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DOI
10.1080/07317115.2022.2060157

Publication date
2025

Document Version
Final published version

Published in
Clinical Gerontologist

CLINICAL GERONTOLOGIST
2025, VOL. 48, NO. 1, 110–120
https://doi.org/10.1080/07317115.2022.2060157

Routledge
Taylor & Francis Group

Features and Needs of Autistic Older Adults: A Delphi Study of Clinical Experiences

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ABSTRACT

Objectives: *I*n geriatric psychiatry Autism Spectrum Disorders (ASD) are increasingly recognized. This study explores what clinicians know about diagnostic and/or therapeutic aspects of autistic older adults and how aging plays a role in the course of ASD.

Methods: A Delphi study outlines the point of view of 11 clinical experts in the Netherlands and Belgium (Flanders).

Results: *R*egarding diagnostics, age-specific aspects need to be considered. Age-related characteristics (cognitive differences, life events, co-occurring conditions) influence detecting autistic features in older adults. Regarding treatment, counseling methods need to be adapted. Psychoeducation, family therapy, couples therapy, behavioral counseling and psychopharmaca can be helpful in meeting the needs of autistic older adults. There was no consensus on the effects of aging on autistic older adults.

Conclusions: *D*iagnosis and treatment of ASD need adaptation for autistic older adults. Further research is needed on the validation of measurement tools, recorded treatment, therapy, psychoeducation, and the effects of aging among people on the autism spectrum.

Clinical Implications: *A*vailable knowledge helps clinicians to detect ASD in older adults and adapt to the specific features and needs of autistic older adults. The effects of aging on the course of ASD are unclear yet.

KEYWORDS

Autism spectrum disorders; older adult; diagnostics; treatment; Delphi

Introduction

In recent years Autism Spectrum Disorders (ASD) in older adults have become a topic of more interest in literature and empirical studies, even though it lags behind the number of studies on children and younger adults. It is commonly acknowledged that ASD persists into older adulthood and that in this life stage a need for care can occur (Wright, Wright, D'Astous, & Wadsworth, 2019). Prevalence of ASD in the general population is estimated at around 0.7% (Baxter et al., 2015). The population of older adults is increasing with an expected peak in 2050 of 22% of the population being over the age of 65 years (World Health Organization, 2015). Therefore, geriatric psychiatry will be increasingly faced with patients on the autism spectrum (Mukaetova-Ladinska, Perry, Baron, & Povey, 2012).

Several authors have stressed the need for a research agenda to obtain more knowledge on diagnosis and therapeutic aspects for autistic older adults (for instance Happé & Charlton, 2012; Michael, 2016; Piven & Rabins, 2011; Robison, 2019; Roestorf et al., 2019). Autistic older adults may have specific characteristics or needs that differ from younger adults. The criteria for ASD in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM 5, American Psychiatric Association, 2013) include two core domains of symptoms, which focus on limitations in social communication and interaction and the presence of restricted repetitive behaviors. An important point to notice for geriatric psychiatry is the fact that features must be present in the early developmental stages. It is acknowledged however that these features can be masked by learned

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strategies and may not become fully manifest until social demands exceed limited capacities. Often autistic people have been able to adjust their former lifestyle complementary to their characteristics. They have learned to adjust and compensate for difficulties they encounter in life (Hull et al., 2017; Zıvralı Yarar, Howlin, Charlton, & Happe, 2021).

In clinical practice we are faced with patients who only come into contact with mental health care late in life. In the later life stages, changes can occur that are too difficult to adjust to. Later life stages can be divided in young-old age (65–80) and old-old age (80+). Young-old age follows after adulthood and starts around retirement age. Retirement changes daily life structure as individuals have the freedom to engage in any activity in their spare time, and social roles, including relationship dynamics, due to changes in obligations or grandparenthood. In this life stage, people are vital enough to function independently and actively. There is a transition to old-old age when vitality and activity levels decrease and people experience more losses as they lose significant others and suffer from more physical problems. These transitions require the ability to adapt to new situations and roles, as do all life transitions (Adams, Roberts, & Cole, 2011). Older adults are found to be resilient and capable to cope with the changes and challenges in later life. High resilience is associated with aging well (MacLeod, Musich, Hawkins, Alsgaard, & Wicker, 2016). The emphasis in the research of aging has led to a better comprehension of well-being indebted to theories such as "selective optimization with compensation" (SOC) and "socio-emotional selectivity theory" (SST). The SOC model (Baltes & Baltes, 1990) offers an explanation for successful aging that focuses on people's abilities to adjust to losses in a manner that optimizes their remaining capacities and resources. The SST model (Carstensen, Fung, & Charles, 2003) offers the viewpoint that with aging people can profit from rewarding relationships that have formed during their lifetime as a result of preferencing positive over negative social experiences. These theories, providing the framework for adaptation in older age and aging well, are starting points for treatment when adaptation is not successful.

