Issues in disclosing a diagnosis of dementia

Patricia F. Cornetta, James R. Hall

Abstract

As the number of older persons in the U.S. increases there is also an increase in incidence of dementia. Neuropsychologists, because of their role in the assessment of cognitive functioning, will see more aged patients and face many related ethical concerns. Ethical concerns involved in the disclosure of a diagnosis of dementia have produced considerable debate. This paper will discuss a number of issues that may affect the neuropsychologist’s decision to disclose a dementia diagnosis. Topics discussed include the impact of the patient’s mental capacity and awareness of cognitive deficits on the decision process; respect for the autonomy of the patient; the ethical responsibility to “do no harm”; the sometimes-competing wishes of the patient and their caregivers and the impact of not telling the truth. Also discussed are some advantages of disclosing diagnoses to patients and suggestions on the best strategies for disclosing a dementia diagnosis.

Keywords: Ethical issues; Dementia; Disclosure; Capacity; Autonomy

Since elderly individuals are living well into their 80’s, 90’s and even into their 100’s (Marson, 2002), more and more clinicians will be faced with ethical dilemmas related to the disclosure of the diagnosis of dementia to the patient. Neuropsychologists are frequently involved in the formal assessment of cognitive functioning, the presentation of results to the patient and family, and the treatment of patients and caregivers. Whether as member of a multidisciplinary diagnostic team or as the primary evaluator, neuropsychologists have an important role in the diagnostic process and the transmission of the diagnosis. A number of ethical considerations arise that can influence the process of disclosing a diagnosis of dementia to a cognitively impaired patient.

In order to effectively deal with these concerns it is essential that psychologists recognize the nature of the ethical dilemmas and understand the principles that can guide the decision-making process. These ethical principles are described in the APA Code of Ethics (2002) and include respect for patient autonomy, the concept of do no harm (non-maleficence), the concept of helping the patient (beneficence), and providing the care that the patient deserves (justice) (Beauchamp & Childress, 2001). This paper will address factors to consider when facing the disclosure of a diagnosis of dementia to a patient.
1. Capacity

Mental capacity is comprised of an individual’s ability to comprehend, process, and make informed decisions about information that is available to them. The progressive cognitive decline associated with dementia greatly affects an individual’s ability to understand and process information necessary to make informed decisions (Butler, 2004; Dalnis, 2005; Hughes, 2000; Shah & Dickinson, 1999) and greatly affects their ability to make informed decisions. The issue of informed consent and patients with dementia has been extensively discussed elsewhere (Beck & Shu, 2003; Cohen-Mansfield, 2003; Guerrero & Heller, 2003; Post, 2003; Schiffer & Radebaugh, 2003; Sutton, 2003). A complete discussion of informed consent is outside the purview of this paper but is an important consideration related to the disclosure of a diagnosis of dementia.

Neuropsychologists have to make the decision whether patients with increasing severity of compromised mental capacity are able to process and ultimately benefit from the knowledge of receiving a dementia diagnosis. In patients with dementia, declining mental capacity is inversely related to their level of cognitive functioning (Earnst et al., 2001; Iliffe & Manthorpe, 2004; Shah & Dickinson, 1999). Specifically, capacity is lost when an individual has greatly reduced working memory (Earnst et al., 2001) and impairment of the higher order executive functions (Shah & Dickinson, 1999) that are essential to comprehension, decision-making ability, and cognitive processing. For these reasons, some may consider disclosure futile if the patient lacks capacity (Carpenter & Dave, 2004). On the other hand, if a patient has relatively intact capacity or even partial capacity, disclosure may be appropriate.

Decreased capacity affects the patient’s ability to learn and retain new information, recall historical information, understand even simple concepts, and express themselves. Reduced capacity is not static, but waxes and wanes between lucid and impaired cognitive functioning (Shah & Dickinson, 1999). This waxing and waning of cognitive functioning may be indicative of the fluctuating cognition that is typically seen in patients with delirium and various types of dementia such as dementia with Lewy bodies. Capacity is also case-specific, meaning that an individual may be considered incapable in some domains but be fully capable in others (Brody, 2005). A person may have the capacity to determine where they desire to live but may not be able to manage a complex medication regimen. Capacity is both time specific and task specific. The patient with reduced capacity may have little to no difficulty in understanding and acting on certain tasks, but may have greater difficulty with the same task at certain times of the day, such as at dusk.

Therefore, the determination of a patient’s capacity should be considered relative to the setting, the situation, and the specific skills assessed in order to fairly evaluate the individual. Neuropsychologists and other clinicians involved in the process must assess the patient’s capacity frequently (Butler, 2004) due to the dynamic nature of the dementing process. This assessment is done through the consistent application of clinical judgment (Shah & Dickinson, 1999) comparing the demented person’s capacity to that expected of the “average” person to make specific decisions. The capacity to comprehend the meaning of a diagnosis of dementia may be essential if the disclosure is to be meaningful.

