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Neuropsychological assessment and diagnostic disclosure at a memory clinic: A qualitative study of the experiences of patients and their family members

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ABSTRACT

Objective: The aim of this study was to gain insight into the experiences of patients and their family members regarding a neuropsychological assessment (NPA) and the diagnostic disclosure given by the medical specialist (psychiatrist, geriatrician, or their residents) at the memory clinic (MC).

Method: Patients with and without a cognitive impairment and their family members were recruited from three Dutch MCs. Four focus groups with 14 patients and 13 family members were analyzed using both inductive and deductive content analysis.

Results: Three themes were identified: uncertainty, early diagnostic paradox, and knowledge utilization. High levels of uncertainty were experienced throughout the NPA and diagnostic disclosure. The early diagnostic paradox refers to the coexistence of negative emotions, feeling distressed due to undergoing an NPA that made them aware of their cognitive complaints, and the experience of relief due to insight given by the outcome of the NPA and medical diagnosis. Knowledge utilization refers to a low retention of medical information.

Conclusion: Clinicians can reduce uncertainty by using clear communication, limiting interruptions during an NPA, and paying attention to contextual factors. Low information retention could possibly be improved by involving a family member and using visual aids or written information during the diagnostic disclosure. Finally, participants also appreciated being provided with neuropsychological feedback on the strengths and weaknesses of their cognitive profiles and with guidance on how to manage this diagnosis in their daily lives.

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Introduction

Memory clinics (MCs) focus on a timely diagnosis of dementia, and one of the most often used assessment tools in Dutch MCs is a neuropsychological assessment (NPA) (Gruters et al., 2019). The proportion of patients who undergo an NPA varies, but the most common reason to administer an NPA in these clinics is to support the diagnosis and to collect information for a differential diagnosis. NPAs are not carried out when there is evidence of severe dementia (Gruters et al., 2019). An NPA provides insight into the nature and severity of cognitive impairment (Lezak et al., 2012). The value of an NPA has been described in previous studies and has been shown to be related to increased diagnostic accuracy, referrer satisfaction, benefit prognostic decision-making, and treatment planning (Harvey, 2012; Jansen et al., 2016; Watt & Crowe, 2018).

Current trends in mental health care place more emphasis on the exploration of patient experiences to facilitate patient-centered care and to improve delivered health services (Mohammed et al., 2016). Previous studies exploring the experiences of patients and their family members in an MC report that they initially felt stressed and unnerved and that they often did not know what to expect of their visit to the clinic (Mastwyk et al., 2016). However, in both qualitative and quantitative studies, the overall experience were found to be more positive than negative, and patients and family members were often satisfied with the diagnostic process (Cahill et al., 2008; Foreman et al., 2004; Hailey et al., 2016; Hodge et al., 2013; Park et al., 2018).

To our knowledge, little is known about the perspective of patients and their family members regarding NPAs (Watt & Crowe, 2018). A few studies included patients without dementia from neuropsychology services and found that an NPA was evaluated as useful overall; only a minority of participants reported a negative experience, and most showed generally high levels of satisfaction with the NPA (Bennett-Levy et al., 1994; Westervelt et al., 2007). The few studies including MC patients found that participants experienced mixed positive and negative feelings as result of undergoing an NPA (Cahill et al., 2008), and that feelings of insecurity and discomfort around an NPA were not uncommon in patients who had received a dementia diagnosis (Keady & Gilliard, 2002). The time between referral and the diagnostic assessment itself was considered stressful (Hill et al., 1995). A recent systematic review emphasized that more studies are needed to examine patient perceptions of an NPA, as research in this area is lacking (Watt & Crowe, 2018).

More studies have been performed on the experience with diagnostic disclosure by the medical specialist in the MC. Findings from two studies using retrospective surveys showed that the majority of patients wished to be informed of the diagnosis and found it helpful, and that relatively low levels of distress were reported (Mastwyk et al., 2016; Mormont et al., 2012). This finding is in line with a systematic review and a large prospective study in which the majority of patients favored a diagnostic disclosure (Mahieux et al., 2018; van den Dungen et al., 2014). In contrast, others showed that patients were less positive about the clarity of the information regarding their diagnosis, found the diagnosis vague, and would have liked advice on how to cope with their family member with a dementia diagnosis (Kunne-

et al., 2017; van Hout et al., 2001). Furthermore, there were often unmet information needs and difficulties remembering the information (Abley et al., 2013; Kessels, 2003). In summary, while some studies have specifically examined the diagnostic disclosure experience, there remains a lack of evidence regarding the perspective of patients on the NPA as a whole. It is also unclear how the NPA is evaluated by their family members. Insight into these experiences and identifying possible issues could improve the diagnostic assessment process related to current NPA and diagnostic disclosure procedures to better fit the needs of the MC population. To our knowledge, no focus group studies with both patients and family members have been conducted in this population regarding this topic. Therefore, the aim of this study is to gain more insight into the experiences of patients and family members with NPAs and diagnostic disclosure.

Methods

Memory clinic procedures

Participants were recruited in three hospital-based MCs (Maastricht UMC+, Radboudumc Nijmegen, and Catharina Hospital Eindhoven) to ensure diversity in clinical procedures. The coordinating discipline in one center was psychiatry, while it was clinical geriatrics in the other two centers. All centers informed patients about their visit to the MC by sending a leaflet with additional information about the different assessments after the appointment was made. The following diagnostic assessments were conducted: clinical interview by the psychiatrist, clinical geriatrician, or their residents (a detailed medical history, demographic characteristics, and a neurological, psychiatric, and physical examination), NPA (testing took on average 2.5 hours in two centers and 1 hour in one center), blood tests, brain imaging (MRI or CT scan), and interview with a family member by nurses (to evaluate interference in daily living). In two centers, there was another clinical interview by the psychologist before testing. All diagnostic assessments were performed in one day in two centers. In the other center, it was determined after the initial clinical interview and blood tests whether an MRI or NPA was needed on a separate day. The diagnostic disclosure was done by the psychiatrist, clinical geriatrician, or their residents. In one MC, the diagnostic disclosure occurred on the same day, while in the other two clinics, the diagnosis was given within 3 weeks after the assessment day. Patients could access a copy of the final report via their online personal portal of the hospital. This report was also sent to the general practitioner and contained medical language. In one center, a separate consultation was planned with the neuropsychologist to give feedback on NPA results. During this session, the neuropsychologist evaluated what they still remembered from the consultation with the psychiatrist and answered questions. The neuropsychological test results were discussed, and tips and advice were given on how to cope with their cognitive problems in daily life. Another topic was discussing possibilities concerning practical support (e.g. Alzheimer cafés, daycare, and group treatment for mild cognitive impairment (MCI) patients), depending on the diagnosis. The patients did not receive a written report about this consultation.

