2 Diagnosis and Support of Patients with Dementia: A Patient Perspective on Current Goals and Practice

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Abbreviation

AE	Alzheimer Europe

Introduction

It is estimated that approximately nine million people in Europe have dementia [1]. Although the main symptoms of dementia are cognitive, dementia can affect all aspects of a person's life and their relationships with others. Each person is unique and may experience dementia in a different way. The symptoms that a person experiences may also differ depending on the type of dementia. With appropriate support, many people with dementia can live a good life.

Diagnosis is a key aspect of the management of dementia, in particular the way people affected by dementia (e.g. the patient and the carer) experience it. In addition, to ensure that people with dementia can carry on with their activities and live independently for as long as possible, appropriate and timely support should be provided to the patient and their family. This includes pharmacological as well as psycho-social treatments and interventions, as well as a supportive environment (e.g. inclusive communities where there is awareness and understanding of dementia, and patients with dementia feel safe and enabled to engage). In this chapter, we provide a brief overview of key issues related to timely diagnosis, disclosure of the diagnosis and care and support, followed for each topic by a reflection on the

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current situation, drawing on the findings of existing surveys carried out by Alzheimer Europe (AE) and with supporting commentaries from people with dementia.

Timely Diagnosis

Key Issues

A diagnosis can allow people to plan better for their future and to start treatments/interventions. It may help them to understand the condition better and to find ways of coping with the disease. Some patients with dementia and carers have described certain practical and psychological benefits of being diagnosed, such as putting an end to uncertainties and enabling them to access relevant support and care. Potential negative consequences of diagnosis include feeling distressed or experiencing stigma. "Therapeutic nihilism" may interfere with the diagnosis of dementia. This involves the belief held by some healthcare professionals that it is pointless to diagnose dementia as there is no treatment, a risk of stigma and as they feel they have nothing to offer [2–4].

Access to an early or timely diagnosis of dementia has become a policy and practice imperative [5], but the terms "early" and "timely" are often used interchangeably [6]. However, "timely" refers to a diagnosis that is made at the right time for a particular person, whereas "early" focuses on a diagnosis that is made early (i.e. in the chronological sense) [7]. According to Woods et al. [8, p. 321] timely diagnoses "prevent crises, facilitate adjustment and provide access to treatments and support." In most cases, an early diagnosis is also considered a timely diagnosis but in keeping with a person-centred approach, timely diagnosis is not linked to a particular disease stage but to its potential benefit to the individual patient [7]. It is therefore a very personal matter and raises the issue of whether and how to communicate a diagnosis of dementia, which is addressed in section "Disclosure of the diagnosis."

The underlying processes which result in dementia usually build up over several years, and it may take weeks, months or even years for a diagnosis to be made. Current research trends are moving in the direction of early, pre-clinical indicators of the pathological processes leading to, and underlying dementia. Indeed, the National Council on Ageing, Alzheimer's Association and the International Working Group promote the use of pre-clinical/asymptomatic biomarkers as accurate diagnostic tests, but as Rosin et al. [9] point out, this is primarily within a research framework, and more work is needed before they are incorporated into clinical practice. A key issue in relation to the management of dementia is therefore to agree on when the diagnostic procedure starts and how information that may be available about the risk of developing dementia is communicated to patients.

Another issue is that of equity. All citizens of Europe should have the opportunity to receive information about their risk status and to receive a timely diagnosis of dementia. This is currently not the case. In some countries, diagnosis and the detection of risk factors are fairly advanced. In others, people struggle to obtain a diagnosis at all, do not benefit from the latest scientific advances in diagnosis and/or are assessed using tools and instruments that are not suited to their needs and have not been validated on people with their characteristics (e.g. for many people from minority ethnic groups) [10]. This means that people do not all have access to the same potential benefits, including appropriate treatment and support and taking part in research. Such discrimination may be linked to a range of factors (e.g. attitudes of healthcare professionals, stigma, lack of resources, assumptions about the value of diagnosis, lack of training, etc.). There is still much to be done in order to achieve equity with regard to the diagnosis of dementia in Europe.

Practice and Perspectives

Currently, in Europe, many people affected by dementia still feel that diagnosis takes too long or is made too late. In a survey that AE carried out in 2006 in six European countries [11], carers reported that it had taken on average, 2 years and 2 months to get a diagnosis of dementia (i.e. from first symptoms to diagnosis). In addition, the survey also revealed important differences between countries, as carers in Germany reported on average 10 months to get a diagnosis whereas carers in the UK who had experienced a much longer timeframe (32 months on average). In a similar survey carried out in 2018, over a decade later [12], and involving 1409 carers in five European countries, carers reported an average length of time of 2.1 years between problems being noticed and the diagnosis being made, with the shorter times reported in the Czech Republic (1.6 years) and the longest in the Netherlands (2.6 years). These two surveys conducted a decade apart, showed that the length of time elapsing between the patient with dementia or carer noticing problems and a diagnosis being made had pretty much stayed the same.

The second survey [12] also showed that it often took more than 1 year for people to seek help since the first symptoms are noticed and that the decision to seek help is more likely to be made by a family member (64% in the AE survey) or in some cases, jointly by the patient with dementia and a family member (27%) (but only in 4% of the cases by the patient on his/her own). The quote below from a member of AE's European Working Group of People with Dementia (EWGPWD) refers to this time prior to diagnosis when first symptoms may be noticed but the patient often cannot make sense of them:

> My diagnosis came after a number of years of wondering what was wrong with me. At work the in-tray was not moving, I found myself at a Board meeting struggling for words. I thought I was losing my mind. (Helen Rochford-Brennan, Ireland)

Other important aspects include the stage of dementia at the time of diagnosis, and the perceived “timeliness” of the diagnosis. In the 2018 AE survey [12], 40% of people had been diagnosed at moderate or advanced stages of dementia and over half of the carers felt that the diagnosis should have been made earlier. Carers of people diagnosed at later stages tended to report more often that the diagnosis should have been made earlier and vice versa; when people with dementia had been diagnosed at a milder stage, carers tended to identify this as “the right time” for diagnosis. Still, more than a third of the people diagnosed at a mild stage would have preferred an earlier diagnosis.

The most frequent reasons mentioned by the carers in the survey for the late diagnosis were related to the carer’s lack of awareness of dementia, the patient refusing to seek help, and the attitudes of the doctor (e.g. not considering that anything was wrong, or that it was worthwhile pursuing diagnosis). Also, waiting lists or long time needed for referral or assessments were highlighted as reasons for the delay. The excerpts below from two members of the EWGPWD provide examples of additional challenges and reasons for the delay of diagnosis experienced by people with dementia who are diagnosed before the age of 60 or with a less common form of dementia:

> Many people know of Alzheimer’s disease only as disease of older people, and only of the last stage of the disease. They don’t know about the different stages of the disease and that this disease can affect younger people. (Nina Baláčková, Czech Republic)

> I received a diagnosis of Frontotemporal dementia (FTD) at the age of 52 (…) Before the diagnosis of FTD I was diagnosed with depression. This is not unusual for people with dementia. Also, FTD is very rare in Finland and this made the diagnosis even more difficult (…) Several doctors were taking care of me, but they did not talk enough to each other. No one seemed to know what was happening to me. (..) (Petri Lampinen, Finland)

Disclosure of the Diagnosis

Key Issues

The potential benefits of a timely diagnosis are largely dependent on disclosure of the diagnosis, which is also linked to the ethical principle of autonomy. Some carers do not want the patient with dementia to be informed [13–15]. However, three recent systematic literature reviews of the diagnosis of dementia all report that the majority of people with and without cognitive impairment, within the primary care context as well as in memory clinics, prefer to be informed of a possible diagnosis of dementia [16–18]. Nevertheless, some people do not want to know and state this very clearly [19]. The right not to know is equally important, and for this to be a genuine choice, people need to understand fully what such a diagnosis means and hence what the implications of a diagnosis might be for them.