2. Awareness/insight

The patient’s awareness of the nature and severity of their cognitive deficits is another issue for consideration (Whitehouse, Frisoni, & Post, 2004). An individual who possesses good insight and awareness into their deficits is able to verbalize the nature, the severity, and the consequences that their deficits can have on themselves and others. The extent of this awareness has been associated with the patient’s psychological response to receiving a dementia diagnosis (Whitehouse et al., 2004). Prior to receiving a diagnosis, individuals who are aware of their cognitive deficits may experience feelings of isolation and confusion due to their uncertainty of whether they are developing a cognitive disorder (Vernooij-Dassen et al., 2005). Maguire (1996) found that the more aware persons are of their deficits, the more at risk they are for experiencing adverse psychological outcomes subsequent to receiving a diagnosis of dementia. The patient in the late mild to moderate stages of Alzheimer’s may not have adequate awareness to relate the diagnosis of dementia to their own behavior and will likely not benefit from disclosure.

This impaired insight into the nature and severity of the individual’s cognitive deficits is not always due to dementia. It may also be linked to denial and the patient’s inability to cope with the bad news (Monaghan & Begley, 2004; Tuckett, 2004; Whitehouse et al., 2004). The presence of denial adds another dimension to the decision to disclose. It is important to consider the nature and etiology of the lack of insight and the effect that disclosure may have on the patient. The clinical interview, collateral data from family and observation of the patient’s verbalizations during testing can provide information to evaluate the presence of denial. Confronting the patient using denial to cope with fears
about cognitive loss, with their dementia diagnosis may allow them to begin the process of acceptance and prompt the patient to make appropriate lifestyle changes. Conversely, confronting the heavily defended individual with the diagnosis may lead the patient to further retreat from dealing with the disease. Therefore, an important component of a neurocognitive evaluation should include the assessment of the patient’s ability to comprehend and cope with the diagnosis.

3. Autonomy

Understanding the patient’s capacity and level of insight provide the background for the application of ethical principles to the decision to disclose a diagnosis of dementia. One of the cardinal ethical principles in psychology and medicine is respect for the autonomy of the individual. Disclosure decisions are frequently based on respect for the patient’s autonomy (Bamford et al., 2004; Downs, 1999; Heal & Husband, 1998; Hughes, 2000; Husband, 2000; Keightley & Mitchell, 2004; Monaghan & Begley, 2004; Whitehouse et al., 2004; Woods, 2001). Patients have the right to make autonomous decisions concerning their medical and mental health care (Pinner & Bouman, 2003). However, individuals who lack mental capacity are considered incapable of making informed decisions and therefore are considered incapable of giving or actively withholding consent to treatment (Shah & Dickenson, 1999; Smith & Beattie, 2001). This limitation on autonomy means that others must make decisions on their behalf (Dalinis, 2005; Butler, 2004). Most often family members make this decision.

The views of the family may be at odds with the desires of the patient (Hirschman, Joyce, James, Xie, & Karlawish, 2005). A number of studies have found that a majority of families request that dementia diagnoses not be disclosed to their loved one due to their fear of the negative psychological impact of the diagnosis (Maguire, 1996; Pucci, Belardinelli, Borsetti, & Giuliani, 2003; Smith & Beattie, 2001) and for fear that their loved one lacks the capacity to make decisions for themselves (Hirschman et al., 2005). There is the fear that the patient may experience guilt and shame about their diagnosis due to the stigma of being perceived as less capable than others (Brody, 2005; Husband, 2000; Smith & Beattie, 2001). For these reasons, some health care professionals opt to disclose the diagnosis to the patient’s caregivers rather than to the patient (Pinner & Bouman, 2003). This withholding of diagnostic information occurs even when the patient wishes to be told their diagnosis regardless of their caretaker’s desires (Carpenter & Dave, 2004).

Patients, who have the capacity to process and understand information to make an informed decision, retain autonomy. The decision to be told the diagnosis rests with the capable, autonomous patient. If the patient is determined to be capable, their wishes, whether they coincide with their caregiver’s wishes or not, should be the primary determinant for disclosure decisions. If the patient is determined to be incapable, then the wishes of the caregiver must be considered. This does not mean that the patient has to be excluded from the decision-making process. Obtaining the patient’s assent to treatment and disclosure helps to ensure that the patient’s preferences are considered. Obtaining a patients’ assent involves providing ample information that is explained in terms appropriate to the patient’s level of cognitive functioning and asking their desires. For example, asking “Even if it is bad news, do you want to be told what we have found from our testing? Do you wish to know your diagnosis?” are questions that give us an indication of the patient’s wishes.

The patient is then provided the opportunity to agree to participate in their care with the legal responsibility of consenting to treatment being provided by their legal caregiver/guardian. Obtaining assent not only honors the autonomy of the patient but also involves the patient with dementia in the decision process. The patient retains a level of autonomy but decisions concerning the patient’s medical and mental health care needs are made by a capable individual (Coverdale, McCullough, Molinari, & Workman, 2006).

