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To what extent does diagnosis matter? Dementia diagnosis, trouble interpretation and caregiving network dynamics

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Abstract   Contemporary research into health and mental health treats diagnosis as a central step in understanding illness management and trajectory; consequently, in the last two decades, sociology of diagnosis has attained increasing influence within medical sociology. Deeply embedded in social constructionism, the set of research divides between those who focus on the social and historical construction of diagnoses as categories, and those who see diagnosis as a process. Regarding the latter, this approach explores the constitution of the medical production, highlighting how it constitutes a starting point for entering a 'sick role', for being labelled, for naming one's problem and by extension, for framing one's illness narrative.

Keywords: dementia, diagnosis, caregiving, Alzheimer's disease, time to diagnosis, labelling

Introduction

Most current studies that deal with dementia,[1] as well as with other health issues, are generally grounded on a usual model of the diagnosis process: symptoms → diagnosis → meaning and caregiving network mobilisation.[2] Accordingly, 'time to diagnosis', meaning the time elapsed from the onset of symptoms to the diagnosis itself, is often interpreted as a tool which measures the efficiency of informal caregiving and health care systems (Alzheimer's Association 2015, Cattel *et al.* 2000, Salloway & Correia 2009). Theoretically, the shorter the time, the more efficient professionals and patients' relatives are in detecting the disease, and by extension, organising caregiving. Since Western societies are undergoing population ageing, as well as an increase in the number of people diagnosed with dementia, reducing time to dementia diagnosis would be a major concern. Indeed, from a medical point of view, having an early diagnosis might maximise the effect of medication (Chu 2012, Petersen *et al.* 2005)*,* and from a social point of view, it would foster the organisation of care (De Vugt & Verhey 2013, Teel 2004). From a public health and economic point of view, early diagnosis would reduce the cost associated with dementia for public institutions (Getsios *et al.* 2012) and it therefore appears as one of the most sustainable economic attitudes towards dementia (Banerjee 2012, Chinthapalli 2012, Wimo *et al.* 2013). Consequently, most national and international health authorities, such as the World Health Organisation, call for early diagnosis (Waite 2012),

understood as a reduction of the time to diagnosis. Extensive literature attempts to identify social determinants of this time (Schrauf & Iris 2011, van Vliet *et al.* 2013, Rapp 2014), while the benefits of early diagnosis are rarely questioned.

Many works address pathways to dementia diagnosis, from a familial perspective (Koehn *et al.* 2014, Krull 2005), or a professional perspective (Gove *et al.* 2015, Hansen *et al.* 2008). Furthermore, they examine how relatives make interpretations of and react to the diagnosis disclosure, highlighting either diverse representations of the disease (Belgrave *et al.* 2004, Béliard and Eideliman 2014), diverse reactions to its announcement (Aminzadeh *et al.* 2007, Robinson et al. 2005, Smith and Beattie 2001) or diverse social impacts, especially on relationships (Vernooij-Dassen *et al.* 2006, Weaks *et al.* 2015). Furthermore, the emphasis on diagnosis in dementia research is partly due to a methodological necessity: most researchers can recruit their participants, only because they are diagnosed and under the assumption that diagnosis marks the beginning of medical monitoring and family caregiving, or even a 'biographical disruption' in patients' lives (Bury 1982).

However, the results of our longitudinal interview study, conducted among 60 caregivers of patients diagnosed with Alzheimer's disease, suggest that the usual model of diagnosis [symptoms → diagnosis → meaning and caregiving network mobilisation] should be nuanced, at least in the case of dementia. On one hand, our research suggests that the diagnosis does not really follow increased symptoms, but occurs rather through a process involving the observability of patients' troubles and their interpretation of said troubles as requiring medical assistance – what we will call the trouble-observability-interpretation convergence. On the other hand, diagnosis does not systematically trigger a mobilisation of a caregiving network, as already suggested by Carpentier *et al.* 2010. Conversely, our study shows that the caregiving network mobilisation may follow the diagnosis, but that it can also provoke it, prevent it for a certain amount of time, or it may even have no immediate impact on the patient's situation. As Harris (2009) revealed with hepatitis C, diagnosis does not always imply a biographical disruption.