The practice of disclosing the diagnosis to carers and not to people with dementia used to be quite common [20]. Informing relatives of a diagnosis of dementia, but not the person who has dementia, could be considered as a failure to respect the autonomy and right of the latter to privacy and as breaching medical professionals’ obligations with regard to confidentiality. It could be considered as running counter to the principles of beneficence and non-maleficence, although in some cases, disclosure to relatives may be considered justifiable (e.g. to ensure the care of a patient with very advanced dementia), provided that the patient had not clearly stated that certain people should not be informed. Disclosing the diagnosis solely to relatives makes them responsible for informing the patient even though they may lack the necessary information, understanding of the condition or skills to be able to carry out this task effectively and might not even be in favour of sharing the diagnosis.

Medical professionals should not inform carers of the diagnosis simply to avoid personal responsibility for disclosure of the diagnosis to the patient with dementia. Responsibility for the disclosure of the diagnosis must be clear and transparent. It should not be left to hazard or assumed to have been addressed by relatives and close friends of the person with dementia. People with dementia have a legal right to be informed (even if they choose not to be informed) and it should be documented whether and by whom the diagnosis was communicated. However, it should not be assumed that because someone has a diagnosis, they necessarily accept it or want to talk about having Alzheimer's disease, for example. Some people may be aware of their diagnosis but prefer to refer to the condition by a different name (e.g. preferring to talk about having "memory problems") [21].

Bailey, Dooley and McCabe [22] emphasise the need for doctors to tailor communication of the diagnosis to their patients' preferences and awareness, to consider which information can be discussed in the presence of carers and to create the right balance between honesty and hope when discussing prognosis and medication, bearing in mind how the cognitive impairment affects understanding. They point out that misunderstandings may limit the opportunities that people with dementia have to take an active role in decision making and hence in exercising their legal capacity, otherwise offered by timely diagnosis. According to Bailey et al. [22], disclosure is a delicate, complex and nuanced task, which can also be emotionally challenging, and for which many healthcare professionals would benefit from training and supervision.

It is considered unethical and illegal to treat or involve people in research who have not given informed consent (i.e. have not consented after having been provided with information that is suited to their ability to understand and that they have understood). With diagnosis, the same principle should apply. It might be argued that with diagnosis, there is no decision to be made and no issue of interference with a person's physical integrity. However, a diagnosis can be life changing and affect a whole range of future decisions, not least deciding whether to consent to symptomatic treatment that might be proposed. Clarity, precision, sensitivity and an understanding of people's current understanding of dementia are needed when informing people of a diagnosis. More research is needed into the psychological, emotional and social impact of receiving information about AD at all stages along the continuum (linked to pre-clinical, including at-risk status, prodromal AD or MCI due to AD and AD dementia).

Recent changes in the conceptualisation of Alzheimer's disease necessitate care and attention by healthcare professionals and researchers using such terms. Increasingly, laypeople have access to information on the Internet about dementia research where the use of the term "Alzheimer's disease" by professionals and academics does not necessarily correspond to their everyday use and understanding of that term. The use of euphemisms or non-medical terms by doctors to help patients understand diagnoses of dementia [23, 24] may further muddy the waters. Papers on the conceptual framework and lexicon (e.g. [25, 26]) are important for healthcare professionals and academics in clarifying conceptual changes and the accompanying terminology, but at the level of actual diagnosis and in society in general, it is important to address broader perceptions and understandings of disease, health and risk, the boundaries between the two and the implications of these for people's lives.