Study participants

Patients were included if they (1) were referred to an MC and underwent an NPA and (2) were diagnosed with no cognitive impairment (NCI), MCI, or mild dementia (Clinical Dementia Rating Scale [CDR] 1). The referral question was similar in all patients: *“Does the patient have cognitive impairment, and if so, does this meet the criteria due to a neurodegenerative disease?”* They were excluded if there was a severe cognitive impairment ($CDR \geq 2$), aphasia, or moderate to severe visual impairment. Family members were asked to provide their opinions. Patients and their family members were recruited using purposeful sampling to account for variability in age, gender, diagnosis, and disease severity. This strategy was used to look for common patterns and capture this across the MC population (NCI, MCI, and dementia).

Between January and March 2018, 18 patients and 17 family members were recruited. Participants received written information about the study from the neuropsychologist during the assessment day. At least 2 weeks after receiving the diagnosis, the neuropsychologist contacted each patient to ask if he/she wanted to participate. Two dyads (patient and family member) declined to participate because of refusal of the patient or unavailability when the focus groups were planned. One dyad did not show up at the meeting as a result of illness, and another dyad forgot about the appointment. In total, 14 patients and 13 family members participated in this study (11 dyads). The patients in the dyads had the following diagnosis: NCI: $n=5$, MCI: $n=3$, Alzheimer’s disease (AD) dementia: $n=1$, and other causes of dementia: $n=2$. Three patients participated alone because their family members were not available during the focus group meetings (NCI: $n=1$, MCI: $n=1$, AD dementia: $n=1$). Two family members participated alone; the first indicated that the patient already had mild AD dementia, and the other stated a preference to come alone (the patient had a MCI diagnosis). The Medical Ethics Committee of the Maastricht University Medical Center confirmed that the Medical Research Involving Human Subjects Act did not apply to this study (#2017-0095), making the study exempt from formal ethical review. Prior to the group discussions, written informed consent was obtained.

Procedures

Four focus groups were planned with six to eight participants per group. Based on recommendations from previous studies, the modal size of six to eight participants per focus group was used (Guest et al., 2017). The number of participants in each group was based on the equal distribution of patients and family members during the four sessions. The group discussions lasted approximately 90 minutes and were conducted in Dutch. Previous studies indicate that information saturation was reached, and most topics were captured after four focus groups (Francis et al., 2010; Guest et al., 2017; Hennink, 2007). After the fourth focus group, two authors independently confirmed data saturation, as no new themes had emerged. Each focus group session included an introduction and explanation of the procedure by the moderator and assistant (taking notes and distribution of materials). A semistructured guide was used (Appendix A). First, participants were asked about their experience of the NPA, and they had to choose between a green light for a positive experience, a red light for a

negative experience, and an orange light for an experience that was both positive and negative. Using visual aids during in-depth interviews in patients with cognitive impairment is recommended (Cridland et al., 2016). It gives participants time to reflect on their experience. During the second part, they were asked about their experience with the diagnostic disclosure given by the medical specialist (psychiatrist, geriatrician, or their residents) and whether they had difficulty remembering the information. The moderator summarized key points throughout the session to obtain participant verification (Hennink, 2007). All group discussions were video- and audio recorded. These recordings were stored on a protected server and were deleted after data analysis. To assure validity, triangulation of within-method data sources was used; the data consisting of video and audio recordings, as well as field notes taken by the assistant to identify potentially relevant cues and observations given by the participants.

Data analysis

The video recordings of the focus groups were transcribed verbatim. Both the transcripts and observations were analyzed independently by two authors using ATLAS.ti, version 8.1.3. One of these authors was not involved in conducting the focus groups but involved at a later stage to have an independent view when carrying out the data-analysis. Both authors were experienced and trained in carrying out qualitative analysis. A combination of inductive and deductive content analysis was used. First, we used a deductive approach by determining the two themes based on our semi-structured guide: experience with an NPA and experience with the diagnostic disclosure by the medical specialist. Then, an inductive approach was applied, using inductive reasoning and constant comparison to identify categories within these two themes. This approach was carried out by adding open codes in the transcript and reading it thoroughly. The open codes were first separated into two overall themes (experience with NPA and experience with diagnostic disclosure). After that, they were merged into categories and higher-order themes. To obtain consensus regarding the categories' discrepancies and interpretation, the categories were discussed with a third and fourth author. This approach is described by previous authors to improve credibility (Graneheim & Lundman, 2004). The focus groups were analyzed separately to gain insight into differences in experiences between the three MCs. The quotes used in the results section were selected and translated from Dutch to English by two authors.

Results

Background characteristics

Table 1 describes the characteristics of the 14 patients and 13 family members. The majority of family members were spouses ($n = 11$, 85%).

Focus groups

Based on the evaluation of the participants' experiences with the NPA and the diagnostic disclosure by the medical specialist, three major themes were identified: (1)

Table 1. Characteristics of patients ($n = 14$) and family members ($n = 13$).