These observations beg the question: 'To what extent does diagnosis matter?'. We indeed aim to question the centrality of diagnosis in the early illness trajectory, its crucial role on the mobilisation of a caregiving network, the way in which increased symptoms lead to diagnosis, that are often taken for granted, especially in the case of dementia. In the field of mental health, some works have addressed these issues, especially through the labelling theory (Scheff 1966), but diagnosis continues to be treated as a self-evident turning point. After presenting our research more specifically, we will examine the processes at stake in the time between the onset of symptoms and the official diagnosis and later, the intertwining relationship between diagnosis and the potential mobilisation of a caregiving network. Furthermore, we intend to discuss the status of diagnosis in illness trajectory and will distinguish 'anticipation diagnosis' from 'emergency diagnosis'.

Research design

This article is a result of a research study which addresses more broadly how caregiving networks – networks associating relatives as well as professionals – take place around patients diagnosed with dementia, along their whole illness trajectory. It examines the mechanisms underlying the creation, maintenance, and dissolution of ties in caregiver support networks.

To address this question, we recruited 60 caregivers from two clinics specialised in the detection and treatment of memory problems in Montreal, Canada. These two facilities were chosen because, at the time, they were the most active facilities in the field of dementia detection and specialised care. The first clinic is run by a small team and has only just begun

research activities. The second has been open longer and employs a greater number of biomedical researchers that specialise in pharmacological research. The latter has developed a network of over 100 family doctors who promptly refer any elderly patient whom they suspect has memory problems. Referred to us by their relative's geriatrician, participants had to meet two selection criteria: they had to be the primary caregivers of persons over the age of 65 years who were diagnosed with dementia of the Alzheimer type, and they had to be in the initial stage of their caregiving careers, that is, in the first few months following diagnosis. The aim of this research was not to constitute a representative sample, but to meet a broad diversity of participants; thus, these caregivers are mostly women (43 out of 60) and patients almost equally men (28) and women (32). Caregivers mainly belong to middle classes (34), then working classes (16) and upper classes (10); they are Francophone (30), Anglophone (24) or from other linguistic communities (migrants, 6). They are mostly the spouse of the patient (40), and the rest are their children (20).

The survey initially started in 2003, following an investigative phase which started two years prior. The initial interviews with participants lasted until 2006. We then tracked the evolution of the caregivers' situations and conducted interviews every two years, until 2012. At this point, we organised our data and focused on analysis. An increasing number of participants could not be located (most likely related to the institutionalisation of the patient), while others had died or were in such physical and cognitive conditions that they were no longer able to participate. Consequently, we conducted a second interview with 50 participants (most of them from 2005 to 2008), a third one with 40 participants (from 2007 to 2010), a fourth interview with 20 participants (2009 to 2011), a fifth with 11 participants and a sixth with only 4 participants (from 2010).

The qualitative interviews were comprised of three sections, inspired both by social sciences literature on caregiving (which allowed us to review all different forms of care we could question participants about) and a network approach (what we needed to know, in order to reconstitute the caregiving network – i.e. the 'name generator'). In the first section, we asked a series of questions, focusing on the beginning of the care trajectory. The caregiver was asked to describe the context in which s/he lived at the time the symptoms first manifested and to give her/his impressions of the initial manifestations of the disease. In the second section, the caregiver's social network was reconstructed, using a 'name generator', derived from seven questions concerning the composition of the actors providing the patient with emotional, instrumental, social or information-related support. For each member of the network identified, we obtained socio-demographic information, as well as details on the duration of the relationship and their experience of caring for an elderly person. In the third section, the question, 'What brought you to visit a doctor and seek help from the memory clinic?', was used to document the respondent's social relationships, as well as the resources and assistance obtained during his/her entry into the care trajectory. The interviews, which on average lasted 1 hour, were tape-recorded and fully transcribed. Because we use a standardised coding system, we did not change the questions over time; however, interviews were relatively flexible, depending on the interviewee's developments and we invited the participants to add whatever information they found relevant.

This paper is primarily based on qualitative analyses, with the help of a coding system aimed at emphasising action sequences and the role of each actor in the patient's network (Carpentier 2011). Our goal is to go back and forth between standardised coding and systematic reading of interviews, in order to examine recurrent processes: trying to combine (and in doing so, extend beyond) the generalisation potential of coding and the precision of case studies. When possible, we quantified some 'variables' that appeared to be significant in the progress of patients' stories, without any pretension of being representative (for example 'time to diagnosis'). More specifically, the first analytical session comes from the systematic study of

the parts of interviews that narrate what happened from the onset of symptoms to the actual diagnosis. In all narratives, we identified what processes were at stake and synthesised them with the categories of observability and interpretation. The second analytical section stems from a more formalised procedure: we reviewed the mobilisation of caregiving networks and put them in perspective with the timing of diagnosis. This led to the identification of the four possibilities presented below.