Additional attention is needed when discussing dementia and disclosing a diagnosis of dementia to people from minority ethnic groups, many of whom (but by no means all) may have limited knowledge of the national language, lower levels of education and different beliefs about the origin and nature of dementia (Alzheimer Europe 2018). In some ethnic communities, there is no word for dementia in everyday language and dementia is not seen as a medical condition. This has implications for preventive measures, diagnosis of dementia, disclosure of that diagnosis and subsequent access to care and support.

Practices and Perspectives

Disclosure and Quality

The AE 2018 survey [12] indicated that, although disclosing the diagnosis to the patient with dementia may have become a common practice in many countries, this is still not the case everywhere. People living in some countries may be less likely than others of being informed of their diagnosis. In the AE survey, whilst 99% of people living in Finland had been told their diagnosis, 59% of the Italian carers stated that the patient had not been informed of the diagnosis.

Overall, the reasons for not informing the patient with dementia included: the belief that they would not understand or were not aware, not wanting to upset them, or that the family thought it unnecessary, or the doctor had advised against telling the patient. In only a small proportion of cases (10%) had the decision to not inform been based on the expressed wish of the patient not to know.

The reasons for nondisclosure fell into four main categories: not wishing to upset the person, the person would not understand or was not aware, the family thought it unnecessary, and the doctor advised against telling the person.

Half of the carers stated that the patient with dementia had not been consulted in advance about who they would like to be present when the diagnosis would be disclosed. A carer had been present in the meeting where the diagnosis had been disclosed in 89% of the cases. Although in only a small proportion the carer had not been present during the disclosure, the following quote from a member of the EWGPWG highlights the relevance of this topic:

> A psychologist that I'd never met before was called in and she said "I'm sorry to tell you the scan has shown vascular dementia" (…) Nobody should be told they've got a serious illness alone (Carol Hargreaves, UK).

When the diagnosis was communicated, the experience of the carers in the survey tended to be quite positive, and many felt satisfied with the way diagnosis was communicated (i.e. 73% of the carers felt the doctor was well prepared and clear, and 62% felt the doctor had established a good relationship with the patient with dementia and the carer). Issues to improve in the disclosure to the carers, including the length of the meeting and opportunities for asking questions without the patient being present. There was also room for improvement in the disclosure to the patient with dementia as 28% of the carers thought the patient had not understood the diagnosis, and one in five stated that, during the meeting, the doctor had spoken mainly to them (rather than to the patient with dementia).

Reactions to Diagnosis

Some common reactions to the diagnosis are worry, uncertainty and sadness. In the 2018 AE survey [12], at the time of diagnosis, 74% of carers and around 30% of people with dementia felt worried about the future, and several were uncertain about the implications of the diagnosis. Over time, whilst many carers still felt worried about the future, acceptance was also very often reported. Feelings of sadness seemed common in both people with dementia and carers at the time of diagnosis and over time.

The results of the AE survey also suggested that the way the patient reacts to diagnosis may be linked to the timeliness of the diagnosis and the quality of the disclosure [6]. Carers who felt the diagnosis was not timely were more likely to report negative emotions and worries about the future at the time of diagnosis and 4 years later [6]. On the other hand, the survey also showed that a higher quality of diagnosis-sharing was associated with lower sadness and depression, despair, and greater acceptance and reassurance, both immediately after diagnosis and some time afterwards [6].

Sharing the Diagnosis with Others and Perceptions of Their Community

The decision to share the diagnosis with others is very important, as this may be an important step towards integrating dementia into the person's life. In the AE survey, only 2% of the carers said that no one else knew about the diagnosis. The people with whom carers had more often shared the diagnosis with were family members and, to a lesser extent, friends and neighbours. However, as the quote from a member of the EWGPWD describes below, telling people, even the closest ones is not always easy,

> After meeting with the doctor, I had to drive home over 60 miles and wondered how I was going to tell my husband and son (Helen Rochford-Brennan, Ireland)

The diagnosis was more rarely shared with other members of the community, such as members of clubs/churches attended by the person with dementia or local shopkeepers.

