The Sharing of the Diagnosis to Patients with Dementia

Controversy exists within the medical community in regards to whether or not a person with dementia should be informed of their diagnosis.\textsuperscript{1, 2} Research findings show that family members were significantly more likely to be informed of the diagnosis and symptoms to expect in dementia than the patients themselves.\textsuperscript{3}

Some research studies have found that although many patients have appropriate insight and would like to know about diagnosis, many patients receive information that is poor and does not allow the patient to have the opportunity to appropriately discuss the illness.\textsuperscript{4} One particular study found that even though the majority of family members believed patients should be told their diagnosis, half had reported that informed patients reacted poorly to being told about the diagnosis and about one-third felt it was helpful to the patient.\textsuperscript{5}

Other research findings have revealed that people with dementia who know their diagnosis have worries which affect their behavior in a way likely to result in low self-esteem, shame, and impaired quality of life.\textsuperscript{6}

There is great variation in the extent to which clinicians disclose the diagnosis of dementia, with about 50\% of practitioners regularly telling patients with dementia their diagnosis.\textsuperscript{7} Factors that influence practitioners in the disclosure of a diagnosis are the uncertainty of whether a person desires to know the diagnosis, fear of potential harm that the disclosure may cause, the degree of certainty with the diagnosis, the degree of insight of the patient, and the severity of dementia.\textsuperscript{8, 9}

The degree to which a disclosure of a dementia diagnosis is preferred by families can vary. The research that has been conducted shows that both families and dementia patients feel that it is important for the person with dementia to be informed of the diagnosis.\textsuperscript{10} However, other studies have found a majority of caregivers to prefer the withholding of the diagnosis from the person with dementia.\textsuperscript{11} Interestingly, research has shown that most practitioners and caregivers would wish to know themselves if they had the illness.\textsuperscript{12}

Some of the results of these studies suggest that physicians should better involve patients and their families in disclosing diagnoses and information. It is also suggested that the current guidelines for physicians in regards to the diagnosis of dementia are inadequate to address the clinical complexities of the issue. Ultimately, the research findings reveal that health care professionals need to be appropriately attuned to the situations of patients and act accordingly.

Written by Parker Campbell, M.S.W.
Helpline and Information Specialist
Alzheimer’s Association of Orange County

Sources:
