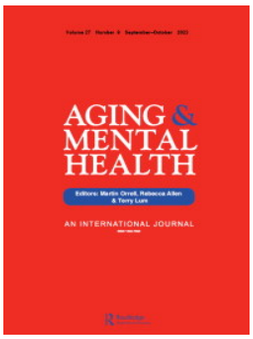

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Perceived barriers and solutions by generalist physicians to work towards timely young-onset dementia diagnosis

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ABSTRACT

Objectives: Timely diagnosis of young-onset dementia (YOD) is an important prerequisite to initiate appropriate support. However, YOD diagnosis is often late. We aimed to explore the perspectives of referring general practitioners and occupational physicians, to better understand their barriers to YOD diagnosis and reveal potential solutions to facilitate timely diagnosis.

Methods: We conducted 16 semi-structured qualitative interviews with general practitioners and occupational physicians in the Netherlands. Inductive thematic analysis was applied to the transcripts with a team including researchers from various (clinical) backgrounds.

Results: Thematic analysis revealed three themes related to: (1) disease characteristics that hinder YOD recognition, being the low incidence and the fact that they mimic other prevalent conditions like burn-out and depression; (2) physicians' attitudes that delay YOD diagnosis, as fear of mis-diagnosis and therapeutic nihilism; and (3) proposed solutions to navigate the challenging YOD diagnostic trajectory including monitoring people with depression and burn-out to consider YOD when recovery stagnates, and more effective interprofessional collaboration.

Conclusion: In this study, referring physicians confirmed barriers known to YOD diagnosis and suggested potential solutions to improve YOD diagnosis. Future prospective studies in people with a primary diagnosis of depression or burn-out may show whether these interventions are potentially effective.

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Young-onset dementia; diagnosis; general practitioners; occupational physicians

Introduction

Timely diagnosis of young-onset dementia (YOD) is important. It provides clarity for patients and caregivers and is a prerequisite to initiate appropriate care and supportive services (Bakker et al., 2010; Couzner et al., 2022). However, establishing an accurate diagnosis seems particularly challenging in the case of YOD, which is the case when people develop symptoms before the age of 65 years (Van de Veen et al., 2022). The average time to diagnosis is estimated at 4.4 years in the Netherlands (Van Vliet et al., 2013), 3.4 years in Australia (Loi et al., 2022) and 5.5 years in Norway (Kvello-Alme et al., 2021). These prolonged diagnostic trajectories cause uncertainty, frustration and fear in patients and relatives (Lai et al., 2023; Van Vliet et al., 2011). Moreover, the initiation of appropriate support is equally delayed (Millenaar et al., 2016).

Reasons for the delay in diagnosis seem to relate to the low prevalence with a global prevalence of 119 cases per 100,000 population (Hendriks, Peetoom, Bakker, et al., 2022), the variety in which YOD manifests itself (Mendez, 2006; Van de Veen et al., 2022), and the atypical nature of YOD symptoms compared to late onset dementia (O'Malley et al., 2020). Another reason for the diagnostic delay may be the lack of knowledge about YOD among physicians, who are responsible for recognition of possible first symptoms, adequate referrals and/or diagnosis (Couzner et al., 2022). When physicians are not aware of the range in clinical presentations and overlap of symptoms with other diseases, there is often a downplay of symptoms or misdiagnosis (O'Malley et al., 2020). Therefore, it has been stated that a comprehensive, specialist and multi-disciplinary assessment is needed to be able to diagnose dementia in persons under the age of 65 (Couzner et al., 2022).

Although specialist expertise is needed to diagnose dementia at a young age, general practitioners or occupational physicians are usually the first healthcare professionals to be confronted with younger persons expressing possible dementia symptoms. In the Netherlands, general practitioners, who serve as gatekeepers, can refer people for specialist diagnosis (Kroneman et al., 2016). When the general practitioners suspects dementia before the age of 65, guidelines (Nederlands Huisartsengenootschap, 2020) recommend referral to a Memory Clinic in which elaborate diagnostic work-up and disclosure take place (Ramakers & Verhey, 2011). Whether referral takes place thus depends on the ability of the general practitioners to recognise possible first symptoms of dementia. This underlines their crucial role in the process towards a timely dementia diagnosis at a younger age in the Netherlands. Caregivers however stated that their general practitioners did not take them seriously when expressing worries about their loved-one and often considered psychological diagnoses (Van Vliet et al., 2011).