Overall, 38% did not agree with the statement about people in their community being aware of dementia; however nearly 60% felt that the patient with dementia was valued and respected by other people and continued to have an important role in his/her family and 44% felt that the patient was still part of their local community.

The quote below from a member of the EWGPWD describes the relevance, from the perspective of this person with dementia, of sharing the diagnosis with others and feeling included and part of the community where he lives,

> I was diagnosed with vascular dementia in 2010. (…) From early on it has been important for me to make other people aware of my situation. Whether I have lived in a large or small community my experience is that being open about my situation has made everyday life easier. People around me are accommodating and I feel included. Although my contributions may be somewhat limited at times, I experience that I still have a role to play and something to give, practically or in discussions and meetings. (Alv Orheim, Norway)

It is important also to consider, as in the examples provided by members of the EWGPWD below, that in some cases, people with dementia may feel that their freedom or their role in the family or in society may be restricted (e.g. not being allowed to do things on their own, not being asked or making decisions on their behalf, etc.)

> Two years after the diagnosis I had to return my driving license based on neuropsychological tests. I had been driving since I was 18 and it felt like I was deprived of my human rights. (Raoul Grönqvist, Finland)

> In the early days of my diagnosis, I jokingly said 'I'm not ready to give up my credit card just yet'. I said this because we know too often that a dementia diagnosis can mean a person is denied basic rights like the right to manage their own finance or the freedom to travel (Helen Rochford-Brennan, Ireland).

Care and Support

Key Issues

Receiving a timely diagnosis of dementia ideally opens the door to support, care and symptomatic treatment. Unfortunately, there are regional and national differences with regard to the availability of and access to post-diagnostic support. Sometimes, support is unavailable, too expensive, not suited to a person's needs or they are not entitled to it (e.g. if it is means tested, prioritised for people at a certain stage of dementia or restricted to certain age groups).

Where care or support is simply lacking, it could be asked whether this is linked to the lower value and priority attributed to older people, people with disabilities or people with mental health conditions (depending on how dementia is perceived in different societies), and thus a reflection of stigma. Stigma, linked to having the condition, or in some minority ethnic groups linked to whole families (based on the belief that dementia is a punishment or test from God), may also interfere with people's readiness to use available services because doing so would mean being associated with the condition and other people knowing about it. This issue also applies to seeking a diagnosis.

Other barriers to seeking post-diagnostic support and care include, amongst others, a distrust of healthcare professionals and the feeling that outside help would not be appropriate or is not yet needed. In some cases, people are not aware of available services or have difficulty navigating the complex healthcare system to benefit from them. Such barriers may be particularly common amongst, but in no way limited to, people from minority ethnic groups, especially those who have difficulties with the national language or who have experienced discrimination and prejudice in the past within the healthcare system [10]. Information about care and support needs to be communicated in different languages, in culturally appropriate places, by trusted members of the community and not solely in written form (so that people who have language or literacy problems, or visual impairments, can also benefit from such information).

This is a matter of equity in the provision of care and support, which applies to everyone. Particular groups of people risk discrimination and exclusion in the context of care and support not because of personal characteristics but because of historic, economic, political and social factors which result in the care and support available being less suited to their needs and preferences. The principles and practice of person-centred care and reasonable accommodation[1] should help ensure that care and support are provided which corresponds to each person's needs and preferences, and that they are involved in defining what these are. In keeping with the right to exercise their legal capacity, a full discussion about needs and preferences requires that people with dementia are informed of their diagnosis, understand the personal implications of it, and that they have the opportunity to benefit from shared or supported decision making if they so wish.