Let us note that in our sample, the mean time to diagnosis is 18, 67 months (with a standard deviation of 13, 7), keeping in mind that this is not a representative sample and that we generally observe striking discrepancies in surveys measuring time to diagnosis in Alzheimer's disease: 22, 4 months in a Kentucky hospital (Wackerbarth & Johnson 2002), 13, 8 in a memory clinic in Roma (Cattel *et al. 20*00), 28, 4 in Spain (Alom Poveda *et al*. 2013), 12 in a set of countries including Australia, France, Italy, Spain and the United Kingdom (Wilkinson *et al*. 2004).

This method presents some limitations. On the one hand, recruitment was made through the healthcare system, which means that the consenting participants may have been more inclined to endorse the medical point of view regarding diagnosis. On the other hand, we met with only one caregiver in each caregiving network and we may have collected different data if we had met with multiple caregivers of the same network. However, these limitations appeared to be necessary for the feasibility of the study. We needed to recruit a consequent number of participants (which required the help of some health institutions) and preferred to meet with one caregiver, in order to create a privileged link of confidentiality throughout our longitudinal survey.

For practical reasons, and in order to preserve their anonymity, we numbered participants in chronological order of recruitment. We mainly use the word 'case' to describe them and their relatives, in order to emphasise the fact that the participants surveyed reported situations involving several individuals, not only themselves. All names are anonymised. This research has been formally approved by the ethical committee of the Montreal Geriatric University Institute (CER IUGM 2003-0404 - Carpentier).

The trouble-observability-interpretation convergence

This section starts with a single observation: formal diagnosis does not always coincide with a specific evolution of symptoms, but observing some 'troubles' and defining them as potential dementia-related symptoms are the key operations during this period of time. Although Koehn *et al.* (2014) have already focused on the first pre-diagnosis contacts with health services, we emphasise steps taken, when troubles are not already qualified as requiring medical assistance, as primarily sketched by Krull (2005). In which conditions does the entourage of the future patient observe that 'something goes wrong'? Under which conditions does a potential caregiving network define this trouble as a medical problem?

Trouble
In employing the expression 'trouble'*,* we refer to Emerson & Messinger (1977), according to whom any deviance, before being institutionalised, begins with a diffuse feeling that 'something goes wrong'. This expression is purposely vague, for in these initial stages, people experience disturbing, undefined troubles and gradually interpret them throughout the troubleshooting process. Methodologically, troubles are induced retrospectively, because they are, by definition, embedded in posterior interpretation. The concept of trouble fits particularly well with dementia, since dementia-related problems can be interpreted in many different fashions, before being formally qualified; from little difficulties due to the 'normal' process of

ageing, the emotional consequences of retirement, or the effects of another health problem (Béliard and Eideliman 2014). The range of possible interpretations varies all the more across cultures (Cohen 1995).

Consequently, it is useful to distinguish troubles depending on their type and consequence on the diagnostic process. In 41 cases, the first manifestations of the disease, as reported by the interviewed caregiver, are mere memory problems ('losses of memory', 'little omissions'). In 10 cases, the first manifestations are memory problems coupled with disorientation, domestic troubles or personality changes. In nine cases, caregivers describe disorientation, domestic or personality concerns, without coupling it to memory issues. The type of trouble may imply different consequences on the lives of both patients and relatives. Occasional memory loss does not affect the domestic organisation as much as hygiene problems. Furthermore, fairly independent from the specific type, troubles provoke different reactions: some do not receive special attention, some raise concerns, some trigger a reconfiguration of the family organisation, while some lead to an appointment with the doctor, and so forth.

It is important to stress the range of possibility from first troubles to diagnosis. Seldom do patients follow the 'classical' model [trouble → decision to attend a medical consultation → diagnosis], such as in case 50:

> My wife and I went on a visit to England and she was in the process of writing a book. And when we arrived in the UK, she was having some problems of orientation in the terms of, you know, the changes in places and things. This continued for quite a number of days. First I thought that perhaps it was jet-lag, but she traveled extensively with me previously, so . . . and then that set up a question mark in my mind as to were there any other causes for that kind of disorientation. I sort of . . . we came back to Canada and then I saw my general practitioner, who arranged for a visit to the memory clinic.

