Feeling valued versus abandoned: Voices of persons who have completed a cognitive assessment

Marie Tyrrell RN, PhD, Lecturer1,2 | Ragnhild Hedman RN, PhD, Lecturer1 | Bjöörn Fossum RN, Professor1,3 | Kirsti Skovdahl RN, Professor4 | Dorota Religa MD, Professor2 | Pernilla Hillerås RN, Professor1,2,5

Abstract

Aim: To describe older persons’ experiences of a cognitive assessment and possible neuropsychiatric symptoms [NPS] related to a neurocognitive diagnosis.

Background: A cognitive assessment in primary care is offered to persons with suspected dementia with subsequent referral to a specialist clinic if required. The assessment process, with the likelihood of receiving a dementia diagnosis, is surrounded by uncertainty with long waiting times. Although NPS are common among persons with cognitive impairment persons are not routinely asked about these symptoms during a cognitive assessment.

Method: Interviews were held with 18 participants who had completed a cognitive assessment. The Neuropsychiatric Inventory [NPI] was incorporated into one of the interview questions enabling participants to self-report NPS, if present. Interview data were analysed using Interpretive Description.

Results: Two main themes were identified: a matter of trust and making sense of a cognitive diagnosis. Experiences of the assessment process ranged from feeling valued to abandoned with variations of trust in the process. A diagnosis of mild cognitive impairment was experienced as an abstract diagnosis devoid of follow-up support. A lack of preparedness for the assessment existed among participants. Some experienced the process as standardised. One half of participants self-reported the presence of one to four NPS, regardless of neurocognitive diagnosis. Irritability and depression were most common NPS identified.

Conclusions: Experiences of a cognitive assessment varied from feeling valued by society to abandoned in the absence of follow-up support. The assessment was viewed as a standardised procedure failing to see the person behind the testing. Diagnosis disclosure conversations were experienced as diffuse with participants unprepared for a dementia diagnosis. The NPI enabled participants to identify and report the presence of NPS which otherwise could go undetected during the cognitive assessment, impacting on the person’s well-being and daily life.
1 | BACKGROUND

There is a push in society for persons with cognitive impairment to receive a timely dementia diagnosis (Alzheimer’s Association, 2018; Waldemar et al., 2007). Receiving a ‘timely’ dementia diagnosis means the person receives a diagnosis at the right time for them in relation to their situation (Dhedhi et al., 2014), reflecting a person-centred approach (Watson et al., 2018) and high-quality health care (Morley et al., 2015). A dementia diagnosis can help the person access relevant support services and treatments to alleviate symptoms (Roliniski et al., 2012) and eliminate possible reversible factors triggering cognitive decline (Borson et al., 2013).

Time delays exist from the onset of cognitive decline to when the person seeks contact with primary care (Perry-Young et al., 2018), often the first-line access point in health care (Boustani et al., 2007). Health guidelines (National Institute for Health and Care Excellence [NICE] United Kingdom; National Board of Health and Welfare [NBHW] Sweden) recommend persons with suspected dementia receive a basic cognitive assessment in primary care. If cognitive impairment is confirmed, the person should be referred to a specialist cognitive clinic for further investigations such as neuropsychological testing and magnetic resonance imaging of the brain. If the person receives a dementia diagnosis, a person-centred approach is recommended to meet individual care and support needs (NBHW, 2017; NICE, 2018). At the core of person-centredness, in both research and practice, is the building of healthful relationships to promote human flourishing. Values such as, respect for the person, promoting self-determination and embracing mutual understanding are essential in the formation of such relationships (McCormack & McCance, 2010).

Dementia is a feared condition (Sabat, 2019) which can explain why persons over 65 years rarely contact health care explicitly for memory (cognitive) impairment (Begum et al., 2012) and therefore are under-diagnosed in primary care (Prince et al., 2016). A cognitive assessment process, with the likelihood of receiving a dementia diagnosis, is surrounded by uncertainty for the person with long waiting times (Campbell et al., 2016; Samsi et al., 2014). Obstacles identified in making a timely dementia diagnosis are fears of stigmatisation, risk of suicide, lack of support services available (Dubois et al., 2016) and the absence of curative treatment (Dubois et al., 2016; Thies & Bleiler, 2012; Alzheimer’s Association, 2018).

Watson et al. (2018) found that the majority of persons who commenced a cognitive assessment, and family members, were keen to receive a diagnosis. However, not all wish to share this information outside of the immediate family (Hellström & Tores, 2013). Boustani et al. (2006) identified that approximately half of persons who had screened positive for dementia and viewed themselves as not having cognitive impairment, refrained from continuing the cognitive assessment process. Older persons who were informed about potential benefits and risks associated with a diagnosis of Alzheimer’s disease (AD) were less enthusiastic about commencing an assessment and receiving a diagnosis (Robinson et al., 2014). In a previous study by the authors, older persons described that they were often encouraged by others to commence a cognitive assessment, conflicting views existed within the families about the impact cognitive impairment had on daily life (Tyrrell et al., 2021).