	Focus group participants ($n = 27$)	
	Patients ($n = 14$)	Family members ($n = 13$)
Age (mean \pm SD [min-max])	66.1 \pm 7.9 [49–76]	62.9 \pm 15.1 [30–82]
Women n (%)	5 (36%)	8 (62%)
Diagnosis MC visitor		
NCI	6 (43%)	5 (39%)
MCI	3 (21%)	4 (30%)
AD dementia	3 (21%)	2 (15%)
CBS	1 (7.5%)	1 (8%)
FTD	1 (7.5%)	1 (8%)
Relationship to MC visitor		
Spouse		11 (85%)
Child		2 (15%)

Notes. Demographics are represented in n (%) unless stated otherwise. Abbreviations. SD = standard deviation, NCI = no cognitive impairment, MCI = cognitive impairment, AD = Alzheimer's disease, CBS = corticobasal syndrome, FTD = frontotemporal dementia.

Table 2. Overview of major themes and categories.

Themes	Categories
Uncertainty	Uncertainties about complaints, NPA, and diagnosis Influence of contextual factors
Early diagnostic paradox	Feelings of distress due to awareness of cognitive complaints while undergoing an NPA More insight due to outcome of NPA and medical diagnosis adapting to diagnosis
Knowledge utilization	Retention and communication of medical information Unanswered questions Lack of postdiagnostic support

uncertainty, (2) early diagnostic paradox, and (3) knowledge utilization (Table 2, Figure 1).

Uncertainty

When looking back at their visit to the clinic, both patients and their family members expressed that they had experienced high levels of uncertainty. These uncertainties could be identified on different levels during the entire diagnostic phase. From the point of referral by their general practitioner to the diagnostic disclosure by the medical specialist, they had felt very uncertain. There were uncertainties about the general diagnostic procedure at the MC. For example, the participants indicated that the procedure from assessment until diagnostic disclosure had taken too long. In the MC where the diagnostic disclosure was provided on the same day as the assessment, this issue was not reported. In some patients and family members, the question of whether a dementia diagnosis was valid based on the diagnostic assessment conducted in the MC was raised. These concerns and feelings of uncertainty remained even after the diagnostic disclosure.

The intake and test day were very far away from each other. Almost two months. So, this was something that I thought took too long ... I was in a sort of waiting period for over six months. I wondered what was going on in my head and which direction it was going. (FG04, patient)

I am overwhelmed. I have all kinds of doubts about the assessment [NPA], because the diagnosis is something abstract ... How bulletproof is the diagnosis? What happens following these assessments? (FG23, family member)

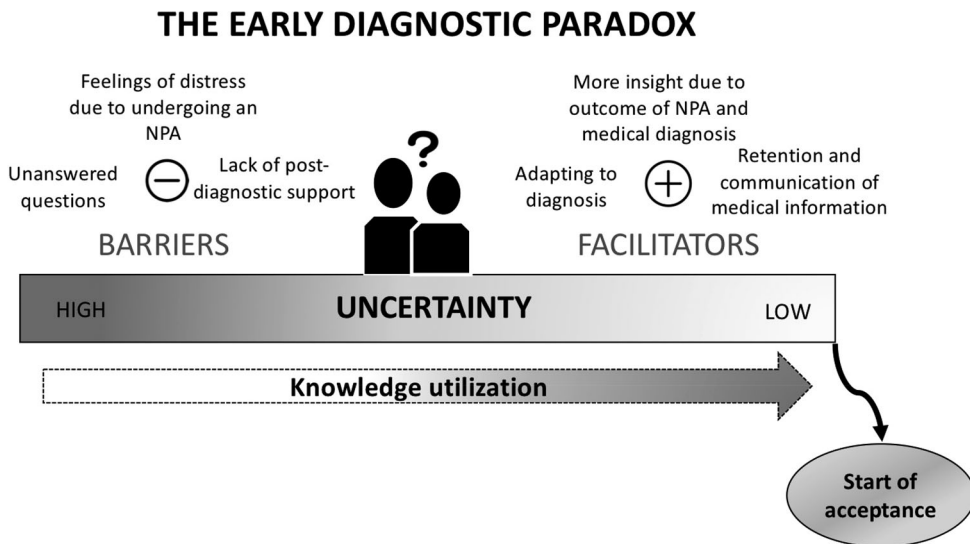


Figure 1. Visual representation of the major themes: uncertainty, early diagnostic paradox, and knowledge utilization in patients and their family members.

There were also uncertainties about the NPA itself. For example, it was unclear what the tests meant and what they were used for. They often wondered if they were performing well or not.

I don't know why I had to do those tests, and I am still curious about that. Like those colors [Stroop test], what do you do with my results? Does it say something about the conditioning of my brain? (FG10, patient)

What I wrestled with? The things I had to draw ... I don't know why I had to do that, and that is what I am curious about. What do you do with these results? ... And I could not judge it. If you have a page with symbols and numbers and you can make it only halfway, then I don't know whether it's bad or good. (FG10, patient)

Uncertainties during an NPA could also be caused or reinforced by contextual factors during the assessment (e.g. when clinicians would walk away during administration of the tests, when the clock was not set to the right time, or when the test assistant was searching for the right forms). Clear communication about the procedure could facilitate lower levels of uncertainty.

After the assessment, he returned like; 'Pf, I don't understand this at all'. The intern kept walking away, and that made him very insecure. Like: 'I don't get it, maybe they don't get it themselves' (FG25, family member)

Early diagnostic paradox

During the visit at the MC, a paradox could be identified. On the one hand, negative experiences and emotions were present during the NPA. Undergoing an NPA-induced feelings of distress by making them aware of their cognitive complaints, and was seen as an exhausting experience that often increased their feelings of uncertainty. Furthermore, a stigma toward dementia was apparent.