Practices and Perspectives

Information Received

Access to high-quality information at the time of diagnosis and over the course of the disease is essential for helping the individual adjust to dementia and to facilitate access to adequate support and services. The surveys carried out by AE in 2006 and 2018 [11, 12] suggested that some people with dementia and carers may not receive any information at the time of diagnosis. Although the surveys were conducted a decade apart, in both cases, 19% of the carers participating in the surveys reported that they had not received any information at the time of diagnosis. The following quote from a carer of a member of the EWGPWD describes this in a very powerful manner:

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[1] Principle in the Convention on the Rights of Persons with Disabilities (2006), which states that reasonable adaptations should be made to ensure that people with disabilities enjoy the same rights and opportunities as other members of society.

> We were given the diagnosis, passed a few leaflets, and sent home. The silence was deafening. We didn't know who to turn to or where to go for information, for help, for solace. We each hit the internet separately, not wanting to upset the other, especially with what Dr Google told us. We had no hope (Jayne Goodrick, UK)

In the cases where information was provided, carers felt somewhat satisfied with the quality of the information received (i.e. 3.5 on average on a scale from 1 to 5). This information was most often related to the medical aspects of dementia (e.g. drug treatments, dementia and disease progression). Only around a quarter of the carers had received information on available services, support groups and healthy lifestyles. In all cases, the patient with dementia was less likely to receive information than the carer. Information about taking part in research was the type of information which fewest carers received. Topics, where carers would have appreciated further information, included practical advice about coping and living well with dementia, available services and disease progression. Other areas that were often neglected were information on care allowances, legal rights/issues and existing help and support groups.

The findings of the AE survey [12] also suggested that there were important differences in the type of information provided by country. For example the information received at the time of diagnosis in Italy and the Czech Republic tended to focus on medical aspects, whereas in the Netherlands, Finland and Scotland, carers were more often informed about Alzheimer's associations and available help/support groups.

In addition to the information received at the time of diagnosis, people affected by dementia often wish to keep up-to-date with issues related to dementia in order to better manage the disease. In the AE survey, the most popular sources of information were the Internet and Alzheimer's associations—with around two-thirds of the carers reporting these were the main sources of information used in their daily lives.

Care and Support

In the AE survey [12], the services which most carers were offered and which they used in the 6 months following diagnosis were contact with a named person or service ("case-manager" for signposting to services), day care and assessment of the needs of the patient with dementia. The information for which more carers took action included starting a drug treatment, arrangements for the management of the finances of the patient with dementia in the future and joining an Alzheimer association.

Services not offered but which carers would have liked to use included: assessment of needs, counselling/emotional support, education about living with dementia and memory training for the patient with dementia. The quote below from a member of the EWGPWD exemplifies the importance of receiving adequate support and interventions:

> My diagnosis led me to cognitive rehabilitation therapy, research through Trinity College and the Irish Dementia Working Group. (Helen Rochford-Brennan, Ireland)

Conclusions

There is widescale agreement about the importance of a timely diagnosis of dementia, but further work is still needed to address factors affecting the readiness to seek diagnosis, such as stigma, the normalisation of dementia, linguistic barriers, lack of health literacy and the belief that nothing can be done. Improvements are also needed with regard to disclosure and the provision of appropriate support and care following diagnosis. In the last decade, despite medical progress and better diagnostic procedures, as well as several national dementia strategies addressing the topic of diagnosis, there seems to be a lack of progress with regard to disclosure of the diagnosis to people with dementia. There is also an important gap in terms of equity and access to good quality post-diagnostic services and support across Europe. This is often even more challenging for people from minority ethnic groups. As Alzheimer's disease has been reconceptualised as a spectrum, careful attention needs to be paid during diagnosis as to how terms such as MCI, prodromal AD or AD dementia may be understood by patients.

Every person with dementia should have the opportunity to be informed about their diagnosis and the right not to be informed. People should be given the opportunity to be accompanied, if they so wish, by a relative, friend or person of their choice when being informed of the diagnosis. This should be communicated in a way that is clear and adapted to each person's needs, including written information and signposting about services and support. A diagnosis of dementia should be perceived as a process rather than a one-off exchange of information and should be followed by post-diagnostic support within a framework of advanced care planning.

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