The presence of neuropsychiatric symptoms (NPS) is recognised as an integral part of the dementia disease trajectory (Livingston et al., 2017) with most persons with dementia experiencing NPS (Lyketsos et al., 2011). Symptoms include hallucinations, delusions, agitation/aggression, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behaviour, sleep and night-time disturbances, and appetite and eating change (Cummings et al., 1994).
Mortby et al. (2017) identified that 40 per cent of older adults reported NPS across the cognitive disorder spectrum; depression was most common followed by agitation and sleep disturbance. According to Hill et al. (2016), affective symptoms such as depression and anxiety commonly occur in older persons with subjective cognitive decline with feelings of anxiety related to self-awareness surrounding loss of function. The presence of NPS in older persons can signal the presence of underlying cognitive disorders and help identify the aetiology of the associated disorder (Gallagher et al., 2017).

Few studies have investigated persons with NPS at the point of neurocognitive diagnosis with empirical knowledge sparse regarding persons with mild cognitive impairment [MCI] and NPS (Tchalla et al., 2018). The majority of research has focused on the impact of NPS has on persons with dementia living in residential facilities (Lövheim et al., 2008; Osland Vik-Mo et al., 2018).

Living with NPS has a negative impact on the person and their families (Cerejeira et al., 2012; Mukherjee et al., 2017) causing suffering for the persons concerned (Shankar et al., 2014). The presence of NPS is correlated with acute admissions to hospitals for persons with dementia, high morbidity and mortality (Okura & Langa, 2011; Van Den Wijngaart et al., 2007) and admissions to residential accommodation (Toot et al., 2017; Van Den Wijngaart et al., 2007). The preferred treatment of NPS is non-pharmacological and secondarily pharmacological (Magierski et al., 2020). Despite knowledge about the negative impact of NPS on persons with dementia and their families, symptoms are under-identified in the cognitive assessment process (Braun et al., 2019). In a previous study by the authors, 23 older persons who had commenced a cognitive assessment were interviewed, 16 of 23 self-reported the presence of one to four NPS (Tyrrell et al., 2021). This study aimed to capture the experiences, of the same persons, after completing the cognitive assessment and follow-up on previously reported NPS.

1.1 Aim

To describe older persons’ experiences of a cognitive assessment and possible neuropsychiatric symptoms related to a neurocognitive diagnosis.

2 | METHOD

We recruited participants from an urban primary care clinic. A purposeful sampling method was chosen to capture experiences which could enhance the knowledge of the field (Polit & Beck, 2017). Thorne (2016) describes purposeful sampling as a more representative form of sampling of persons by the nature of their experiences and specific settings. Staff at the primary healthcare clinic proposed potential participants after first obtaining permission from participants. All participants were then contacted per telephone (by the first author) to ensure that they were aware and understood the purpose of the study and what was involved in participating. Inclusion criteria were persons 65 years of age and older with a Mini Mental State Examination [MMSE] (Folstein et al., 1975) score ≥15p as described by Stormoen et al. (2017) as a cutoff point for informed consent and ability to converse and communicate in Swedish or English.

A total of 31 older persons were approached to join the project, 23 participants met the inclusion criteria and commenced the assessment (Tyrrell et al., 2021), and of those, 18 completed the cognitive assessment process and were therefore included in the present study (Table 1). The remaining five persons, who had started but not completed the cognitive assessment, due to medical reasons or other, were consequently not interviewed.

In this study, interviews took place 1 to 2 months after the participants had completed their cognitive assessment, between March 2018 and March 2019. The duration of the cognitive assessments was on average 3 to 4 months. All interviews were held at a place of convenience for the participant, for example the participant’s own home or place of employment. Of the eighteen interviews, four were not audio-recorded for technical reasons or that the person felt uncomfortable about the interview being recorded. Notes were taken during all interviews, and interview data were transcribed directly after each interview by the first author.

Interview questions were posed from a semi-structured interview guide which focused on participants’ experiences of a cognitive assessment, receiving a cognitive diagnosis and the presence of NPS related to cognitive impairment. Applying a similar format to our previous study (Tyrrell et al., 2021), the Neuropsychiatric Inventory-Nursing Home version [NPI-NH] (Cummings et al., 1994) was presented to the participants during the interview. We used the NPI as a complement to a question in the interview guide pertaining to if participants had developed new symptoms which they could relate to their cognitive impairment. The NPI acted as a checklist to assist participants in identifying and discussing the presence of NPS, where relevant. Information regarding type and amount of NPS or other symptoms identified by participants was gathered.