I thought it was very disconcerting that my short-term memory was so bad, I cried the first time I did the test. (FG14, patient)

He had a very strong feeling of failing, you know. You cannot fail in one of these tests. But, he felt that strongly. 'I don't know this anymore, I can't do it anymore' ... To get insight was difficult. (FG26, family member)

Then I heard "Alzheimer's" for the first time ... It's like you get a stamp. Alzheimer's. You imagine drooling men in a chair and you have to get used to that. But, I told my wider circle of friends what was going on because I do not want to be a pathetic man walking around ... If you break your leg or something physical ... This is something taboo. (FG22, patient)

On the other hand, both patients and their family members appreciated the additional value of undergoing an NPA and realized that the outcome of an NPA contributed to receiving a clear diagnosis and therefore giving more certainty about their situation. It gave them insight and answered their question whether it was dementia or not. When the results indicated NCI, they were often reassured. Relief was, however, also experienced when someone received a dementia diagnosis, as this explained complaints and changing behavior.

The test was a confirmation that I was not crazy. All these things I experienced at home for years and talked about with the children. The other hospital gave me the impression that I did not quite understand everything. Because nothing was wrong with him. (FG04, family member)

I also experienced it with my mother and then I noticed I did everything a whole lot better ... That was a very nice experience. I thought, 'Everything is alright.' I found that to be a very nice experience during the tests. (FG03, patient)

Being reassured or receiving a confirmation was observed as the start of acceptance, and it decreased the level of uncertainty in most of the patients and their family members. Some of the patients and family members stated that they could now do something with the feedback they received. Some started using memory strategies in their daily life, and some family members were now more able to adapt their behavior to their partner (e.g. not getting angry as quickly as before).

But now I know that if something goes too fast and I do now write it down that I will forget it. So, I have to write it down immediately, and then, you learn to live with it. You also know the reason [for forgetting] now. (FG07, patient)

I was not always as accommodating for him. If he did not respond quickly enough, I had to tell myself to stay calm. I can do that more now, but I still think it is difficult to deal with. (FG14, family member)

Knowledge utilization

The ability to understand and remember the information that was relayed during the medical diagnostic disclosure was seen as a prerequisite for decreasing the level of uncertainty they experienced. However, information retention was reported to be low, and patients and family members expressed several times that they did not remember the same information. Both patients and family members emphasized that the manner of communication was important. All participants preferred a face-to-face consultation. Using visual aids or receiving something on paper would have been considered

helpful in remembering the information. The diagnosis should be conveyed in understandable language.

The specialist tells me everything, but in my mind, I am occupied with my disease. The words washed over me like water over stone, and I liked that if he [son] could not be there [during the visits to the MC], that my daughter could be there. Two know more than one. (FG11, patient)

They really tried with effort to explain me what my results were. However, subsequently, I forgot all the details of the information ... Afterwards, I would have like to have received something on paper, because then I could have read it later again. (FG03, patient)

The medical terms are understandable for you or for my general practitioner. But, if I reread the letter [from the medical specialist] after a few weeks, then I wouldn't understand it anymore. (FG16, family member)

Furthermore, after having received the diagnosis, both patients and family members expressed that they needed some time to fully appreciate the information that they remembered. Often, they had new questions one or two weeks after the consultation. One family member felt like that there was little to no information for the partner during the diagnostic disclosure.

I needed some time afterwards [diagnostic disclosure] to process it, and then I had the need to know more about what it precisely meant. (FG03, patient)

When you are standing outside, you find there are a thousand questions that you did not ask. (FG07, family member)

This need to process the information left some with unanswered questions after the consultation, and it remained unclear where they could go to receive the information or care they needed. Many remaining questions were related to how they could cope with their own diagnosis, or their partner's diagnosis, and to practical tips they could use in daily life. Where participants had a separate consultation with the neuropsychologist, participants were very satisfied and this was seen as an additional value. In the other two clinics, the need for a follow-up consultation was reported. In case of a dementia diagnosis, in all centers, a care professional whom they could regularly contact (e.g. a case manager) to ask questions was preferred. This was considered a lack of postdiagnostic support, especially when less was known about a specific diagnosis.

It would be nice if the consultations [at the MC] were maintained. It would help to have an appointment every two years to see what the decline or improvement is. (FG19, family member)

What I missed after the diagnostic disclosure was how to proceed from this? ... We are wondering what we can do, what we have to do, what do I have to arrange? ... All this is also very vague with this disease [Corticobasal syndrome]. (FG26, family member)

Discussion

Following the discussion with both patients and family members, the evaluation of the experiences regarding an NPA and medical diagnostic disclosure at a MC resulted in the identification of three themes: "uncertainty," "early diagnostic paradox," and "knowledge utilization." It is important to note that an NPA was one of several

diagnostic assessments used at the MC. Participants were not prompted to reflect on their perspective on other diagnostic procedures (e.g. neuroimaging, cerebrospinal fluid) because that was not within the aim of the current study. The diagnostic disclosure by the medical specialist focused on the results of all the different assessments conducted at the MC. However, the analysis showed that the experiences with an NPA and the diagnostic disclosures were overlapping and they are therefore described together. During the analysis, we also evaluated possible differences between patients and family members or between men and women, but these differences could not be identified. An important insight from this study was that both positive and negative experiences coexisted during the diagnostic procedures at an MC. In addition, feelings of uncertainty were present before, during, and after the MC visit. In this study, the feelings of distress and negative experiences, resulting from undergoing a cognitive assessment, eventually led to relief and decreasing levels of uncertainty, as well as an improved ability to start the acceptance process.