Case 34 represents a more sinuous path. Although the patient's husband noticed that his wife had lost her short-term memory two years before the interview, he had initially assumed that she was suffering from diabetes. Her behaviour changed after their 50th wedding anniversary and this change led her children to make an appointment with the doctor from the memory clinic:

> It began with the decline of her memory, around two years ago. We've been to Saint-Luc [a hospital], because there is a geriatric service there. My children have dealt with that, they set up the meeting. Then it's Dr. Yen that came because she [his wife] did not want to collaborate, because she still had a clear memory of the past and to her, it was going well. In going out the Saint-Luc hospital we did nothing because we thought it was in relation with sugar, she has diabetes. [. . .] We celebrated our 50th wedding anniversary, it was a joy . . . and suddenly she completely changed, she was jealous, she hid things, she accused me of all kinds of things, and she did not remember where she had hid the car key, or my personal papers. This is how we became alarmed. Then, a Chinese doctor from the CLSC [health centre] came, she prescribed a medicine and from that moment, my wife kisses me every night.

In 19 of 60 cases, the first trouble observed was not the same as the one which actually provoked the medical consultation. This suggests that another issue, in the evolution of the patient's situation, suddenly disturbs her/his network. In case 34, the patient's memory loss is bearable, but her personality changes worry her relatives. Case 34 is one of 10 cases where a diagnosis is sought only when memory problems, apparently non-problematic to the patient's

network, turn out to be another problem (disorientation, etc.). We also observed that when patients experience memory problems alone, their mean time to diagnosis is shorter (16, 8 months when the first trouble is only memory and 15, 4 when the trouble that leads to the medical consultation is only memory), as opposed to when memory problems are associated with other troubles (respectively 26, 2 and 26, 4 months). Evidently, a more direct association – from the relatives' or the patients' point of view – between memory loss and dementia-related problems may explain this discrepancy; whereas, the association of disorientation or personality changes with potential dementia appear to be less obvious.

Observability

While social representations fostering or preventing the use of health services have been well documented (Carpentier *et al.* 2008, Wackerbarth & Johnson 2002), little has been done to understand under which conditions certain troubles are initially observable. By observability, we mean the potentiality that at least one person in the patient's entourage perceives that 'something goes wrong'. It is not only a matter of being visible, which denotes a feature of the troubles, but one of being observable, which involves the social configuration in which the trouble takes place.[3]

This feature is important because with Alzheimer's disease, patients seldom make the decision to consult a practitioner on their own. In this sense, they do not experience a self-labelling process, as identified by Thoits (1985), but rather a labelling process – proceeded by others – primarily developed by Scheff (1966). Relatives in 47 of 60 cases reported their first troubles. In six cases, a health professional has suspected cognitive troubles; for instance, on the occasion of another medical examination. Seven future patients have noticed on their own account, that they were experiencing some trouble, but in almost all of these cases, relatives organise encounters with family doctors and/or with professionals of a memory clinic. Patients 'at best' collaborate with the organisation of their follow-up appointment and in some cases, they agree with it. Some patients try to avoid this progression as much as possible, most likely due to the potential medium-term consequences of such an encounter: nursing home placement. In fact, dementia diagnosis processes are almost always run with the patient having little or no participation in the decision-making. This observation corroborates other research results (Brossard 2015).

It is crucial for an initial distinction to be made between patients who are living alone and those who live with their spouse or children. In the latter situation, any cognitive problem can immediately be observed; whereas, in the former, memory loss can easily go unnoticed. For instance, in case 34, the caregiver is the husband of the patient; they live together and he monitors his wife's memory problems until he decides, a year and a half later, to see the doctor:

> I think it was around two and a half years that I began to notice that she had been having memory problems. Let's say, she forgot her keys, or other stuff, and I began to worry a bit. For this reason, I came to see her family GP.

Case 10 illustrates a dramatically different configuration. The caregiver is the daughter of the patient, her mother, who lives alone. Since the daughter always believed her mother did not have a 'strong memory', she does not appear to worry over small oversights, until she notices more serious troubles at the event of a family dinner – a 'pivotal event', as Krull (2005) words it:

> In 2002, we celebrated her 82nd anniversary. On that day, I went to pick up my mother. We had a party of about 70 people. I was in my mother's room and I saw that there were

some dirty clothes and unwashed socks in her drawers. We began to realise that her personal hygiene was deteriorating and she forgot to wear deodorant. I didn't know when she last washed.