A person-centred approach promoting connectivity with study participants was applied by the first author in her contact with participants. Connectivity, as described by Jacobs et al. (2017), entailed that study participants’ needs, values and wishes were prioritised. All dialogues in this study were grounded in mutual respect maintaining a critical approach throughout the research process.

Interview data were analysed using Interpretive Description [ID] (Thorne, 2016). As an approach, ID is used to answer real-world inquiries and is grounded in the researcher’s disciplinary context, acknowledging their positioning in research. It is a strategy used to illuminate and disseminate knowledge relevant for the disciplinary practice, where thematic patterns and meanings of a described phenomenon provide insights and knowledge development in the field (Thorne, 2016). Guided by the aim of the study, preliminary patterns were identified through coding of interview data by the first author using a constant comparative approach as
recommended by Thorne (2016). Patterns developed into themes by focusing on relationships and associations within the data, which is in keeping with an ID approach. Meaning and understanding of relationships were discussed in the research team. From these collaborative discussions, preliminary subthemes and themes were proposed by the first author. After deliberation, a consensus was reached within the team, and subthemes and themes were agreed on (see Table 2).

Regarding this study’s credibility, a combination of a purposeful sampling procedure, thorough fieldwork and a systematic approach which was pursued by the research team in exploring interview data and during the analysis process, guided by the aim of the study. This is in line with what Patton (2015) describes as essential elements in ascertaining credibility in a qualitative study. Additionally, the first author, who conducted the interviews, has experience of working as a Registered Nurse in a cognitive assessment clinic. All authors have experience of the research field, which in turn can further strengthen the credibility of this research (Patton, 2015; Thorne, 2016). This research also has disciplinary relevance to gerontologic nursing and ethical aspects were carefully considered which Thorne (2016) describes as a vital aspect of credibility.

### 2.1 Ethical considerations

The study received approval from the Regional Ethical Review Board. The study participants received verbal and written information regarding the study by the staff at the primary health care and the first author. Participants were informed that participation in this study was voluntary and that at any time they could decline their involvement without consequences. As the participants in this study had cognitive impairment, this information was shared with extra sensitivity, often involving family members. In some cases, family members were present during the interviews to support the informant. Consent from the persons to participate in the study was obtained in accordance with the Helsinki Declaration (World Medical Association Declaration of Helsinki, 2013).

<table>
<thead>
<tr>
<th>Participant</th>
<th>MMSE</th>
<th>Cognitive diagnosis</th>
<th>Self-reported NPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>*87 years/Male</td>
<td>21/30</td>
<td>Vascular dementia</td>
<td>None</td>
</tr>
<tr>
<td>*84 years/Male</td>
<td>16/30</td>
<td>Mixed dementia</td>
<td>None</td>
</tr>
<tr>
<td>*85 years/Male</td>
<td>24/30</td>
<td>Alzheimer’s disease</td>
<td>Irritability</td>
</tr>
<tr>
<td>*86 years/Male</td>
<td>27/30</td>
<td>Mild cognitive impairment</td>
<td>Apathy, aberrant motor behaviour, appetite</td>
</tr>
<tr>
<td>76 years/Male</td>
<td>28/30</td>
<td>Mild cognitive impairment</td>
<td>Appetite, irritability, depression</td>
</tr>
<tr>
<td>*91 years/Male</td>
<td>20/30</td>
<td>Alzheimer’s disease</td>
<td>None</td>
</tr>
<tr>
<td>91 years/Female</td>
<td>28/30</td>
<td>Mild cognitive impairment</td>
<td>None</td>
</tr>
<tr>
<td>80 years/Male</td>
<td>29/30</td>
<td>Mild cognitive impairment</td>
<td>None</td>
</tr>
<tr>
<td>82 years/Female</td>
<td>28/30</td>
<td>Alzheimer’s disease</td>
<td>Appetite</td>
</tr>
<tr>
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<td>Mild cognitive impairment</td>
<td>None</td>
</tr>
<tr>
<td>*83 years/Male</td>
<td>24/30</td>
<td>Alzheimer’s disease</td>
<td>Agitation, irritability, depression</td>
</tr>
<tr>
<td>77 years/Female</td>
<td>29/30</td>
<td>Mild cognitive impairment</td>
<td>Agitation, depression</td>
</tr>
<tr>
<td>82 years/Male</td>
<td>29/30</td>
<td>Mild cognitive impairment</td>
<td>Depression, night-time behaviour</td>
</tr>
<tr>
<td>71 years/Male</td>
<td>30/30</td>
<td>Other cognitive diagnosis</td>
<td>Irritability, apathy, depression</td>
</tr>
<tr>
<td>79 years/Male</td>
<td>29/30</td>
<td>Mild cognitive impairment</td>
<td>Night-time behaviour, irritability</td>
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<td>80 years/Female</td>
<td>28/30</td>
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<td>None</td>
</tr>
<tr>
<td>91 years/Male</td>
<td>27/30</td>
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<td>None</td>
</tr>
<tr>
<td>*79 years/Male</td>
<td>27/30</td>
<td>Mild cognitive impairment</td>
<td>None</td>
</tr>
</tbody>
</table>