It is unclear whether this also applies to autistic older adults. One study found that being autistic was not experienced as an obstacle to aging well in itself, but social and relational circumstances have an important bearing to aging well for autistic adults (Hwang, Foley, & Trollor, 2017). Autistic older adults may have learned to adjust with the same resilience as neurotypical older adults, but may also be at risk of not being able to cope with the social and practical demands of later life (Hickey, Crabtree, & Stott, 2017). Also, cognitive changes and decline, that go along with aging, may negatively affect this ability to adjust. As compensating requires cognitive demand, some autistic older adults could experience more psychological stress as a result. The question is: if people keep learning throughout their lives but are faced with changes that can exceed capabilities in older age, how does this change the characteristics and needs of older adults on the autism spectrum? Empirical studies on aging and autism are aimed mostly at cognitive functioning, co-occurring difficulties and symptom severity, but also on validating measures and on behavioral, social and neuro-(psycho)logical differences (Davids, Groen, Berg, Tucha, & Van Balkom, 2016; Geurts, Pol, Lobbestael, & Simons, 2020; Geurts & Vissers, 2011; Heijnen-Kohl, Kok, Wilting, Rossi, & van Alphen, 2017; Torenvliet et al., 2021; Torres, Caballero, & Mistry, 2020; Tse, Lei, Crabtree, Mandy, & Stott, 2021; Zıvralı Yarar et al., 2021). Whether diagnostic criteria and general guidelines regarding diagnosis and treatment are applicable to autistic older adults remains unclear. Also, the effects of aging on the functioning and well-being of autistic older adults are still largely unknown as ASD in older adults is an underexposed research topic.

Our goal was to chart the professional point of view on the basis of expert opinions of clinicians to add to this growing body of research (Hitzert, Schmidt, Geurts, & van Alphen, 2016). In the current study we have asked clinicians to share the insights on aging and autism based on their research, experience and interactions with autistic older adults. We intend to make a scientific contribution to a better quality of treatment for older adults on the autism spectrum.

The key research questions are: What do professional experts in clinical practice currently consider specific diagnostic and/or therapeutic aspects of autistic older adults? And what role does aging play in ASD according to their opinion?

Methods

Design

The Delphi method was applied as a qualitative research method. This method is a technique that can be applied in an area where knowledge is available mainly with people in a specific field of expertise as opposed to (published) research data and is a common research method in this situation (Powell, 2003). In addition to gathering experts' opinions it also allows for a feedback process so that participants can adjust their initial responses based on the input of each other (iterative character). There are various forms of Delphi research (Hasson & Keeney, 2011). The classic Delphi method consists of structured rounds of questionnaires alternating with controlled feedback to reach the most reliable consensus of an expert panel (Hsu & Sandford, 2007; Yousuf Muhammad Imran, 2007). Other Delphi forms have less focus on the iterative character and they have other goals such as charting various expert viewpoints (Keeney, McKenna, & Hasson, 2011). We have utilized a Delphi method with three rounds of structured online questionnaires, each with a different subtopic (diagnosis, treatment and "aging and ASD"). In this study, the emphasis was on taking inventory of the various clinical expert visions. The questionnaire rounds took place in the period January-April 2015.

Participants

The reliability of a Delphi study is dependent on the expertise of the participants in the expert panel (Powell, 2003). Therefore, clinical experts must be representative of the field of research (in this case geriatric psychiatry and/or ASD in adults and older adults) and they must meet carefully defined expert criteria. Participants had to fulfil the following qualifications:

- Demonstrable affinity with ASD in older adults, specifically expertise in diagnostic and/or treatment-related aspects (such as camouflaging and coping mechanisms in autistic people and cognitive functions in relation to aging and ASD), at least four years of demonstrable clinical experience, as evidenced by employment in geriatric psychiatry and publishing on the topic, teaching in accredited professional training programs (for instance for medical and psychological specialists) in combination with contributing to empirical research either as professionals supplying data or participants for studies or as scientists practitioners conducting their own clinical research.
- Active in the Netherlands and/or Belgium (Flanders).