Thus, patients' living situations significantly influence average time to diagnosis. There is a difference between those who lived alone and those who did not: 15 months in the former and 26 months for the latter. We assume that this discrepancy can be explained as follows: when the patients live alone, the first observable manifestations are relatively more serious than when they do not, so they more quickly cause daily problems. The two previous examples of cases 34 and 10 support this hypothesis. In case 10, the husband notices his wife's memory loss straightaway, but according to him, this loss did not require specific attention, in order to preserve the pattern of her daily life. In case 34, 'little' memory losses were not observable and the patient's daughter could only notice more obvious troubles, such as hygiene problems. In other words, the difference between 15 and 26 months does not tell us about early diagnosis matters, but rather about the later observability of troubles.

Some events and activities enhance the observability of troubles. In 24 of 60 cases, caregivers reported driving-related events, such as accidents or the loss of a driving license (5 cases), other health problems concerning the patient or their spouse (5 cases), and troubles while traveling or on holidays (5 cases). The latter can be observed in case 15:

I would say that was, now, around three years ago. I took a holiday with her to France and Italy and I started to notice problems when we were packing and preparing. When she was choosing her clothes, she had some difficulties knowing how much to bring and I had to help her ... It's certain that, when you're with someone 24 hours a day, after a moment, there are normal conversation topics and after we made all of them, I realised she wasn't making a lot of the usual comments on what we saw.

We do not observe variations of time to diagnosis depending on whether such an event does or does not occur, but depending on the type of event. Cases involving health-related problems have a mean time to diagnosis of about 7, 6 months; whereas, cases involving driving-related events have an average mean time of 36. The data reveals that the discrepancy must be linked to the pre-existent network that surrounds patients with health-related problems; whereas, in the latter case, cognitive troubles have been observed over a longer period of time, with no immediate reaction: a sudden event makes pre-existing difficulties a more concrete issue.

Interpretation

The observability of trouble constitutes an essential step in the decision to consult a practitioner, but it alone is not sufficient. The trouble has to be interpreted as a medical problem requiring medical assistance. Medical sociology has shown that the search for a diagnosis broadly consists of an attempt to make sense of some disturbing trouble (Jutel 2009) and that the initiative to see a doctor mostly depends on the seriousness attributed to the symptoms, as well as on the expected efficiency of a medical intervention (Lydeard & Jones 1989). With Alzheimer's disease, some additional parameters should be taken into account. This disease recently gained important media coverage, frightening some elders who sometimes go to memory clinics for the slightest memory loss (Brossard 2013). Furthermore, there are many ways to present such disorders (Béliard & Eideliman 2014) and some of them prevent from the use of health services (Carpentier *et al.* 2008): 'little' memory loss or even punctual disorientation episodes can be considered as due to 'normal' ageing; therefore, formal medical advice is not necessary. Moreover, major shifts in a person's lifestyle could explain momentary fatigue; for

example, job loss, retirement or mourning. This is what Krull (2005) has conceptualised as normalisation in the case of Alzheimer's disease, a process which was observed long ago in many mental disorders (Scheff 1966).

For instance, in case 54, the patient's wife interprets her husband's troubles as a consequence of his recent retirement:

> When he retired, and just before he retired, we had lived in the same semi-detach house on Doris Avenue for over thirty years. He walked past our door and went up to the second house, to the next door, and tried to get in. I saw him, I was standing by the garage and he didn't see me, and he tried to go to that house. So, he missed the house and it's the only time he ever did in over thirty years. [...] I didn't know what else it could be, other than after he retired, right after he retired, he wouldn't do anything except sit and watch television ... I just got mad at him, because he had no interest and all we wanted was freedom, he wanted his freedom, he didn't find freedom. Now, if I look back, I can think that's probably a symptom. At that time, I thought 'ha, this is the classic retirement problem', particularly with men, no hobbies, no interest, all work, and suddenly they're cut and gone. [...]

> What brought you to go at the memory clinic?