*Persons accompanied by a family member during the interview.*

<table>
<thead>
<tr>
<th>Subthemes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiencing trust in the process</td>
<td>A matter of trust</td>
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<td>Trust undermined in the process</td>
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<td>Acknowledging the presence of neuropsychiatric symptoms</td>
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<td>Navigating the future</td>
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3 | RESULTS

The findings are presented under themes and subthemes (Table 2).

3.1 | A matter of trust

Trust and mistrust were issues described during the entire process of assessment and diagnosis disclosure. Experiences shared by participants of a cognitive assessment were mainly related to the specialist cognitive clinics which they were referred to from primary care. Participants spoke favourably about their contact with their GP and referral to a specialist clinic. Experiences of the assessment process were mixed ranging from gratefulness to ambivalence and strong feelings of violation. Experiences shared by participants echoed levels of trust in the cognitive assessment process which they had undertaken.

3.1.1 | Experiencing trust in the process

A prerequisite for having trust in the assessment process was that participants had expectations and beliefs that healthcare professionals worked with advocacy and were skilled and competent in the field. Feeling confident and safe in the knowledge that a cognitive assessment was a systematic, standardised procedure in health care was expressed by some participants. Several participants claimed that referral to a cognitive assessment by their GP was symbolic of how society cared and valued older persons and they were thankful for efforts made.

'I didn’t think it was really necessary to send me for a memory assessment… It’s great that society is interested in old people'.

For some the assessment was recalled in a positive light, enjoying the testing experience. Testing was described as often challenging and an opportunity to display cognitive capacity and reserve which otherwise was not in the spotlight. For others, the cognitive assessment left them feeling exposed, as the neuropsychological testing revealed tangible limitations. These limitations were often contrary to a previously self-held estimations of high cognitive function which had not been put to test in a controlled environment.

'I must admit that the tests I did made me feel quite depressed when I left the place, somehow, I have a feeling that I am still capable of doing things …'

3.1.2 | Trust undermined in the process

Building a trusting relationship with healthcare professionals was highlighted as an important factor in the assessment process. This trust was undermined in some cases where healthcare professionals were described as stressed and unprofessional in manner, attire and in their approach raising concerns about the quality of the assessment. A participant, who received an MCI diagnosis, recalled how the psychologist fell asleep during the neuropsychological testing. Others spoke about a non-inviting clinical environment and language barriers with staff using medical terminology and not always mastering the Swedish language. Another participant who received a dementia diagnosis explained how the assessment process lacked empathy, and comparisons were drawn with other assessments they had undergone in health care which appeared more compassionate in nature.

'They [the occupational therapist] were talking to me like a child…. I think it [cognitive assessment] was not fitting in the society I live in; it was cold and theoretical... more empathy is needed'.

Lacking knowledge and preparedness for a cognitive assessment was shared by several participants. A participant who received a dementia diagnosis explained how they were under the impression that they were there to train their memory. Other participants were unaware that their performance was rated and played a part in the setting of a cognitive diagnosis. They felt that they were lured into a cognitive assessment without fully understanding the process and outcome.

'As I wasn’t prepared for testing and unaware that I was under an assessment the whole thing was a shocking experience... which has left me with negative memories that haunt me... no one said that I was under an assessment… it was horrendous… like being attacked from behind'.

The cognitive testing felt like being compared to a standardised psychometric assessment package for some participants, in a non-inclusive process failing to see them as unique persons. Assessments were not personalised to meet participants needs and requirements, instead test scores were compared to statistical norms, this was a cause of disappointment and irritation for some participants. Explanations and the meaning of the cognitive tests and results were not always clear.

'They compared me with some statistical database ... it [testing] wasn’t adapted for an individual. The aim of [the testing] is important and that it is explained'.

Some participants were critical to the type of testing offered as it was not deemed relevant to how they functioned in everyday life. They felt that the life they led met their cognitive levels of function. Several participants explained how they consciously made fun of the situation in protest of the stringency and lack of flexibility of the testing situation. Cognitive testing offered was regarded as not representative
of everyday life and lacking background information regarding context and relevance for the participants.