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Another generalist physician that may play an important role in recognition of dementia symptoms in younger persons is the occupational physician, whose role focusses on keeping people healthy (both physically and mentally) at work. Symptoms related to YOD frequently affect people's functioning at work (e.g. due to lack of concentration or lack of overview) already in earlier stages of the disease, which emphasizes the importance of occupational physicians being able to recognise these symptoms (De Graaf et al., 2020).

Despite the important roles of general practitioners and occupational physicians in the process towards diagnosis of dementia in younger persons, little is known about their perspectives on this topic. Therefore, we aimed to explore the experiences, perspectives, and attitudes of general practitioners and occupational physicians to better understand their barriers to a YOD diagnosis. We additionally aimed to identify directions that can support these generalist physicians to facilitate a (more) timely dementia diagnosis at a young age.

Methods

Study design

We chose a qualitative study design using semi-structured interviews, as it allows for exploring new topics that are not yet widely studied (Korstjens & Moser, 2017). The Consolidated criteria for reporting qualitative research (COREQ) were used for reporting (Tong et al., 2007).

Participants

General practitioners and occupational physicians were eligible to participate. Including two types of generalist physicians enabled us to explore the study topic from different perspectives (data triangulation). In total, 108 general practitioners and 46 occupational physicians in the south of the Netherlands were invited to participate in the study. There were no inclusion or exclusion criteria, nor did we apply selection criteria (convenience sampling). Participants were contacted by one of the authors (RT) *via* an e-mail with a description of the study and its aim. The e-mail addresses were collected *via* the regional general practitioners' network in West-Brabant, the Netherlands, which included almost all general practitioners in the area, and *via* the association for occupational physicians in the same region.

Data collection

When eligible physicians agreed to participate in the study, they were contacted separately by one of the researchers (RT) to make a face-to-face appointment for the interview at the physician's workplace. The researcher who conducted all interviews (RT) was a nurse specialist with a master degree in advanced nursing practice, and experienced in performing qualitative interviews. The interviews were held from June until October 2020, and lasted between 20 and 60 min. All interviews were conducted individually and face-to-face, except for one online interview with three occupational physicians. The main reason for this online group interview was convenience, as they were willing to participate together. The session was online because of the occurring COVID-pandemic at that time.

Table 1. Key themes from topic guide.

1. Familiarity with YOD
2. Experiences with people with YOD by generalist physician
3. Reflections on the previous YOD trajectories and the related symptoms
4. Perceived barriers to be able to recognise YOD symptoms earlier
5. Needs and wishes concerning YOD diagnosis trajectories

The semi-structured interviews followed an interview guide that included five topics (see Table 1) in order to discover the participants' perspectives on the diagnosis trajectory in YOD. These topics were derived from literature (Kvello-Alme et al., 2021; O'Malley et al., 2021; Thorsen et al., 2020) beforehand and agreed upon by three researchers (RT, JM, MP). All interviews were audio-recorded and transcribed verbatim.

Data analyses

We applied a constant comparative approach in data collection and analysis (Moser & Korstjens, 2018), which was performed as follows. After each interview, RT and JM (researcher integrated care, MSc Global Health, with qualitative research experience) reflected on the interviewing process and content, and adapted the interview guide when new relevant topics arose from the interviews. When half of the interviews had taken place, three researchers (MP: general practitioner– PhD and a qualitative research expert, RT, JM) reflected on preliminary outcomes. Afterwards, one researcher (RT) started to analyse the interviews *via* open, inductive coding (Moser & Korstjens, 2018) to stay as close to the data and stories of the interviewees as possible. A second researcher (JM) coded three interviews independently. During a session with two researchers (RT, JM), compared codes of these three interviews and discussed the coding until consensus was reached. Using this preliminary list of codes and formulating additional new codes, RT continued coding the remaining interviews. These codes were checked by JM. After the 13th interview, RT, JM and MP discussed data saturation and decided it was reached as no essential new topics came up during the last two interviews (Malterud et al., 2016). To confirm data saturation, we conducted three additional interviews. The three researchers (MP, RT, JM) identified overarching categories and themes after iterative discussions during three collaborative sessions. These categories and themes were discussed with a fourth researcher (CB: psychologist, PhD and YOD expert), and adjusted accordingly. The research team additionally included a professor in elderly care and elderly care physician (RM) and a YOD-researcher with expertise in both quantitative and qualitative research (KP). This illustrates the variety of perspectives, research and clinical—generalist and specialist, represented in the data analysis which enhances the credibility of our outcomes (investigator triangulation).