4. Harm

The ethical principle of non-malificence requires the consideration of the psychological impact the diagnosis may have on the patient. There has been a concern that patients receiving a diagnosis may experience psychological harm (Pinner & Bouman, 2003; Pucci et al., 2003; Smith & Beattie, 2001). This harm may occur in the form of depression (Smith & Beattie, 2001; Waite, Bebbington, Skelton-Robinson, & Orrell, 2004) and/or suicidal ideation (Carpenter & Dave, 2004; Jha, Tabet, & Orrell, 2001). Although this concern is widely held, there is no significant evidence that being told a dementia diagnosis causes depression (Jha et al., 2001).
Receiving a diagnosis of dementia has been related to short-term negative affect rather than depression (Carpenter & Dave, 2004). Those who do experience significant depression may have already had a diagnosable depression that was exacerbated by their learning the new diagnosis (Pinner & Bouman, 2003). A recent exploratory qualitative study of the emotional impact of disclosure (Amirinzadeh, Byzewski, Molnar, & Eisner, 2007) found a range of responses from active denial, to grief to positive coping in response to a dementia diagnosis. Applying the principle of “do no harm” requires the neuropsychologist to take into consideration the patient’s history of depression, available cognitive and social resources and coping skills in the decision to disclose.

5. Truth telling

Helping the patient and providing the best treatment for the patient requires giving the patient the best information available. In the past, it has been common practice (Downs, 1999; Tuckett, 2004) for health care professionals to either not tell the patient the truth about their diagnosis, or to use deceit when delivering the diagnosis. The patient may be told that they have “memory problems” or “have trouble remembering” (Pinner & Bouman, 2003) instead of being told their actual diagnosis of dementia. Even though this has been common practice in medical settings, most patients want their clinician to be truthful with them (Tuckett, 2004; Jha et al., 2001). The practice of not being truthful with the patient has significant consequences. Deceit can greatly compromise the professional relationship (Marzanski, 2000; Wilkinson & Milne, 2003) and can lead to a breakdown of the patients’ trust. This loss of trust increases the likelihood of the patient having a negative emotional response (Waite et al., 2004). Deceit can be seen as infringing on the rights of the patient (Marzanski, 2000) and can impact the patient’s relationship with family members as well as health care professionals (Pinner & Bouman, 2003). Consideration of the individual’s capacity, level of awareness, psychological and social resources and the wishes of the patient is essential in deciding whether to directly disclose the diagnosis or to soften the blow of the diagnosis by using deceit. In general there is little to be gained by deceit and more harm than good may be the result.

6. Conclusions

When, how and if the diagnosis of dementia should be disclosed to the patient is an issue with ethical and practical consequences. It is our view that advantages of disclosing a dementia diagnosis to a patient outweigh the disadvantages. Disclosure respects the patient’s autonomy and makes it possible for the patient to be a more active participant in their treatment to whatever degree their level of cognitive functioning allows. If the patient is early in the dementing process disclosure ensures that the patient can be an informed participant in treatment decisions (Carpenter & Dave, 2004; Smith & Beattie, 2001; Wilkinson & Milne, 2003). Timely knowledge of the diagnosis may help the patient make lifestyle changes and put their personal affairs in order prior to becoming incapable to do so on their own (Jha et al., 2001).

Gauging the patient’s emotional response and responding to it is vital in respecting the patient’s feelings. This may help to reduce psychological harm to the patient. Moreover, it is important to provide ample information about dementia to the patient to help ensure that they understand their diagnosis. Follow-up sessions and possibly therapy may be needed to answer the patients’ questions and also help them to cope with their diagnosis. Simply asking the patient whether they want to be told their diagnosis prior to assessment enables the patient to be more autonomous thus improving the therapeutic relationship (Wilkinson & Milne, 2003).

Disclosure does not necessarily need to occur in one session. Many patients may benefit from gradual disclosure over a few sessions while others may be able to cope with a more immediate disclosure with minimal adverse reaction (Whitehouse et al., 2004). The neuropsychologist needs to take into account the characteristics of the patient that may affect the pace and approach to disclosing the diagnosis. Different methods of disclosure such as disclosing the diagnosis separately to the patient and family or having a trusted caregiver present to provide support for the patient are options that can be discussed with the patient and family. The careful choice of individualized methods of disclosure will enhance the effectiveness of the health care professional and maintain the dignity of the patient.

In many settings the disclosure of the diagnosis is done by another health care professional who uses the report of the assessing neuropsychologist as part of the overall diagnostic determination. Neuropsychologists may have little or no direct involvement in the decision. However, neuropsychological assessment involving a clinical interview, rapport building and extended interaction may place the neuropsychologist in the best position to assess the wishes and possible
impact of disclosure. It is important to transmit to the attending either through the report or other written means any specific information that may impact the decision to disclose the dementia diagnosis.

The process of disclosure should be individualized to take into consideration the needs of the caregiver and the patient’s cognitive and emotional state, along with their specific needs and desires. Disclosing the diagnosis not only respects the autonomy of the patient but also maximizes the value of the diagnostic process. The method of delivering a diagnosis should be carefully considered. The patient’s capacity and awareness of their deficits are especially important in the decision to disclose. No single approach to the disclosure process is more valuable than any other. Being flexible and using clinical judgment is critical when making disclosure decisions. Ethical considerations are important guides to help us keep the patient’s best interest in mind throughout this process.

References