‘... It [cognitive assessment] was just hilarious I didn’t take it seriously. I mean to get a question to remember a number, nothing to do with banking or distance, so how could I remember that’.

Several participants viewed the level of testing as very basic and not extensive enough to cover their subjective concerns about cognitive impairment or how they functioned as a person. For some the low level of testing was interpreted as an insult to their intelligence leading to feelings of frustration and humiliation among participants.

‘They wanted a type of clock in their way... I think you can answer a question in different ways.... I would not say it [assessment is science, when you have to pretend to have a tea-party... I don’t think it is an appropriate way of doing things, I would rather quote Shakespeare’.

A few participants spoke about the use of a stopwatch during the cognitive testing which gave rise to anxiety for some. They highlighted that they were not informed that the cognitive testing would be timed, and the stopwatch was held out of apparent vision under the table during the testing. This was experienced as a dishonest and unprofessional action which overshadowed the testing situation. Another participant was surprised seeing the stopwatch during the testing and questioned its use and relevance.

‘I observed during the testing that they [psychologist] had a stopwatch... I was curious about it and asked what they had a stopwatch for... what I gathered from the answer was that there are certain limits for how long certain tasks should take and they probably class the times the answers are given in...’

3.2 | Making sense of a cognitive diagnosis

Making sense of a cognitive diagnosis refers to the participant experiences of the final phase of the assessment process and their reflections about the future. To receive a cognitive diagnosis, either AD or other evoked varied reactions from participants ranging from relief, confusion to shock and devastation. Present and future concerns surrounding living with a cognitive diagnosis were expressed. Seven of eighteen participants received a dementia diagnosis with most receiving an MCI diagnosis (Table 1). Parallel to receiving a cognitive diagnosis, participants reported the presence of NPS. The NPS self-reported were unique and varied and appeared not characteristic of a specific cognitive diagnosis (Table 1).

3.2.1 | Acknowledging the presence of neuropsychiatric symptoms

Participants reported the presence of NPS upon self-assessment using the NPI. Regardless of neurocognitive diagnosis, nine of eighteen participants self-reported the presence of NPS. NPS reported varied from one to four co-existing symptoms with the most common NPS identified being irritability followed by depression (Table 1).

Many participants reported NPS which had subsided or disappeared (when the authors compared to data on NPS in the previous study) post-cognitive assessment. Other participants reported NPS which were consistent or had increased during the cognitive assessment period. Both participants with MCI and dementia diagnoses reported individual variations in the presence of NPS both pre- and post-cognitive assessment.

Self-reported NPS such as irritability and agitation were considered emotional reactions to the frustration experienced in their situation with cognitive impairment, rather than a pathological state. Depression and apathy, in some cases, were deemed directly related to a life with cognitive impairment. Other self-reported NPS, concerning sleep and food intake, were tangible concrete NPS, which could be observed by family appeared easier for the participants to report and discuss than other psychological and behavioural symptoms.

‘I have lost the feeling of hunger however I do eat with an appetite, but I am not hungry, if you know what I mean ... I eat after the clock’.

Of the participants reporting multiple NPS, they tended to have high MMSE scores (Table 1) and reported, in some cases, depression as a symptom. Depression as an NPS was a dominant symptom which over-clouded daily life. In most cases, depression was experienced as a symptom directly associated with the presence of cognitive impairment and posed a real threat to the mental health and well-being of the participants. For others who had physical diseases, the combination of both physical and cognitive symptoms was overwhelming and resulted in depression.

‘I feel sad and down and now realise that my life will not end, as I had hoped, with a fall on a rock at the age of 93 years, dying there and then. Instead it can entail many years sitting like this and this I find deeply humiliating’.

Some participants, who did not report NPS, were aware that the presence of certain NPS was not easily identifiable as a subjective experience. Instead, it was an objective observation which should be explored by asking family or friends. Humorous comments were made regarding reporting certain NPS, as they were deemed farfetched and not a realistic subjective experience.
Thoughts of developing certain NPS were implied by one participant as a possible pleasant escape from the reality of living with cognitive impairment.

‘Hallies? (hallucinations) [laugh]. No, I don’t think I can say so; however, I miss the fantasy I had before [cognitive assessment] and my experiences with colour which now somehow have faded. This is a source of anxiety for me….no matter what I do everything is grey’.

3.2.2 | Responding to a cognitive diagnosis

Most participants received a diagnosis of MCI which was perceived as a diffuse, abstract diagnosis lacking clarity for those concerned. Commencing an assessment to explore possible causes of cognitive impairment and upon completion of the assessment to receive a diagnosis of MCI, was not viewed as beneficial. Uncertainties were present about if the assessment was complete and if a follow-up was planned.