Ethical considerations

The study was conducted according to the principles of the Declaration of Helsinki (2013). The study did not fall within the remit of the Medical Research Involving Human Subjects Act (WMO) and did therefore not need official ethical approval. Prior to each interview, the participants gave written consent to audio-recording of the interview and to processing the data anonymously.

Results

In total, 16 Dutch generalist physicians participated in the interviews, nine of which were general practitioners (seven females and

two males) and seven (male) occupational physicians (Table 2). Despite the lack of purposive sampling, their characteristics were heterogenous. About half ($n=5$) of the general practitioners worked in an urban area and the other half ($n=4$) in a rural area. The occupational physicians all worked in an urban area and most of them were employed by multiple large companies, with the exception of two physicians working for merely one company.

Analysis of the transcripts revealed three themes: (1) Disease characteristics that hinder recognition of dementia at a young age, (2) Physicians' attitudes towards dementia diagnosis in younger individuals, and (3) Proposed solutions to navigate the challenging YOD diagnostic trajectory (Table 3).

Table 2. Characteristics of the interviewees.

Interview nr.	Gender	Profession	Work region	Age (years)
1	Male	Occupational physician	City, employed by 1 company	52
2	Female	General practitioner	City, homogenous neighbourhood	35
3	Female	General practitioner	City, heterogenous neighbourhood	48
4	Female	General practitioner	Village, +− 5000 inhabitants	61
5	Female	General practitioner	City, homogeneous neighbourhood	42
6	Female	General practitioner	Village, +− 26,000 inhabitants	39
7	Female	General practitioner	Village, +− 16,000 inhabitants	36
8	Male	General practitioner	City, homogenous neighbourhood	59
9	Female	General practitioner	Village, +− 5000 inhabitants	61
10	Male	General practitioner	City, homogenous neighbourhood	54
11	Male	Occupational physician	City, employed by multiple companies	61
12	Male	Occupational physician	City, employed by multiple companies	64
13	Male	Occupational physician	City, employed by 1 company	38
14	Male	Occupational physician	City, employed by multiple companies	50
15	Male	Occupational physician	City, employed by multiple companies	57
16	Male	Occupational physician	City, employed by multiple companies	63

Disease characteristics that hinder recognition of dementia at a younger age

Both general practitioners and occupational physicians felt that (the first) symptoms of YOD are difficult to recognise for several reasons. First, they reported a (self-identified) lack of knowledge about the occurrence of dementia in people aged under 65 and how the first symptoms of dementia can present in younger individuals.

> We relate dementia to the age of 65 years and older. The insight that it [dementia] can also occur at a younger age is very important. (General practitioner, nr. 4)

> I don't know how many people [with YOD] we have in our practice, as I'm afraid that we don't always recognise them as such… There are cases in which, years later, it turned out to be YOD. (General practitioner, nr.7)

Besides the notion that generalist physicians often do not consider dementia in individuals under the age of 65, the recognition of symptoms becomes even more challenging due to its similarity to other conditions that are much more prevalent at a young age, such as burnout syndrome and depression.

> …especially with this [younger] group you usually think about depression or burn out, and you don't really think about dementia. (General practitioners, nr. 8)

The above quote also relates to the notion that general practitioners and occupational physicians rarely see people with YOD due to its low prevalence. Therefore, they do not prioritise training to enhance their knowledge on YOD.

> I don't know how to improve the recognition of symptoms among general practitioners because we don't see them often enough. I only had three or four people [with YOD] in my whole career so far. It is the role of the neurologist, who is specialised in neurological disorders, to recognise and diagnose YOD. (General practitioner, nr. 10)

> I find it out of proportion to follow a training for maybe three people with young onset dementia, when there are about 6200 people with late onset dementia in this region. (General practitioner, nr. 8)

Even if they would be able to recognise YOD symptoms, general physicians have the idea that people with YOD symptoms often have a lack of insight into their disease and do not feel the need to visit their doctor. In many cases of YOD, they felt that the partner is often who is most worried, while the person with undiagnosed YOD does not always consider their

Table 3. Overview of themes, categories and descriptions.