The first theme, uncertainty, reflects how patients and family members expressed their feelings of uncertainty and nervousness before and during the cognitive assessment, and these feelings even persisted for some people after the diagnostic disclosure. The responses of patients showed that the theme of uncertainty was present throughout the whole diagnostic trajectory (as illustrated by the long bar labeled “uncertainty” in [Figure 1](#)). For instance, they questioned how reliable the diagnosis was based on the tools used or what the cognitive tests were measuring and whether they performed well. These findings support and build on a small body of studies focusing on the experience with an NPA and diagnostic disclosure in MC patients (Cahill et al., 2008; Hill et al., 1995; Keady & Gilliard, 2002). To our knowledge, no other studies have investigated the experience of both NPA and medical diagnostic disclosure in an MC population. It is important to gain more insight into these experiences, as a recent study found that family members who were unsatisfied with MC services reported more caregiver burden after 2 years (Park et al., 2018). These findings contrast with the results of two previous studies that investigated the experience of NPAs in patients without dementia, who were referred to a neuropsychologist in a hospital, rehabilitation center, or academic neuropsychology service. More positive experiences were found in these studies, and they also found that perceptions could be moderated by different factors, such as expectations regarding the assessment, perceived relevance, and provision of feedback (Bennett-Levy et al., 1994; Westervelt et al., 2007). While this may appear to be in contrast to the previously described studies on the MC population specifically, this difference may be explained by the characteristics of patients visiting an MC, such as reporting more cognitive complaints, experiencing lower quality of life, having more worries due to a positive family history of dementia, and more deterioration in daily life (Ramakers et al., 2009). The current study further extends evidence of the NPA experience to a clinical population actively seeking help for their cognitive complaints.

Regarding the second theme, early diagnostic paradox, our findings on the experience of patients and their family members showed that both negative (e.g. feelings of distress due to awareness of their cognitive complaints while undergoing an NPA) and positive experiences (e.g. less uncertainty due to the outcome of the NPA) were

present during the visit at the MC (illustrated in [Figure 1](#)). Reducing uncertainty could facilitate the start of the acceptance process in cases of cognitive impairment. This is in line with a recent study that showed that an early diagnosis with high quality diagnostic disclosure was associated with better adjustment and less negative emotional impact both in the short and the long term (Woods et al., 2019). In our study, patients without a cognitive impairment were relieved when they learned that the NPA was going well. They were even further relieved after obtaining the confirmation that they did not have a cognitive impairment or dementia during the diagnostic disclosure. Receiving a dementia diagnosis was often experienced as a confirmation and was also accompanied by relief, which was previously described by other authors (van Vliet et al., 2013). Another study showed that the diagnostic disclosure was a crucial moment, after which patients and their family members had to start making important decisions regarding the future (Karnieli-Miller, Werner, Aharon-Peretz, et al., 2012).

A too early diagnosis of MCI and dementia has been criticized when no disease modifying therapies are available (Alzheimer Europe, 2016; Pelosi et al., 2006). Receiving an MCI diagnosis might even be related to more uncertainty compared to a dementia diagnosis. Patients with MCI have been shown to have an increased risk of conversion to dementia, while some remain cognitively stable (Vega & Newhouse, 2014). Many patients with MCI are unsure about their future and may live with the fear of eventually developing dementia. de Vugt and Verhey (2013) described the impact of an early dementia diagnosis and found that it offered family members the opportunity to adapt to their role as caregivers. The authors emphasized that, especially in this early phase, the level of stress and burden are still low and therefore create a window of opportunity to empower caregivers. Effective psychosocial interventions have been developed that help caregivers improve adaptation to changes that are characterized by the progressive nature of dementia, improve caregiver well-being, maintain psychological health, and delay institutionalization (Boots et al., 2014; Dickinson et al., 2017). A systematic review examining positive aspects of caregiving in dementia demonstrated that one of the key factors for a positive experience was acceptance of the situation and its ongoing consequences (Lloyd et al., 2016). A qualitative study also showed that acknowledgement (e.g. acceptance of the disease and symptoms and strategies to cope with the symptoms) and resistance (e.g. denial and normalization) are simultaneously present in caregivers of patients with early stage AD dementia (MacQuarrie, 2005). With respect to the early diagnostic paradox identified in this study, it is therefore important to stress that a low level of uncertainty facilitates the acceptance process, which in turn enables caregivers to be more compassionate and empathetic and to approach the situation with a more positive attitude (Lloyd et al., 2016).

The final theme, knowledge utilization, sheds light on the fact that the reported information retention following the medical diagnostic disclosure was generally low. Patients and family members experienced differences in who remembered what, and many details were reported to be forgotten. This is in line with previous findings describing that up to 40–80% of medical information provided by professionals was forgotten immediately (Kessels, 2003) and may especially be the case with people visiting a MC. Low information retention and difficulties with understanding the diagnosis might lead to less adequate coping (Lee et al., 2014). As illustrated in [Figure 1](#), low

knowledge utilization would lead to more uncertainty. This information retention problem might be related to health literacy, which refers to the understanding that is needed to make well-informed decisions (Pratt & Searles, 2017). Previous authors have suggested that providing more detailed and clear information might be helpful, or else providing written information to improve the retention of information (Cahill et al., 2008; Hodge et al., 2013; Westervelt et al., 2007). Visual aids have also been shown to improve professional-patient discussions, information retention, and health literacy (Kessels, 2003; Pratt & Searles, 2017).

In Dutch MCs, it is often the medical specialist who discloses the diagnosis, also explaining and discussing the conducted assessments (e.g. MRI, blood tests, and NPA). Previous research showed that providing the patient and family with extensive feedback on the neuropsychological findings was not a universal service in Dutch MCs (Gruters et al., 2019). However, providing patients with feedback on their cognitive performance was shown to lead to improved quality of life and social adjustment (Rosado et al., 2018). Other studies have also shown that patients evaluated the feedback they received from the neuropsychologist as useful (Bennett-Levy et al., 1994; Postal & Armstrong, 2013; Westervelt et al., 2007). Offering a follow-up consultation made it possible for the patient and their family member to evaluate whether the information is understood, to answer remaining questions, and to further explore the need for help. In our findings, we observed that participants who received a separate consultation with the neuropsychologist appreciated this consultation, while the participants who did not receive them reported experiencing a need for this consultation. Therefore, the authors see it as an example of good practice. In the Dutch healthcare system, it is mandatory to be referred by a doctor for it to be covered by the insurance companies. The proportion of patients who remained in care of Dutch MCs varied between 10% and 100% (Gruters et al., 2019). However, most clinics do not offer a second consultation shortly after the diagnostic disclosure, which might be related to financial barriers or procedures within the clinics themselves. In addition, Dutch MCs focus on the diagnostic assessment, and for additional treatment, the patient is often referred back to the general practitioner or to other organizations (e.g. mental health institutions or local care organizations) (Gruters et al., 2019). In the case of a dementia diagnosis, an appointed case manager might be helpful. This is in line with findings from a European study focusing on the evaluation of access to timely formal dementia care (Kerpershoek et al., 2019).