‘I had expectations that they could tell me and see... see what is wrong in my head ehh... they’ll call me back I presume, maybe, but it probably will take a year or two years and then I’ll be dead... [laugh]’

Not all participants were aware of the diagnosis they had received and spoke about desires to gain more information and further clarification. There was a reluctance to ask for further clarification as it may be interpreted as being confrontational or rude.

‘I haven’t really understood what the outcome was... it was very diffuse I would have liked to see their notes, if you know what I mean. Of course, I can do that if I like but I don’t want to be rude towards the doctors... I like to be polite’.

Of the participants who received a diagnosis of MCI, it was interpreted as a static condition which would remain unchanged. Participants recalled that their diagnosis of MCI was disclosed indirectly by the treating physician by being told that they did not have AD. For some, this came as relief for both participant and family and for others, no previous concerns or thoughts had arisen about a diagnosis of AD. Placing focus on the elimination of other diagnoses left the actual diagnosis of MCI in the shade.

‘Mmm the final message I got was... I don't have Alzheimer’s disease [laugh] the rest of the diagnosis I have forgotten, it didn’t stick in my head. It personally didn’t give me very much saying that it wasn’t Alzheimer’s... I hadn’t even contemplated the possibility that it could have been [laugh]’.

Diverse reactions were experienced and shared by participants who received a dementia diagnosis. Due to their memory impairment, some of the participants could not recall if they had received a diagnosis or not. In these circumstances, a diagnosis was not deemed to impact their life to a great extent. Reactions ranged from the diagnosis being helpful in gaining an understanding of their situation to shock and strong feelings of violation. A participant compared receiving a dementia diagnosis to a sexual violation. A dementia diagnosis entailed major threats to their autonomy, identity and expectations for the future. Several participants who were prescribed cholinesterase inhibitors medication spoke about the presence of gastrointestinal side effects. A participant explained that they had been advised to discontinue the medication due to the extent of the side effects experienced. Other participants were relieved that there was available treatment and that they had been prescribed in belief that it would stop the disease process.

‘It was a very, very good overhaul ... they could draw some conclusions and found, when they looked at the results and everything, ... they saw some signs that it was the start of Alzheimer's ... they decided that I should start with these tablets [Memantin]... from my point of view it felt good to get that [diagnosis] as it was discovered, thankfully, in good time before it had spread, so to speak’.

Some participants who received a dementia diagnosis explained how their life would never be the same again. They had been encouraged by others to commence an assessment, not reflecting fully about the possibility of receiving a dementia diagnosis. They felt betrayed by family members who had proposed the assessment. Regrets were expressed by some about commencing an assessment considering the diagnosis received and consequences. A participant in combination with a dementia diagnosis received a driving ban while awaiting referral for a driving assessment. The possibility of losing their driving licence was overwhelming for the participant concerned.

‘Going through this memory assessment I found offensive but, I have never confronted my family member about it... I feel betrayed by them, but they have their own issues and thought that they were doing right ... my GP told me that they had contacted him, it was then I understood the connection’.

Variations in how participants experienced the diagnosis disclosure conversations existed. Some participants expressed uncertainty regarding what type of diagnosis they had received. Another experience shared by a participant was that of being informed flippantly about a dementia diagnosis and then subsequently objectified in the discussion.

‘The physician looked at all the test results... by the way you have Alzheimer’s ... just like that... then
turned to my wife and said this is what you need to do about Alzheimer’s regards meetings and therapists ... I hadn’t asked about that... I felt humiliated’.

3.2.3 | Navigating the future

One to two months had elapsed for the participants since receiving a neurocognitive diagnosis. This post-diagnostic period was experienced by many as a time of uncertainty. Both confusion and anticipation were present among participants regarding referrals to a recovery programme or a memory training programme after completion of the cognitive assessment. Parallels were drawn with other areas of health care where for example physical illnesses rendered referrals to rehabilitation programmes. As none of the participants had been referred to follow-up care, many participants experienced that they were abandoned by health care. This was not the case for participants who received an AD diagnosis in combination with pharmacological treatment, and they were eligible for follow-up care. A participant with MCI explained that they had been informed during the cognitive assessment that it was possible to counteract memory loss through memory exercises and training, and they were anxiously awaiting a referral.

‘The doctor from the memory clinic said that help is available [for MCI] through exercises and training and therefore I deeply regret and am angry about it ... one should go directly into some sort of memory treatment and up until now I haven’t received any treatment, I have not received any tips if I should do one thing or another...’