Themes	Categories	Descriptions
Disease characteristics that hinder recognition of dementia at a younger age	Perceived lack of knowledge about YODLow priority due to low prevalenceYOD symptoms similar to other conditions Lack of contact/interaction between generalist physicians and people with YOD symptoms	Not knowing YOD symptoms, no awareness of existence of YOD.Almost never seeing people with YOD, not our priority due to low prevalence.Burnout, depression, feeling down, feeling restless, feeling stuck at work for a long time.Poor awareness of illness among people with YOD, they are themselves responsible to make an appointment with generalist physicians, role of occupational physician has changed over time, cutbacks in occupational physicians in companies.
Physicians' attitudes towards dementia diagnosis in younger individuals	Burden of diagnostic trajectory for persons with YOD symptoms Fear to be wrongTherapeutic nihilism	Want to be sure of right trajectory due to burden, burdensome label.Fear to miss signals, fear to make the wrong diagnosis.Resistance towards giving the diagnosis, questioning the need for diagnosis because of lack of an effective treatment.
Proposed solutions to navigate the challenging YOD diagnostic trajectory	Importance of hetero anamnesisMonitoring of depression or burn-out trajectories to pick-up an unusual course(More) low-key interprofessional collaborations	Ask family member/partner to join consultation, take worries from partners seriously.Discuss timelines with people, decide per case how to monitor and who is responsible for it, proactively invite people to a new consultation, actively follow-up on trajectory at specialist.Low key contact between general practitioner and occupational physician, low key contact between occupational physician and managers at companies, specialists inform the generalist physicians when the diagnosis is definite, discuss cases with colleagues during peer coaching meetings.

symptoms as worrisome. This hampers generalist practitioners to observe the symptoms.

> In most situations, it is not the patient itself but the partner or someone else in the social circle who shows signs of being worried. They say that something feels off. (General practitioner, nr. 9)

Physicians' attitudes towards dementia diagnosis at a younger age

Besides the previously mentioned disease-related factors that may form barriers towards early recognition of dementia symptoms in younger individuals, we also identified attitudes among generalist physicians that delay the start of a diagnostic trajectory. First of all, physicians reported fear of confronting a younger person with a potentially serious condition:

> It is always scary and confronting if a person younger than you appears to have dementia. It is confronting for me since I would like to aid the person and the company wherever possible. I want to do it the right way. (Occupational physician, nr. 12)

The above quote also **represents** another attitude **of** multiple generalist physicians: the feeling of wanting to make the 'right' decisions in the trajectory towards diagnosis. Participants **had** different perspectives on what is considered the 'right' decision. For some, it meant to refer people as soon as possible to the neurologist to either confirm or discard YOD. Others mentioned being hesitant **about** referrals to the neurologist, as they believe**d** that even the possibility of YOD is already too confronting for their patients. They would rather wait a little longer to exclude other diagnostic options first.

> I am careful in giving people the dementia label. Normally I first refer people to a psychologist to exclude a depression. (General practitioner, nr. 6)

Additionally, **some** generalist physicians questioned the need **to diagnose dementia**, as having **this** label can be burdensome. They especially doubted the necessity for diagnosis because of the lack of **effective** treatment options. Some generalist physicians argued that the diagnosis merely adds to emotionally **instability** and they would therefore rather delay the official diagnosis.