> We heard of it before. I actually got Alzheimer information from the Alzheimer Society[4] about a couple of years before because of my mother-in-law was a candidate for it. Then ... I guess when we started, when he started doing the car thing and missing the house, [...] I, we maybe, we did suspect Alzheimer's and we didn't know that there was nothing we could do about it, but if we could catch something early, we might have a chance. So, and I knew the General Hospital had a Memory clinic, somebody told me about it. I've gone to social work myself a long time ago, saw the program at Dawson College and had some friends who worked in the General Hospital. So, we went to see Dr. Bern.

This example, in addition to illustrating hesitations in interpreting potential Alzheimer's-related troubles, shows two features of patients' networks which foster the medical interpretation of troubles. The first one is a previous experience of caregiving. People who have already had to take care of a relative diagnosed with dementia may more easily develop a medical interpretation than others. Also, they already know where to seek information; for example, in Canada, information can be found through the 'Alzheimer Society'. The second feature involves professional knowledge of the medical point of view on dementia, when at least one member of the patient's network works in the medical or social field, or when she/he has been educated in this field. Returning to case 54, even if the interpretation of the patient's trouble, as a consequence of his retirement, somehow 'slowed down' a medical interpretation, his network features led to the 'countering' of this process. Due to the previous care of her mother-in-law, the patient's wife already had information about dementia; moreover, she had friends who work at the hospital and she herself studied social work.

Even if time to diagnosis is much shorter when troubles are initially observed by health professionals (mean time = 9, 8 months), rather than by patients (19 months) or relatives (20 months), there is no significant difference in the meantime to diagnosis, due specifically to previous experience of care or on professional knowledge of the medical point of view on dementia in the patient's network. The narratives indicate that when relatives decide to look for some explanation of a trouble, they ask people around them for advice, but do not necessarily make decisions or launch any initiatives from the initial moment of concern.

Intertwining between diagnosis and caregiving network mobilisation

While many public health oriented publications presuppose that a short time to diagnosis fosters a faster coverage of patients' and caregivers' difficulties (for example, Alzheimer's Association 2015, Cattel *et al.* 2000, Prince *et al.* 2011) our data shows a wider variety of situations: sometimes diagnosis has no effect on the caregiving network (29 cases), sometimes it follows a network mobilisation (13 cases), sometimes it triggers mobilisation (14 cases) and sometimes it prevents mobilisation (4 cases). Let us note that the second possibility – when the diagnosis follows a mobilisation – implies a shorter mean time to diagnosis and it is quite logical that a mobilised network around a patient is a more efficient way to obtain a diagnosis.

First possibility: latent information
In 29 of 60 cases, diagnosis is information that has no immediate consequence on the network. It is taken by the interviewed caregiver as information which will potentially have an effect in the future, but not necessarily at that moment: no relative or friend mobilises in order to help the patient, whose daily life may not require it, and no professional is contacted. However, because a diagnosis still makes the caregiver and eventually the patient aware that something will happen down the line, it acts as latent information – latent meaning 'kept in mind,' without triggering any action. Case 25 represents this situation. The interviewed caregiver is the husband of the patient:

> I can't remember exactly what led us to go to the memory clinic; it could have been a recommendation by a doctor, Dr. Gout, our family doctor. And, since that time, this is all the manifestations of dementia that we have seen. In fact, she keeps repeating herself. All the things I could say, the more serious signs of disease, is that she doesn't remember what she did sometimes, she would ask.

Once diagnosed, nothing changes in terms of network mobilisation, except that the couple has established contact with the memory clinic and that the husband expects that something will have to be done for an undetermined period of time. When the interviewer asks him if he would like to talk with the doctor of the memory clinic or with the nurse, he answers:

> That's what I need, because right now I seem to be going in an adventure that I don't know anything about and I'd like to be (aware) of what I may expect. I hear stories and people who have gone through these experiences mention things but still, I keep thinking all the time that my wife, the situation there she is now, will last for a long time.

Second possibility: an outcome of the network mobilisation
In 13 of 60 cases, the diagnosis is an outcome of the network mobilisation: in other words, when the diagnosis occurs, this mobilisation has already been happening, for several months or years and diagnosis is one of its results. Insofar as it provides the current mobilisation's object a legitimating medical label, it then consolidates relatives' and professionals' representation that their intervention is justified.

Case 48 illustrates this possibility – in addition to showing another example of a trouble-observability-interpretation convergence in the making. The interviewed caregiver is the daughter of the patient. When she and her siblings began to notice that their mother seems to experience some difficulties, they gather:

Actually, each of us, we saw there were some problems with our mother. We made a family meeting, with my brothers and sisters, to share all our experiences. We said: 'How do you find mom?' [...] Everybody didn't see the same things, but from the moment when we met up, it started. It's like we realised that she needed help and that it wasn't about exchanging anymore. I mean, in the past, with me, because I lived nearby her home, we used to help each other.