According to one participant, the subject of trusteeship was discussed by the physician in connection with the disclosure of their cognitive diagnosis. The participant explained experiencing shock when they were presented with an application form to apply for trusteeship. Suggesting the need for a trustee was disturbing and posed threats on their personal identity, autonomy and dignity.

‘I had my children with me, I heard just, you have Alzheimer’s and because of this you need medication ... Ohh and you have to have a trustee... imagine what a shock to get for a person with over 50 years of a career in projects both national and international which I have led myself, you know it is like eliminating all of my history...’

4 | DISCUSSION

Feeling valued versus abandoned depicted contrasting experiences of a cognitive assessment shared by participants. The possibility of receiving a cognitive assessment evoked experiences of feeling valued by society for some participants. Others questioned the relevance of the process and felt abandoned after completing the assessment due to the absence of follow-up support and care. Experiences of abandonment were mainly shared by participants who received an MCI diagnosis. No information regarding follow-up support or recommendations was offered to these participants at the diagnosis disclosure meeting. This resonates with Kelly and Innes’ (2016) findings describing how persons, post-cognitive assessment, felt dismissed like ‘being sent away’ by healthcare staff, or left in ‘limbo’ as described by Xanthropoulou and McCabe (2019).

Follow-up support and recommendations were important for persons who received a cognitive diagnosis. Examples of such support were cognitive training, group meetings (Abley et al., 2013), and recommendations of physical activity, healthy eating, and social and intellectual stimulation (Rosenberg et al., 2018). Lifestyle recommendations should be an integral part of the diagnosis disclosure conversation to promote strategies for well-being and meet the needs of the person and could be offered in a follow-up appointment. Abley et al. (2013) highlight a need for sensitivity in providing practical information surrounding a cognitive diagnosis so the person has time to come to terms with the situation first.

Participants disclosed uncertainties about the type of cognitive diagnosis they had received after completing the assessment. A diagnosis of MCI was experienced as ambiguous and sometimes diffusely disclosed by treating physicians, with emphasis placed on the absence of AD. During the diagnosis disclosure conversations, participants did not always feel that they were the focus of the conversation. The disclosure of a diagnosis of dementia is a difficult task for practitioners (Bamford et al., 2004; Iliffe et al., 2003) and is related to risks of stigmatisation (Dubois et al., 2016). Prior to a diagnosis conversation, the wishes of the person should be sought (Frederiksen et al., 2020). Practitioners are recommended to provide a written account of diagnosis and possible treatment and support options for persons with MCI (Frederiksen et al., 2020; Grill et al., 2017). Grill et al. (2017) recommends that a significant other is present to support the person during the MCI disclosure conversation. As MCI is in some cases a precursor to dementia, it is important to identify the person’s expectations and understandings before planning further assessments (Grill et al., 2017). The communication of a cognitive diagnosis finalises the cognitive assessment and can be regarded as a stressful time for the person. Pre-counselling should be offered to help prepare the person for the possibility of receiving a dementia diagnosis and enable them to better understand the process and outcome (Guss et al., 2017). Poyer and Tickle (2019) also describe the importance of communicating hope for the future to the person and their family member when disclosing a dementia diagnosis.

Levels of trust in the cognitive assessment process varied among participants. For some participants, having knowledge that they were part of a standardised process provided trust and confidence in the cognitive assessment. Others described the standardised process as offensive, disregarding them as unique persons. Samsi et al. (2014) and Manthorpe et al. (2013) also described cognitive testing
as lacking a person-centred approach and thus causing distress for the person concerned. Kitwood (1997) highlighted how maintaining personhood for persons with dementia is based on recognition and trust. Failures in seeing the person behind a cognitive diagnosis can negatively influence the person’s view of self and impact on the creation of healthful relationships as described by McCormack and McCance (2010). Hedman et al. (2016) described how a sense of agency and communion are important aspects of a person’s identity which might be threatened in dementia. Agency is concerned with a person’s search for autonomy and independence, and communion is related to desires to belong to a group. Both are motivational driving forces for persons in life (Bakan, 1966). It has been described that some people are predominantly agency driven, while others are more communion-orientated, and further that this orientation can vary in persons during their life span (Diehl et al., 2004). In line with this theory, it might be interpreted that the persons who felt offended by the standardised assessment procedures were more agency driven, and that the persons who were assured by the same process were more orientated towards communion.

Some participants in this study described the use of ‘elderspeak’ (Brown & Draper, 2003), being treated like a child, and other approaches by healthcare professionals which contributed to experiences of humiliation and feeling undermined. Such encounters are indicative of what Kitwood (1997) described as signs of oppressive care practice. These unprofessional encounters, which were most likely unintentional, impacted negatively on the participants levels of trust in the process and feelings of being valued as a person. Birt et al. (2019) emphasised the importance of establishing a trusting relationship with healthcare professionals to enhance outcomes of a cognitive assessment. The findings in this study highlight the need for further training in person-centred approaches of healthcare professionals who work in the field.