The expert panel consisted of two geriatric psychiatrists, one clinical psychologist/psychotherapist, one clinical psychologist, two clinical neuropsychologists, five mental healthcare psychologists/ psychotherapists/neuropsychologists (one in training to be a clinical psychologist and one in training to be a mental healthcare psychologist). Ten of the panelists were active in the Netherlands and one was active in Flanders (Belgium).

Measures

A questionnaire was developed by three of the authors. The topics were selected based on the subjects of the Dutch Multidisciplinary Guideline for diagnosis and treatment of autism spectrum disorders in adults (Multidisciplinaire richtlijn diagnostiek en behandeling van autismespectrumstoornissen bij volwassenen; Kan, Geurts & Sizoo, 2013).[1]

The questionnaire consisted of statements linked to three subtopics: diagnostics, treatment and aging. The statements are reported in Tables 1, 2 and 3. On the basis of a five-point Likert scale (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree) the clinical experts indicated the degree to which they agreed or disagreed with each statement. In addition, for each statement the clinical experts had the option to

provide more information explaining their answer. The clinical experts were also asked to evaluate their own expertise in relation to each statement and were able to give no answer for those statements about which they had too little expertise.

Procedures

The expert panel was identified through the professional network of the authors. The second author approached clinical experts in collaboration with a professor of geriatric psychiatry and a professor endowed with a special chair in clinical geropsychology, both of whom have published on this topic and are very familiar with the clinical experts active in this field. The goal was the participation of clinical experts in various disciplines. Eleven experts fulfilled the criteria and all of them were willing to participate. The expert panel was presented with three rounds of surveys sent online (in a web-based application) between January and March 2015. In these three round the clinicians had to fill out the survey based on their own experience and knowledge. We examined the degree of consensus for each subtopic. The next round consisted of the new subtopic. The response rate was high: 100% for each of the first two rounds and 91% for the third round.

Quantitative methods

Consensus was based on two principles:

-at least two thirds (67%) of the clinical experts agree or strongly agree with the survey statement

-at least two thirds (67%) of the clinical experts disagree or strongly disagree with a statement (which is reported in Tables 1, 2 and 3 as <33% "in agreement").

Qualitative methods

Optional explanations by the clinical experts were gathered as additional, qualitative data. These are presented in the result section if the same explanation was given by at least two clinical experts.

Results

Tables 1, 2 and 3 present the statements per subtopic as well as the degree of agreement with and response to each statement. A summary of the results and the expert explanations is provided per component.

Diagnostics

In the first round (Table 1 near here) consensus was achieved on all of the five survey statements relating to the diagnosis of ASD in the older adults. The clinical experts reached consensus on agreeing that the addition of criterion C to the definition of ASD in the DSM-5 (that symptoms must be present in the early developmental period but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life) makes the definition more applicable to the older adults population. There was also consensus that the diagnostic steps as described in the Dutch Multidisciplinary guideline are applicable to the older adults population. Finally, there was consensus on agreeing that the AQ-50 self-reporting list has limited diagnostic value at an individual level and that there are specific co-morbid diagnoses in relation to ASD in older adults.

In explaining the responses to the survey statements, the following comments were made as free text:

Table 1. Overview of Expert Consensus per Statement about Diagnosis of ASD in older adults.

	Statement	% in agreement	*n*
1	The ASD working group for the DSM-5 succeeded in making the criteria more applicable to the older adults population.	91%*	11
2	The DSM-5 criteria are still insufficiently applicable to the older adults population.	18%*	11
3	The diagnostic steps for case identification are applicable to the older adults population.	82%*	11
4	The AQ-50 self-reporting list has limited diagnostic value at an individual level.	80%*	10
5	There are specific co-morbid diagnoses in relation to ASD in older adults.	90%*	10

*These figures meet the required value for consensus (<33% or >67%); *n* = the response to each statement.

Table 2. Overview of Expert Consensus per Statement about Treatment of ASD in older adults.