While they organise a collective system of caregiving around their mother, different interpretations coexist in the network. Some think that their mother is simply ageing, while others assert that her problems may be a sign of Alzheimer's disease. The diagnosis did not really stop these divergences, but the memory clinic practitioner 'joined' the caregiving network, in the sense that he was regularly consulted by the patient's children and was sometimes asked to use his legitimacy to help the caregiving work:

Dr. Armand also helps us when we have problems ... For instance, we knew that she [the patient] did not want to go to the Alzheimer Society. You know, we asked Dr. Armand for prescribing her a social activity! [Laughing]. [...] I think it helped us to convince her.

Third possibility: a trigger to mobilise the network
In 14 of 60 cases, diagnosis triggers network mobilisation. Nonetheless, the manner in which such triggering happens can be more or less direct: sometimes this information almost immediately suffices to convince the patient's relatives to provide care and/or to call professionals and sometimes one caregiver uses the label to convince other relatives to participate in caregiving. This possibility also involves differences in the organisation of health services, since some patients leave the diagnosis consultation with no clue of who to call or what to do, while others are given information about or put in direct contact with a local health organisation.

In case 18, the interviewed caregiver, the patient's daughter, had thought for many years that her siblings should worry more about their mother's situation. After three years, one of her brothers and one sister finally agree to accompany their mother to the memory clinic. Once the diagnosis has been given, all siblings immediately mobilise:

They went to see the geriatrician in Maisonneuve, they made him pass some tests, the famous sheet, that exam [probably referring to the Mini-Mental State Examination]. Following this, he [the geriatrician] met my brother and my sister who were with her [the patient], and he told them: 'Enjoy the good time you have with your mother, because she is at stage 4'. They came back home and they called us all, but I was not surprised because I expected that, I had been telling them for the past three years that there was a problem.

From this moment, they organised a general care system around their mother, accompanying her to eat, to have showers, to arrange her house and to contact nurses from a local health service.

Fourth possibility: a prevention of network mobilisation
It is possible that diagnosis constitutes a motivation to prevent from network mobilisation, or at least to 'delay' it – since this perspective is not sustainable in the long-term, when troubles increase and a patient cannot survive without minimum support. This possibility happens when the patient and/or their relatives mistrust health services or the diagnosis itself, or when they believe that Alzheimer's disease would discredit them in the eyes of their entourage. In the latter cases, patients could try to hide information of the diagnosis, sometimes harming relationships, in order to avoid seeing health professionals or seeking domestic help. Such possibilities

occur in very few cases, only four in our sample; however, these findings could be a result of the method used. Indeed, contacting participants through health services may exclude those who do not have a favourable attitude towards these institutions and/or whose relatives' (the patients) symptoms have not been framed as troubling enough to justify contact with health services. Other studies, where participants were recruited outside of health services, more frequently reported this possibility (Weber *et al.* 2003).

For instance, during the first interview in case 8, the patient's wife hesitates between respecting what her husband wants (not seeking assistance) and her own difficulties in managing him on a daily basis. Yet, caregivers who are in this situation often ensure that people would help them in case of a problem:

> In the world, I don't ask for any help. In addition to that, my husband wouldn't accept it. Not now. This morning he had some difficulties taking his bath. I told him that if it were me and it's too difficult, I would call the CLSC [local health services], they would send me someone. I knew a man who was alone and the CLSC came for nine years. He [my husband] said, 'I don't wanna have anyone'. At that moment, I told him, 'You'll do it. You got no choice'. Now, I'm lucky, one of my boys came back here for some time. It secures me. [. . .] A nurse told me that we could call them, as we want. It gives me a certain safety. At the beginning, he had some problems [. . .] I don't have any confidence. I don't feel the need to confide in anyone. I never involved my brothers and sisters in my decisions . . . My daughter moved to Costa Rica. One of my children stays here for some time. The others, it's the same thing. But if I called, my daughter would come running in.