One of the strengths of this study was the inclusion of patients of three different MCs in the Netherlands, in different regions and with different procedures. By doing this, we used the maximum variation strategy and gained more insight into different experiences in patients visiting MCs that showed service variability. Another strength was the qualitative method of focus groups that allowed for open discussions and offered the opportunity to gain in-depth insight into a range of perspectives (Hennink, 2007; Kitzinger, 1995). The moderators of the focus groups were experienced psychologists with years of clinical experience who made sure that all participants were given the opportunity to express their opinion. Within-method triangulation of the data (e.g. combining observations, field notes, and written transcripts) enriched the analyzed data. Inclusion of both patients and their family members provided information on the experience of both and the dynamics of the couples. Purposive sampling is often

used in qualitative research, as it ensures the selection of participants who are knowledgeable about a topic. In doing so, a wide range of participants with different diagnoses were included. This heterogeneous sample reflects the reality of MCs.

Limitations should be also considered when interpreting the findings of the current study. First of all, the small sample size makes it difficult to gain insight into differences between subgroups (e.g. between men and women, or between patients and family members). Future research should preferably use a mixed-methods design to gain more insight into these differences. Although we took the variability between MCs into account, it might be difficult to generalize our findings to the overall MC population in the Netherlands. A self-selection bias might also influence the generalizability of the results as those willing to participate might be a different group of patients and family members than those who refused. However, in our study only one patient refused to participate. Furthermore, patients with moderate to severe dementia were not included. A severe cognitive impairment might have led to difficulties recalling the experiences they had during the NPA and diagnostic disclosure. However, this makes it a challenge to generalize the results to every type of cognitive impairment. Including both patients and their family members may have affected the responses given during the group interview. For instance, a patient or family member might have not felt comfortable enough to express everything about their significant other (Karnieli-Miller, Werner, Neufeld-Kroszynski, et al., 2012). Another limitation related to focus group methodology, is the risk of conformity where participants might not feel comfortable in sharing their opinion when this differs from the rest of the group or when they are afraid to raise their voice.

Clinical implications and recommendations

1. Clinicians should be aware of the high level of uncertainty and take steps to reduce this by:
 - Using clear communication that is adapted to the needs of the patient and family member.
 - Clearly explaining the procedure of an NPA.
 - Paying attention to contextual details (e.g. making sure the wall clock is set to the correct time or not having to look for papers during the assessment).
2. Clinicians should be aware of the low information retention after an MC visit. This could be improved by:
 - Involving a family member during the consultations.
 - Using visual aids.
 - Providing written information (that can be taken home).
3. After patients have received a diagnosis at the MC, the following procedures are recommended:
 - Provide clear future steps to patients.
 - Offer a second consultation with the patient after receiving the diagnosis.
 - Evaluate the needs and wishes of the patient and their family member.
 - Provide patients with a key contact person in case of dementia diagnosis.
4. A consultation with the neuropsychologist regarding neuropsychological feedback focused on cognitive strengths and weaknesses with recommendations for daily life is helpful.

Conclusion

This study identified an early diagnostic paradox during the NPA and medical diagnostic disclosure at the MC. This paradox consisted of the coexistence of conflicting positive and negative emotions: feelings of distress caused by awareness of their cognitive complaints during an NPA, versus increased insight in the situation by the outcome of

the NPA and diagnosis. This was influenced by the amount of uncertainty experienced during the entire process. Decreasing these levels of uncertainty facilitated the acceptance process associated with the diagnosis, resulting in more positive feelings of validation and reassurance. Another important factor that increased uncertainty was low information retention and inaccurate communication of information, as this information was not always adjusted to the health-literacy level and individual needs of the patient. For early dementia diagnostics, it is recommended that clinicians be made aware of the necessity of guiding the patient and their caregivers through the acceptance process.

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References

- Abley, C., Manthorpe, J., Bond, J., Keady, J., Samsi, K., Campbell, S., Watts, S., & Robinson, L. (2013). Patients' and carers' views on communication and information provision when undergoing assessments in memory services. *Journal of Health Services Research & Policy*, 18(3), 167–173. doi:10.1177/1355819613479945
- Alzheimer Europe. (2016). *Discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer's disease*. <http://alzheimereurope.org/content/download/148609/915430/file/03487%20Alzheimer%20Europe%20ethics%20report%202016.pdf>
- Bennett-Levy, J., Klein-Boonschate, M. A., Batchelor, J., McCarter, R., & Walton, N. (1994). Encounters with Anna Thompson: The consumer's experience of neuropsychological assessment. *Clinical Neuropsychologist*, 8(2), 219–238. doi:10.1080/13854049408401559
- Boots, L. M., de Vugt, M. E., van Knippenberg, R. J., Kempen, G. I., & Verhey, F. R. (2014). A systematic review of internet-based supportive interventions for caregivers of patients with dementia. *International Journal of Geriatric Psychiatry*, 29(4), 331–344. doi:10.1002/gps.4016
- Cahill, S. M., Gibb, M., Bruce, I., Headon, M., & Drury, M. (2008). I was worried coming in because I don't really know why it was arranged: The subjective experience of new patients and their primary caregivers attending a memory clinic. *Dementia*, 7(2), 175–189. doi:10.1177/1471301208091157