With a push in society for a timely diagnosis (Alzheimer’s Association, 2018; Waldemar et al., 2007), it is important that contingency plans are in place to support persons across the spectrum of cognitive diagnoses and stages. In general, a discrepancy exists of perspective taking in dementia research, where caregivers’ perspective often outweighs the voice of the person with dementia (Bartlett et al., 2018). This study lifts the voices of the persons concerned. Several participants stated that they were not adequately prepared for a cognitive assessment and to receive a diagnosis. Testing a person’s cognition is a sensitive and delicate matter which can cause distress and disruption to the self-identity of the person in focus. Receiving a cognitive diagnosis is a life changing event entailing perceived losses on many levels for the person concerned (Robinson et al., 2011).

One half of participants, regardless of neurocognitive diagnosis, reported the presence of NPS. Symptoms reported by participants were not static, for some participants NPS had disappeared and for others increased during the cognitive assessment process. Several participants reported the onset of depression in relation to their situation with cognitive impairment which remained unchanged during the assessment process. NPS reported by participants were presented as mainly emotional reactions to their situation with cognitive impairment. A person-centred approach (McCormack et al., 2017) during the assessment process can help identify if the person experiences NPS and gain insights into unmet care and support needs (Mc Greevy, 2015).

There are both limitations and strengths in this study. An inclusion criterion for this study was that participants should have an MMSE (Folstein et al., 1975) score of 15 points or over. The MMSE is an objective measurement of a person’s cognitive function. Setting limits in MMSE scores for participation was initially chosen for practical purposes regarding consent and communication. However, despite participants’ MMSE scores, individual variations in levels of communication were observed. Taking this into consideration, setting limits for MMSE scores may in turn have excluded participants who could have contributed to the study. Participants recruited from one primary care clinic, however, were referred to different cognitive assessment clinics, which implied that they had a broader range of experiences. This can be considered as a strength as it adds to the richness of the data. Although information about study participants’ levels of education was not gathered, many appeared to have a high level of education which may have impacted on interview data obtained and not representative of a normal population. Educational background and socioeconomic position are closely associated with and affect multiple aspects of living and dying with cognitive impairment (Korhonen et al., 2020).

Seven participants were accompanied by family members who supported their communication when required during the interviews. The presence of a family member may have impacted on interview outcomes by either restricting or enriching dialogues with participants, as couples living with dementia often collaborate in constructing and communicating their experiences (Bielsten et al., 2018; Hydén, 2011). Four of the interviews were not audio-recorded. Extensive note taken during these interviews may have impacted on how nuances of language were documented, and level of contact made with the participant, and this may impact on the credibility of the study.

All participants appeared eager to verbalise in their own way their experiences of the cognitive assessment. Incorporating the NPI in the interviews may have encouraged participants to discuss symptoms which otherwise were not viewed as problematic. On the contrary, the use of the NPI may have provided a forum for participants to discuss and label symptoms which otherwise could go unreported. A further strength in this study is that the first author carried out all interviews which enhances the credibility of a study (Polit & Beck, 2017).

5 | CONCLUSIONS

Participants’ experiences of a cognitive assessment varied from feeling valued by society to abandoned in the absence of a person-centred approach in the assessment procedure and follow-up support. The assessment process appeared as a standardised procedure...
failing to see the person behind the testing. Diagnosis disclosure conversations were experienced as diffuse with persons unprepared for a dementia diagnosis.

To enable a more inclusive and meaningful assessment process, a person-centred approach should be used in dialogue and testing situations. Diagnosis disclosure conversations need to be structured and informative with the person in focus. Pre-assessment counseling and follow-up support should be available and tailored after the persons’ needs. In this study, one half of participants identified the presence of NPS ranging from one to four co-existing NPS with irritability the most common symptom. Completion of the NPI during the assessment process can help the person report NPS which otherwise can go undetected, impacting on the persons’ well-being.

CONFLICT OF INTEREST
The authors declare no conflict of interests.

AUTHOR CONTRIBUTIONS
MT, PH, BF, KS and DR were involved in the conception and design of this study. MT conducted the data collection and commenced the data analysis. Thereafter, all authors were involved in the data analysis process and the manuscript preparation and confirm responsibility for this study.

DATA AVAILABILITY STATEMENT
Data available on request due to privacy/ethical restrictions.

ORCID
Marie Tyrrell https://orcid.org/0000-0002-9589-2560

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Laura Fratiglioni, Hui-Xin Wang, Kjerstin Ericsson, Margaret Maytan, Bengt Winblad
