Memory loss in particular and cognitive impairment in general are among the symptoms most feared by older adults. Because the diagnosis of dementia (formally termed Major Neurocognitive Disorder) is widely understood as a progressive condition without available disease-modifying treatments, evaluation may be avoided by individuals who observe changes in themselves. Friends and family members, too, may disregard or minimize the cognitive changes they observe in a loved one. Discussion even of the possibility of Alzheimer's disease or other neurodegenerative disorders can be extremely upsetting to a patient.

Nonetheless, there are valid reasons to identify and address cognitive symptoms even at an early stage. Recognition of the earliest clinical manifestations of cognitive decline, diagnosed as Mild Neurocognitive Disorder, permits an affected individual and caregivers to understand and learn about functional changes they have most likely already observed. Early detection allows an affected individual to participate fully and effectively in plans for the future, including decisions regarding health care options, finances, residential arrangements, and needs for various kinds of assistance. In the presence of mild cognitive changes, lifestyle interventions affecting disease management, physical activity and nutrition may delay or mitigate further cognitive decline. Once cognitive faculties are more significantly compromised, detection and diagnosis of impairment becomes a necessary aspect of protecting the rights and safety of an affected individual.³

The psychoanalyst and teacher Elvin Semrad famously formulated the importance of helping a patient to “acknowledge, bear, and put in perspective” their suffering.⁴ Cognitively impaired individuals, however, are uniquely impaired in their ability to hear, understand, and process a disturbing and potentially traumatic diagnosis. Acknowledgment may be intermittent and unstable. Diminished short term memory creates an impediment to the reflective contemplation which supports the integration of disturbing information. Changes in language and insight may further undermine comprehension of a diagnosis and prognosis. Social cognition can be affected even at an early stage of cognitive decline, interfering with collaborative discussion and planning for the future.⁵ A previous history of anxiety or mood disorder can create even greater difficulty for an individual coping with a new, serious diagnosis.

Medical trauma, which can include the “psychological traumas that result from medical diagnosis and/or medical intervention,” is a recognized potential consequence of diagnosis disclosure which can induce symptoms similar to those of Post-Traumatic Stress Disorder.^{6,7} Yet, the medical ethical principle of “respect for persons” implies that patients have a right to know their diagnoses.⁸ The 21st Century Cures Act, furthermore, stipulates that patient electronic health information be made available to patients without delay and at no cost.⁹ Furthermore, a recent pilot study showed that the impact of the dementia diagnosis was lower on individuals who had accessed support and referral services available to them as compared to those who had not.¹⁰ Yet many providers are reluctant to discuss a dementia diagnosis explicitly, despite evidence that the majority of patients referred to a memory clinic preferred full diagnostic disclosure.¹¹ Some of this reluctance, of course, comes from experience with patients like Ms. D, who have found disclosure unbearable and traumatic.

In the pressured and complex practice of clinical care, how can clinicians fulfill their duty of diagnosis disclosure to patients, respecting their right to know and learn about their diagnosis without inducing harmful psychological trauma? Dr. Rob Buckman, who crusaded to improve the disclosure process for patients diagnosed with cancer, addressed this dilemma in 1992 in an influential book entitled *How to Break Bad News: A Guide for Health Care Professionals*. He outlined a systematic approach for breaking stressful news. The six steps, summarized in the acronym SPIKES, are: **S**etting up the interview, assessing the patient's **P**erception, obtaining the patient's **I**nvitation, giving **K**nowledge and information to the patient, assessing the patient's **E**motions with empathic responses, and strategy and **S**ummary.¹²

A recent review of the art of disclosing a dementia diagnosis offers some additional clinical guidance focused on the needs of persons with dementia.¹³ Roca and colleagues point out that the presence of memory impairment may require the disclosure discussion to include, with patient's consent, the presence of trusted family members or other caregivers. The patient's readiness for information and ability to understand the implications of a neurocognitive diagnosis must be assessed. A brief appointment may not provide sufficient time to address the inevitable questions. Repeated visits, if appropriate, will reinforce the difficult message, which includes prognosis for emergence and progress of both cognitive and behavioral symptoms. Written materials can serve to emphasize the key points of discussion. A clear plan for additional diagnostic testing, referrals, symptom management and follow up should be reviewed with patient and caregivers. Many people with dementia fear above all their loss of independence and the prospect of abandonment. Open discussion of these fears can be reassuring,

A special concern faced by persons with dementia is the traumatic effect of unnecessary redisclosure of their diagnosis. Caregivers and surrogate decision-makers must know the relevant medical information, and they often benefit from coaching about management of the behavioral issues that arise during dementia's progression. The affected patient who is unable to absorb and process the news of a dementia diagnosis and expected developments, however, need not be continuously re-traumatized. In the absence of an ability to work through and accept a dementia diagnosis, it is reasonable for caregivers to discuss cognitive difficulties euphemistically. "Memory lapses," "memory slips," "having a bad day," and "brain aging" are ways in which clinicians can acknowledge difficulty without invoking a specific diagnosis. Such terms offer an opportunity to avoid inflicting unnecessary pain. Keeping in mind that many essential personality features of a person with cognitive impairment persist well into the course of a progressive illness can help clinicians and caregivers to preserve an empathic, honest, and minimally traumatic relationship with the affected patient.

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