- Cridland, E. K., Phillipson, L., Brennan-Horley, C., & Swaffer, K. (2016). Reflections and recommendations for conducting in-depth interviews with people with dementia. *Qualitative Health Research, 26*(13), 1774–1786. doi:10.1177/1049732316637065
- de Vugt, M. E., & Verhey, F. R. (2013). The impact of early dementia diagnosis and intervention on informal caregivers. *Progress in Neurobiology, 110*, 54–62. doi:10.1016/j.pneurobio.2013.04.005
- Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., & Robinson, L. (2017). Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews. *International Psychogeriatrics, 29*(1), 31–43. doi:10.1017/S1041610216001447
- Foreman, P., Gardner, I. L., & Davis, S. (2004). Multidisciplinary memory clinics: What is important to caregivers and clients? *International Journal of Geriatric Psychiatry, 19*(6), 588–589. doi:10.1002/gps.1086
- Francis, J. J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. P., & Grimshaw, J. M. (2010). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology & Health, 25*(10), 1229–1245. doi:10.1080/08870440903194015
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105–112. doi:10.1016/j.nedt.2003.10.001
- Gruters, A. A. A., Ramakers, I. H. G. B., Kessels, R. P. C., Bouwman, F. H., Olde Rikkert, M. G. M., Blom, M. M., de Vugt, M. E., & Verhey, F. R. J. (2019). Development of memory clinics in the Netherlands over the last twenty years. *International Journal of Geriatric Psychiatry, 34*(8), 1267–1274. doi:10.1002/gps.5132
- Guest, G., Namey, E., & McKenna, K. (2017). How many focus groups are enough? Building an evidence base for nonprobability sample sizes. *Field Methods, 29*(1), 3–22. doi:10.1177/1525822X16639015
- Hailey, E., Hodge, S., Burns, A., & Orrell, M. (2016). Patients' and carers' experiences of UK memory services. *International Journal of Geriatric Psychiatry, 31*(6), 676–680. doi:10.1002/gps.4380
- Harvey, P. D. (2012). Clinical applications of neuropsychological assessment. *Dialogues in Clinical Neuroscience, 14*(1), 91–99.
- Hennink, M. (2007). *International Focus Group Research. A handbook for the health and social sciences*. University Press.
- Hill, K., O'Brien, J. T., Morant, N., & Levy, R. (1995). User expectations of a memory clinic. *Clinical Psychology Forum, 83*, 9–11.
- Hodge, S., Doncaster, E., Moniz-Cook, E., Purandare, N., & Orrell, M. (2013). Two sides of the same coin? Patients' and carers' views of UK memory services. *Aging Health, 9*(3), 275–280. doi:10.2217/ahe.13.12
- Jansen, W. J., Handels, R. L., Visser, P. J., Aalten, P., Bouwman, F., Claassen, J., van Domburg, P., Hoff, E., Hoogmoed, J., Leentjens, A. F., Olde Rikkert, M., Oleksik, A. M., Schmid, M., Scheltens, P., Wolfs, C., Verhey, F., & Ramakers, I. H. (2016). The diagnostic and prognostic value of neuropsychological assessment in memory clinic patients. *Journal of Alzheimer's Disease, 55*(2), 679–689.
- Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., Sinoff, G., & Eidelman, S. (2012). Expectations, experiences, and tensions in the memory clinic: The process of diagnosis disclosure of dementia within a triad. *International Psychogeriatrics, 24*(11), 1756–1770. doi:10.1017/S1041610212000841
- Karnieli-Miller, O., Werner, P., Neufeld-Kroszynski, G., & Eidelman, S. (2012). Are you talking to me?! An exploration of the triadic physician–patient–companion communication within memory clinics encounters. *Patient Education and Counseling, 88*(3), 381–390. doi:10.1016/j.pec.2012.06.014
- Keady, J., & Gilliard, J. (2002). The experience of neuropsychological assessment for people with suspected Alzheimer's disease. In B. H. Harris (Ed.), *The person with Alzheimer's disease. Pathways to understanding the experience* (pp. 3–28). The John Hopkins University Press.
- Kerpershoek, L., Wolfs, C., Verhey, F., Jelley, H., Woods, B., Bieber, A., Bartoszek, G., Stephan, A., Selbaek, G., Eriksen, S., Sjölund, B.-M., Hopper, L., Irving, K. M., Gonçalves-Pereira, M., Portolani,