Conclusion

In analysing the social conditions according to which a diagnosis can occur (the trouble-observability-interpretation convergence) and the different possibilities of intertwining between diagnosis and caregiving network mobilisation, we have attempted to question the usual diagnostic process [symptoms → diagnosis → meaning and caregiving]. First, the time elapsed between the onset of symptoms and a diagnosis depends on the ways in which some patients' troubles are observed by potential caregivers and interpreted as dementia-related symptoms. In addition, caregiving network mobilisation does not systematically follow from the diagnosis, but can also provoke the diagnosis, be prevented by it, or the diagnosis may have no direct impact whatsoever. In sum, diagnosis does not always systematically correspond to a significant worsening of symptoms, and it is not necessarily the starting point for caregiving.

Further conclusions may be drawn from this observation; they involve medical sociology in general and dementia research in particular. In the introduction, we have highlighted the centrality of diagnosis in medical sociology. As most health research starts from the assumption that diagnosis is a crucial step in patients' trajectories, we should interrogate the extent to which this assumption might be, in certain situations, a methodological bias, since by definition, we can only meet 'patients' from the moment they are diagnosed with something. This bias downplays consideration for people who do not actually care about their diagnosis, believe it or want to talk about it. One could object that this comment applies only in the case of dementia, because its symptoms are ambivalent (its troubles may be associated with other things) and that no treatment exists (which means that the diagnosis does not imply great consequences on the patients' life expectancy and comfort). However, we could imagine the same analysis taken with illnesses whose symptoms are apparently more 'obvious'; for example, in

the case of cancer: the symptoms of these illnesses may also be diversely interpreted (fatigue due to work, weight loss due to stress, etc.), and the caregiving network may also be mobilised in different ways, before or after the diagnosis. In other words, while diagnostic categories and practices have been extensively studied, the extent to which these categories affect people and the role they play in people's lives remains unexplored.

Regarding dementia more specifically, an important development is that 'time to diagnosis' does not imply an 'early diagnosis' in all cases. Early diagnosis has initially been a priority in public health because it is expected to improve health institutions' planning and organisation of services and to provide patients' relatives with time to anticipate the necessary adjustments needed for caregiving; for instance, the often unknown expectations of the social role of the caregiver (De Vugt & Verhey 2013). However, the converse situation can occur when time to diagnosis is short; for example, following an accident or serious domestic problem, or any event that suddenly renders the dementia-related trouble observable and thus leads relatives to urgently seek a diagnosis. In some cases, anticipation of the caregiving role started well in advance of the diagnosis. Our data also demonstrates that the diagnosis itself produces different reactions from caregivers and patients, from no reaction at all to a subsequent mobilisation. These reactions may be shaped by numerous social factors, from the availability of informal caregivers to their proximity to the medical worlds. This leads to the assumption that the diagnosis cannot be systematically associated with any generalised response in terms of caregiving.

Consequently, in addition to distinguishing 'early diagnosis' from 'late diagnosis', to assess 'timely diagnosis' or to measure 'time to diagnosis', we suggest that it would be more accurate to differentiate anticipation diagnosis and emergency diagnosis – given that, in reality, these categories should be seen as a continuum rather than as a binary. Anticipation diagnosis denotes situations in which the patient's relatives and/or professionals trigger the diagnosis process, reacting to some trouble which does not at the present time affect the daily life of the patient, but which may require specific medical attention in the future. Emergency diagnosis encompasses situations in which the patient's relatives and/or professionals trigger the diagnosis process, reacting to trouble which does affect daily life at the present time and which requires immediate attention. Namely, it is not so much a matter of time as it is a question of what the diagnosis process means to the patient and to their caregiving network.

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Notes

1   In the medical vocabulary, dementia encompasses many disorders such as Alzheimer's disease, vascular dementia and mixed dementia. Herein, we will use both 'Alzheimer's disease' and 'dementia' to denote these progressive cognitive impairments in older adults.

2   By caregiving network, we mean the set of people engaged in providing any form of help to the patient. Using the word 'network' allows us to take into consideration all actors mobilised around the patient, whether they are professionals or family members, and the relation between these actors. The use of the notion of 'care' includes a broad set of activities, from medical help (a doctor prescribing medication) to domestic help (a neighbour mowing the lawn).

3   This focus on observability is inspired by Moreno Pestaña's (2006) study on anorexia – he deals with the observability of diet among young women – itself referring to the theory of ecological niche proposed by Hacking (1998)

4   The Alzheimer Society is a not-for-profit health organisation. One of its primary goal is to provide the Canadian population with information regarding dementia, from medical issues to care possibilities.

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