> I am not a proponent of early YOD diagnosis. It does not improve the lives of people once they have this diagnosis. (Occupational physician, nr. 13)

Proposed solutions to navigate the challenging YOD diagnostic trajectory

Although not all generalist physicians were convinced of the necessity to timely recognise and diagnose dementia at a younger age, three different types of solutions were suggested to **navigate** the challenging trajectory. Firstly, the importance of **a** hetero anamnesis was a highlighted solution during many interviews. As described earlier, in the eyes of generalist physicians, partners or other close contacts often notice behavioural change**s** at an earlier stage than **the persons** with symptoms themselves. Physicians therefore considered it important to include their perspectives into clinical reasoning:

> At the first consultation, I request people to bring their partners. When something is really wrong, the partner will say so. (Occupational physician, nr. 11)

Secondly, a frequently mentioned solution to distinguish dementia symptoms at a younger age from e.g. a burn-out or depression is to proactively monitor symptoms over time. If burn-out or depression symptoms **would** not improve after a certain amount of time, a follow-up consultation could be implemented to re-evaluate the primary diagnosis and to reconsider dementia. Specifically, it was mentioned to include this suggestion to consider dementia at a younger age in the disease specific guidelines on depression and/or burn-out for general practitioners:

> Well, a burn out needs to show some improvements after about 9 months, so then you should start thinking that something else is at play and investigate it. (General practitioner, nr. 9)

Thirdly, more interprofessional **information** exchange and collaboration were considered to be beneficial for timely recognition of dementia at a younger age. In the early stages, general practitioners and occupational physicians **identified each other as partner for information** exchange when they are both involved in the same case. The **perceived** benefit of sharing experiences and perspectives **was the possibility to decrease** concerns or hesitations to refer people to a specialist. Ultimately, this can contribute to an earlier diagnosis.

Both general practitioners and occupational physicians also suggested to actively **contact** the specialist once referral has taken place. In this way, one might learn from each trajectory which can facilitate future recognition of dementia symptoms in younger individuals. This was confirmed by physicians who had multiple experiences with YOD:

> I currently have four people with YOD in my practice. I refer them to the Memory Clinic and actively follow-up with the specialist about the outcome. Then I look for the appropriate support together with the person with YOD and relatives, and other professionals such as the case manager. (General practitioner, nr. 5)

> I am in close contact with the neurologist, so I can call him to discuss symptoms of people. It also works the other way around, the neurologist calls me to discuss support services. (General practitioner nr. 3)

Discussion

This paper revealed perspectives, attitudes and experiences of general practitioners and occupational physicians towards the process prior to a dementia diagnosis in younger individuals. First, generalist physicians explained that disease characteristics hindered them to recognize dementia at a younger age. Dementia symptoms are similar to burn-out and depression which are diseases with a significantly higher prevalence under the age of 65 than dementia. A proposed solution for this is to proactively monitor symptoms of a depression/burn-out and (re)consider dementia as diagnosis if symptoms do not disappear after appropriate treatment after a certain amount of time. Second, we identified physicians' attitudes towards YOD diagnosis that hamper the timely start of a diagnostic trajectory. These attitudes include fear of missing signals, making the wrong burdensome diagnosis, and the need for diagnosis sometimes being questioned (therapeutic nihilism). In order to help physicians navigate these feelings and fears, it is proposed to seek for more interprofessional exchanges between general practitioners and occupational physicians themselves, but also between them and specialists that are qualified for diagnosis of dementia at a younger age.

Comparison with literature

The low incidence and prevalence of YOD physicians appointed as barriers were recently confirmed in systematic reviews and meta-analyses being 11 per 100,000 and 119 per 100,000 of respectively (Hendriks et al., 2021; Hendriks, Peetoom, Bakker, et al., 2022). The other disease-related barrier our participating physicians identified was the fact that YOD mimics other common middle-aged diseases as depression and burn-out. This was confirmed by caregivers as they mentioned that when expressing worries about their loved ones, their general practitioners often considered the cause of their symptoms to be psychological (Van Vliet et al., 2011). Recent retrospective research in routinely collected primary care data also confirmed our participants' experiences by showing that affective symptoms occur relatively frequently three to four years before diagnosis in both future YOD patients and controls (20–25%) (Hendriks, Peetoom, Tange, et al., 2022). Cognitive symptoms were found to be relatively rare in both future YOD patients and in healthy controls, although significantly more present in future YOD patients. However, the primary care data also revealed that over time, not only cognitive and affective symptoms were more often registered in persons with future YOD, but also social symptoms from three years before diagnosis, behavioral symptoms two years, and daily functioning disturbances one year before diagnosis (Hendriks, Peetoom, Tange, et al., 2022). This supports the potential of the monitoring intervention suggested by our participants to reconsider diagnosis in persons with a primary diagnosis of depression or burn-out that fail to recover.