- D., Zanetti, O., & Vugt, M. (2019). Optimizing access to and use of formal dementia care: Qualitative findings from the European study. *Health & Social Care in the Community*, 27(5), e814–e823. doi:10.1111/hsc.12804
- Kessels, R. P. C. (2003). Patients' memory for medical information. *JRSM*, 96(5), 219–222. doi:10.1258/jrsm.96.5.219
- Kitzinger, J. (1995). Qualitative research: Introducing focus groups. *BMJ*, 311(7000), 299–302. doi:10.1136/bmj.311.7000.299
- Kunneman, M., Pel-Littel, R., Bouwman, F. H., Gillissen, F., Schoonenboom, N. S. M., Claus, J. J., van der Flier, W. M., & Smets, E. M. A. (2017). Patients' and caregivers' views on conversations and shared decision making in diagnostic testing for Alzheimer's disease: The ABIDE project. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 3(3), 314–322. doi:10.1016/j.trci.2017.04.002
- Lee, S. M., Roen, K., & Thornton, A. (2014). The psychological impact of a diagnosis of Alzheimer's disease. *Dementia*, 13(3), 289–305. doi:10.1177/1471301213497080
- Lezak, M. D., Howieson, D. B., Bigler, E. D., & Tranel, D. (2012). *Neuropsychological assessment* (5th ed.). Oxford University Press.
- Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*, 15(6), 1534–1561. doi:10.1177/1471301214564792
- MacQuarrie, C. R. (2005). Experiences in early stage Alzheimer's disease: Understanding the paradox of acceptance and denial. *Aging & Mental Health*, 9(5), 430–441. doi:10.1080/13607860500142853
- Mahieux, F., Herr, M., & Ankri, J. (2018). What are the preferences of patients attending a memory clinic for disclosure of Alzheimer's disease? *Revue Neurologique*, 174(7–8), 564–570. doi:10.1016/j.neurol.2017.10.016
- Mastwyk, M., Dow, B., Ellis, K. A., & Ames, D. (2016). Why attend a memory clinic? What do patients and their families want and/or expect? *Australasian Journal on Ageing*, 35(3), 220–224. doi:10.1111/ajag.12257
- Mohammed, K., Nolan, M. B., Rajjo, T., Shah, N. D., Prokop, L. J., Varkey, P., & Murad, M. H. (2016). Creating a patient-centered health care delivery system: A systematic review of health care quality from the patient perspective. *American Journal of Medical Quality*, 31(1), 12–21. doi:10.1177/1062860614545124
- Mormont, E., de Fays, K., & Jamart, J. (2012). Experiences of the patients and their caregivers regarding the disclosure of the diagnosis of Alzheimer's disease: A Belgian retrospective survey. *Acta Neurologica Belgica*, 112(3), 249–254. doi:10.1007/s13760-012-0069-2
- Park, M. H., Smith, S. C., Hendriks, A. A. J., & Black, N. (2018). Caregiver burden and quality of life two years after attendance at a memory clinic. *International Journal of Geriatric Psychiatry*. doi:10.1002/gps.5053
- Pelosi, A. J., McNulty, S. V., & Jackson, G. A. (2006). Role of cholinesterase inhibitors in dementia care needs rethinking. *BMJ*, 333(7566), 491–493. doi:10.1136/bmj.38945.478160.94
- Postal, K. S., & Armstrong, K. (2013). *Feedback that sticks: The art of effectively communicating neuropsychological assessment results*. Oxford University Press.
- Pratt, M., & Searles, G. E. (2017). Using visual aids to enhance physician-patient discussions and increase health literacy. *Journal of Cutaneous Medicine and Surgery*, 21(6), 497–501. doi:10.1177/1203475417715208
- Ramakers, I. H., Visser, P. J., Bittermann, A. J., Ponds, R. W., van Boxtel, M. P., & Verhey, F. R. (2009). Characteristics of help-seeking behaviour in subjects with subjective memory complaints at a memory clinic: A case-control study. *International Journal of Geriatric Psychiatry*, 24(2), 190–196. doi:10.1002/gps.2092
- Rosado, D. L., Buehler, S., Botbol-Berman, E., Feigon, M., León, A., Luu, H., Carrión, C., Gonzalez, M., Rao, J., Greif, J., Seidenberg, M., & Pliskin, N. H. (2018). Neuropsychological feedback services improve quality of life and social adjustment. *The Clinical Neuropsychologist*, 32(3), 422–435. doi:10.1080/13854046.2017.1400105

- van den Dungen, P., van Kuijk, L., van Marwijk, H., van der Wouden, J., Moll van Charante, E., van der Horst, H., & van Hout, H. (2014). Preferences regarding disclosure of a diagnosis of dementia: A systematic review. *International Psychogeriatrics*, 26(10), 1603–1618. doi:10.1017/S1041610214000969
- van Hout, H. P., Vernooij-Dassen, M. J., Hoefnagels, W. H., & Grol, R. P. (2001). Measuring the opinions of memory clinic users: Patients, relatives and general practitioners. *International Journal of Geriatric Psychiatry*, 16(9), 846–851. doi:10.1002/gps.411
- van Vliet, D., de Vugt, M. E., Bakker, C., Pijnenburg, Y. A., Vernooij-Dassen, M. J., Koopmans, R. T., & Verhey, F. R. (2013). Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychological Medicine*, 43(2), 423–432. doi:10.1017/S0033291712001122
- Vega, J. N., & Newhouse, P. A. (2014). Cognitive impairment: diagnosis, longitudinal course, and emerging treatments. *Current Psychiatry Reports*, 16(10), 490. doi:10.1007/s11920-014-0490-8
- Watt, S., & Crowe, S. F. (2018). Examining the beneficial effect of neuropsychological assessment on adult patient outcomes: A systematic review. *The Clinical Neuropsychologist*, 32(3), 368–390. doi:10.1080/13854046.2017.1414885
- Westervelt, H. J., Brown, L. B., Tremont, G., Javorsky, D. J., & Stern, R. A. (2007). Patient and family perceptions of the neuropsychological evaluation: How are we doing? *The Clinical Neuropsychologist*, 21(2), 263–273. doi:10.1080/13854040500519745
- Woods, B., Arosio, F., Diaz, A., Gove, D., Holmerová, I., Kinnaird, L., Mátlová, M., Okkonen, E., Possenti, M., Roberts, J., Salmi, A., Buuse, S., Werkman, W., & Georges, J. (2019). Timely diagnosis of dementia? Family carers' experiences in 5 European countries. *International Journal of Geriatric Psychiatry*, 34(1), 114–121. doi:10.1002/gps.4997

Appendix A

Semistructured focus group guide

- | | |
|---|--------------|
| A. General introduction and informed consent | (20 minutes) |
| B. Short introduction round | (10 minutes) |
| C. Core question 1: Experience with the neuropsychological assessment | (15 minutes) |

You can see three pictures on the table. A green, orange and red traffic light. You may choose the picture that best reflects your experience with the neuropsychological assessment. Green means you had a positive experience, orange means both positive and negative experiences, and red means a negative experience.

1. Could you explain your choice?
 - 1.1. What was nice? What was not?
 - 1.1.1. Which test did you like most/least?
 - 1.2. What did the family member hear back about it?
 - 1.3. What induced distress?
 - 1.4. What did you think about the length of the assessment?
 - 1.5. What did the neuropsychological assessment give you?

- | | |
|---|--------------|
| D. Core question 2: Experience with diagnostic disclosure | (15 minutes) |
|---|--------------|

2. How did you receive the diagnosis at the memory clinic? What was your experience?
 - 2.1. Was this conversation enough for you? Was there anything that was missing?
 - 2.2. What did you remember from this conversation?
 - 2.3. Did you think about this conversation at a later moment?