

## GUEST EDITORIAL

# Improving diagnostic communication in dementia

In many countries around the world, owing to the lack of specialists and equipment, delay up to a few years in help-seeking and getting diagnostic examinations for dementia is not uncommon (Sayegh and Knight, 2013), and this situation is considerably more serious in “atypical dementias” due to the challenge they present for differential diagnosis. For instance, a survey in the USA showed that misdiagnosis was common in patients with Lewy body dementia who, on average, saw at least three physicians over a year’s time or more before getting the proper diagnosis (Lewy Body Dementia Association, 2010). Furthermore, in multiethnic communities, cultural and language barriers between practitioners and patients may lead to substantial delay as well (Sayegh and Knight, 2013).

To our knowledge, there has not been any research on the effect of diagnostic delay on caregiver and patient outcomes. It is reasonable to assume, however, that the length of time in waiting and pondering, while noticing “something is wrong,” can arouse tension or depressed mood on the part of the patient and family members. It is no wonder, then, that some patients and family members report a sense of relief when the diagnosis is known (Connell *et al.*, 2004; Aminzadeh *et al.*, 2007). Yet, for those who manage to obtain consultations, getting a diagnosis is not always a straightforward matter. Atypical clinical presentations may pose diagnostic challenges in uncommon conditions.

For one reason or another, dementia is perceived as one of the most terrifying conditions by the general public (Harvard School of Public Health and Alzheimer Europe, 2014; Marist Poll, 2012). Because the fear is so widespread, it should not be a surprise that significant concerns arise when practitioners have to convey the diagnosis to patients and family members, especially when they think that the parties have not been well prepared to receive information concerning the nature of the disease. In light of the rising number of dementia cases, assessments and disclosing an initial diagnosis are activities increasingly performed by the general practitioner (GP). Yet, other than confidence issues in their diagnosis, GPs may not favor disclosure (De Lepeleire *et al.*, 2004;

Bradford *et al.*, 2009; Moore and Cahill, 2013; Caruana-Pulpan and Scerri, 2014). For instance, as many as one-fifth of GPs in a UK study believed diagnostic disclosure to be more harmful than beneficial (Bamford *et al.*, 2004).

The reluctance to disclose is not specific to GPs. Surveys in different countries showed that more than half of specialists (including psychogeriatricians, geriatricians, and neurologists) did not disclose the diagnosis of dementia on a regular basis, and concerns about precipitating hopelessness and psychiatric illness were commonly cited reasons for withholding the diagnostic information from the patient (Pinner and Bouman, 2002; Raicher *et al.*, 2008; Segers, 2009; Tarek *et al.*, 2009). Even patients attending memory clinics, with the specific purpose of evaluating their memory problems, might not be given the diagnosis in an explicit manner (Peel, 2015). Therapeutic nihilism and a sense of pessimism about treatment options in dementia might also contribute to concerns about doing harm versus possible treatment gains. The relative lack of diagnostic certainty in the initial stages is also a consideration by practitioners, so that patients are more likely to be told the diagnosis when the symptoms are more advanced (Rice and Warner, 1994; Raicher *et al.*, 2008; Bradford *et al.*, 2009), contributing further to delayed diagnosis.

Some family members also want to withhold the diagnosis from the patient and request diagnostic disclosure in the absence of the patient. The degree to which such wishes are respected by practitioners varies. International studies suggest that while nearly all respondents prefer to be informed of the diagnosis if their relatives have dementia (Robinson *et al.*, 2011), many, ranging from 43% in Belgians to 61% in Italians and 76% in Taiwanese, want it to be concealed from the patient (Pucci *et al.*, 2003; Bouckaert and van den Bosch, 2005; Lin *et al.*, 2005). It is noteworthy that there were more adult children in the Taiwanese sample than in the other samples, who might feel that it was their duty to protect the parent from bad news. On the other hand, there may be cultural factors that influence the acceptance of dementia diagnosis in a family. In communities where older generations are conventionally taken care of within the extended

family, the demand for diagnostic disclosure may be less significant while the practical hand-on skills for everyday care will take priority.

Despite common belief by professionals and family members, the available data do not support the view that diagnostic disclosure would usually result in catastrophic reactions in the patient (Robinson *et al.*, 2011), although there appears to be some disagreement between retrospective and prospective studies. For instance, in a retrospective study of 107 Belgian patients with unspecified intervals between data collection and the diagnostic visit (a common issue in this literature), increased anxiety and depression following the diagnosis was reported respectively by 14% and 4% of the patients (Mormont *et al.*, 2012). However, two prospective studies showed a decrease of anxiety up to 3 months post-diagnosis, with depressive symptoms remaining unchanged (Mormont *et al.*, 2014), while the reduction in anxiety appeared to be more pronounced for those who were highly anxious before hearing the diagnosis (Carpenter *et al.*, 2008). A contributing factor to these results may be the nature of dementia itself, especially Alzheimer's disease—events may be forgotten quickly. Indeed, those who could not remember the diagnosis were far more likely to show a reduction in anxiety than those who could (Mormont *et al.*, 2014). In any case, the prevailing belief that many patients would react catastrophically if given the diagnosis may be exaggerated.