In our study, general practitioners and occupational physicians stated that lack of disease awareness among people with YOD symptoms also prevents doctors from recognition. This was supported by previous research among caregivers who stated that they themselves considered symptoms to result from depression or burnout. Our findings contradict however with an earlier study in which sufficient insight in symptoms and disease were described (Van Vliet et al., 2013). Finally, when it comes to the attitudes of physicians themselves towards dementia diagnosis at a younger age, our study revealed similar clinical barriers among primary care physicians as towards late-onset dementia like lack of knowledge, fear of false positive diagnoses and therapeutic nihilism (Mansfield et al., 2019).

Interprofessional collaboration was identified by our participants as potential support for generalist physicians to overcome these barriers and discuss their diagnostic considerations in younger individuals with dementia symptoms with other generalist and specialists professionals in medics and care. This may reduce their fears. The potential effectiveness of this suggested intervention is underlined by the fact that interprofessional collaboration has shown to improve primary dementia diagnosis and care (Richters et al., 2018). The physicians preferred such collaborative discussions over continuing education on YOD diagnosis. They stated that the low prevalence of the disease limited the applicability of new knowledge acquired in training.

Strengths and limitations

Strengths of this study include a heterogenous study sample of generalist physicians (a broad range in year of expertise, rural vs. urban, women/men), which contributes to the transferability of our study results. Moreover, our researcher team included a mix of generalist and specialist professionals and researchers, most of them even with combined clinical-research positions, which increases the credibility of our results (investigator triangulation). We reached data saturation with our interviews which was confirmed by three extra interviews. Limitations of the study concern the fact that coding by two researchers independently was only performed in 20% of the interviews. In the other interviews, coding was checked by a second reviewer. Moreover, the length of our interviews was divers, due to circumstances in the COVID-19 pandemic with healthcare professionals lacking time for in-depth face-to-face interviews. Also, inclusion difficulties during the COVID-pandemic forced us to deviate from our research protocol by allowing three occupational physicians to participate in an online group interview. Despite these barriers, we managed to reach data saturation.

Future practice and research

Our study revealed that therapeutic nihilism makes generalist physicians insufficiently acknowledge the importance of a timely dementia diagnosis in younger persons. Caregivers however already mentioned that although there is no cure for dementia, a diagnosis itself can already cause clarity and relief in both patients and caregivers (Van Vliet et al., 2011). As dementia training in general approved attitudes of primary care physicians towards dementia diagnosis (Perry et al., 2011), emphasis on the importance of a timely dementia diagnosis, also or even more in persons on younger age because of the additional consequences of the disease related to family and work, could be incorporated in such training programs.

Our study revealed several important directions for solutions towards more timely dementia diagnoses at a younger age. As YOD is rare and mimics other more prevalent disorders, it will always remain difficult to recognize YOD at the first moment a person present possible YOD symptoms. Active monitoring of depression and burn-out trajectories as suggested by the participating physicians may identify those in whom recovery stagnates. In those cases, the primary diagnosis can be re-evaluated and YOD actively considered as a diagnostic option. Practice nurses or primary care psychologists may play an important role in such monitoring processes. Future prospective research in middle-aged persons with depression and burn-out as suggested in the earlier mentioned primary care record study could reveal whether this promising strategy is effective and should then be implemented in practice guidelines (Hendriks et al., 2021).

Interprofessional collaboration as possible solution towards more timely YOD diagnoses could be realized by low key accessibility of YOD specialists. This could be e.g. arranged *via* tele consultation when in doubt to refer a younger person with possible dementia symptoms (Gould et al., 2023). Additionally, dementia case managers with YOD expertise can provide their specialist knowledge to generalist physicians and support recognition of dementia. (Khanassov & Vedel, 2016).

Conclusion & implications

General practitioners and occupational physicians identified disease characteristics to hinder timely YOD diagnosis. Active monitoring of middle-aged patients with depression and burn-out in order to reconsider YOD when recovery stagnates may

contribute to improved diagnostic YOD trajectories. Experienced fear of misdiagnosis and therapeutic nihilism by physicians may be overcome by more sufficient interprofessional collaboration among generalist and specialist professionals. Future research may reveal the potential of these interventions.

Disclosure statement

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