While getting a diagnosis might appear to have little effect on the patient, similar studies on the effect on family caregivers are far fewer. In a large-scale Finnish study, there were more caregivers reporting depressive symptoms in themselves than in their relatives diagnosed with dementia (Laakkonen *et al.*, 2008b). Moreover, a Spanish study of 33 pairs of patients and caregivers found post-diagnosis increase in depressive symptoms in caregivers only, but not in patients (Lladó *et al.*, 2008). While more research on caregivers' adjustment to diagnostic disclosure is needed, the available, yet limited, research evidence suggests that caregivers may have more adjustment issues than the patients themselves. For family members, the diagnosis, if confirmed, signals a major role transition, implying an increase in responsibilities, personal sacrifices, uncertainties, and difficult dilemmas (Adams, 2006; Ducharme *et al.*, 2011), while potentially triggering anxiety about their own risk of getting dementia at some stage in the future (Alberts *et al.*, 2011).

For caregivers who experience significant stress and tension during such times, they may be inclined to think that their relatives cannot handle the news of a positive diagnosis. They may also

feel threatened by the prospect of having to deal with the negative reactions on the part of the relative. They may think that such concerns support concealing the diagnosis from the relative. However, as we have seen, such assumptions may be unfounded or exaggerated, while withholding the diagnosis from the relative may well add to their mental strain, rather than the other way round. As this is the time for caregivers to start making various adjustments in their lives and in the way they relate to their relatives, concealment would mean having to make these changes without being obvious to the patient.

Rather than asking simply whether patients and caregivers suffer after receiving the diagnosis, it may be more useful to examine factors that contribute to or reduce negative emotional reactions when receiving a diagnosis. While no study has been undertaken to address this issue directly, a related study from Australia may speak to this issue. The researchers investigated predictors of quality of life, including demographic and socioeconomic factors, depressive symptoms, performance in various cognitive domains (e.g. memory, praxis, abstract thinking, and language), and whether a "memory problem diagnosis" was ever conveyed to the patient by the GP, in 2,028 patients with or without dementia. Two other variables included were satisfaction with the communication with the GP, as well as satisfaction with what the GP did to enable one's comprehension of and coping with the health issues. Results showed that satisfaction with the communication with the GP explained psychological quality of life above and beyond the effects of the other variables (Mate *et al.*, 2012). In another study, researchers videotaped the consultation sessions of 54 patients with very mild or mild dementia, and rated the physicians for patient-centered communication behaviors. They found moderate use of back channeling (e.g. "hmm," "ok") to show interest in what the patient said and of questioning to check whether the patient understood the messages. But they rarely asked for the patient's (or family member's) opinions or displayed emotional rapport (e.g. empathic listening; Zaleta and Carpenter, 2010).

Furthermore, to avoid the stigma and fear associated with dementia, many practitioners use euphemistic terms instead, such as "forgetfulness," "memory not working as well as it used to," "confusion," or even "not safe living alone" (Downs *et al.*, 2002; Connell *et al.*, 2004; Phillips *et al.*, 2012). Vascular dementia may simply be referred to as "stroke." However, a "vague diagnosis" keeps patients and family members confused about what the problem is and prevents them from acquiring relevant information about the

disease and planning ahead including formulating advanced care directives (Laakkonen *et al.*, 2008a; van den Dungen *et al.*, 2014). For the family members, a working diagnosis helps them make sense of the relative's symptoms, avoid blaming the relative for intentionally displaying negative behaviors, and modify their own behaviors when interacting with the relative. It is also useful to recognize that community awareness on dementia has substantially improved in the past decade. Information disclosure often will not be restricted to diagnosis, but also include update information on management and research advances in dementia to optimize communication.

To conclude, the existing evidence does not support diagnostic disclosure to be generally harmful to patients. Yet, disclosing a diagnosis of dementia is only the beginning to a long-term therapeutic alliance. Clinicians should be ready to facilitate discussions on elaborate management plan, use of pharmacological and non-pharmacological interventions, utilization of social and supportive services, as well as advanced care planning through the course of illness. Communications with openness and fluency for conveying practical tips, on the side of the clinician, will help to reduce the barrier against obtaining and accepting a diagnosis and minimize adverse emotional reactions on the receiving end. Moreover, it is important for clinicians to be sensitive to the needs and concerns of the carers and to address these along the way, as carers are a crucial party in the therapeutic alliance.

## Conflict of interest

None.

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