	Statement	% in agreement	*N*
1	"Treatment as usual" as formulated in the guideline for treatment of adults is sufficiently applicable to autistic older adults.	9%*	11
2	The adjustments to standard psychoeducation make it more applicable to autistic older adults.	91%*	11
3	Family therapy or relationship therapy is a useful component in the treatment of ASD in older adults.	91%*	11
4	Cognitive behavioral therapy is a useful component in the treatment of ASD in older adults.	55%	11
5	Behavioral counseling is a useful component in the treatment of ASD in older adults.	100%*	11
6	Psychiatric medication are a useful component in the treatment of ASD in older adults.	80%*	10
7	The use of psychiatric medication on autistic older adults can entail specific risks or precautions.	80%*	10

*These figures meet the required value for consensus (<33% or >67%); *n* = the response to each statement.

Table 3. Overview of Expert Consensus per Statement about Aging and ASD.

	Statement	% in agreement	*N*
1	Autistic older adults age in the same way as the general older adults population.	11%*	9
2	The differences in cognitive aging can be explained by the fact that the brains of autistic older adults are less able to adapt, because the cognitive reserves are already in use.	56%	9
3	Autistic older adults develop cognitive problems or dementia at the same rate as the rest of the aging population.	40%	10
4	The neuropsychological profile of autism is sufficiently differentiated from co-morbid dementia processes.	44%	9
5	The symptomatology of ASD changes during the aging process.	78%*	9

*These figures meet the required value for consensus (<33% or >67%); *n* = the response to each statement.

- "Age-specific characteristics should be added to the DSM-5, because ASD appears to manifest less apparent in older adults. In the course of their life, older adults may have been able to benefit from symptom masking or social adaptation (especially in the case of highly gifted individuals). It is possible to refine the definition by defining symptoms more explicitly in relation to stage of life and level of intelligence."
- "It is possible to use the diagnostic steps as given in the Dutch Multidisciplinary guideline for diagnosis and treatment of autism spectrum disorders in adults for older adults, but completing a developmental history, from early childhood on, often provides problems. It is advisable, therefore, to make a thorough assessment by using a combination of various sources of information, namely current functioning, biography and informant information."
- "The use of measurement tools can be helpful, but their validity in older adults has been insufficiently studied. Clinical experience with older adult population is important when using measurement tools." The experts pointed out that the Dutch translation of the AQ-50 (Autism Spectrum Quotient; Hoekstra, Bartels, Cath and Boomsma., Hoekstra, Bartels, Cath, & Boomsma, 2008) is used as a screening instrument to gain insight into the degree of self-reflection and the perception of the environment, but has limited value at an individual level. Supplementary measurement tools such as the ADOS (Autism Diagnostic Observation Schedule; De Bildt & De Jonge, 2008) are not always considered suitable for use with older adults. Some of the clinical experts utilize the clinically developed DSM interview (Spek, 2015); a semi-structured interview (both patient and informant version) to evaluate whether ASD is present. However, the methodological soundness of this interview has not (yet) been tested. Often a combination is made with the ADI-R (Autism Diagnostic Interview-Revised; Rutter, LeCouteur, & Lord, 2003). In case of doubt, the WAIS-IV-NL (Dutch version of the Wechsler Adult Intelligence Scale IV; Wechsler, 2012) is used to gain insight into how the individual processes information, with additional neuropsychological tests as needed. Nevertheless, the clinical experts expressed a need for well-validated measurement tools for ASD in older adults.
- "Autistic older adults who seek mental health care rarely present apparent characteristics of ASD. This is due to symptom overlap with often co-occurring conditions and learning effects of masking behavior." The experts added that affective disorders frequently occur when going through difficult life events or the loss of external structure. Cognitive disorders or early-stage dementia can overlap with executive characteristics in ASD.

"Sometimes older adults present ADHD, personality disorders (schizoid, narcissistic, or obsessive-compulsive) or a significant mental disorder with accompanying delusional structure. Relationship problems are also present and are a complicating factor."

Treatment

In the second round (Table 2 near here) consensus was achieved on six of the seven survey statements relating to the treatment of autistic older adults. There was consensus on the fact that adjustments to standard psychoeducation make it more applicable. There was also consensus that family therapy or couples therapy, behavioral counseling and psychopharmaca are all useful components of treatment for autistic older adults. Further consensus was reached on the survey statement that the use of psychopharmaca among older adults on the autism spectrum can have specific risks or precautions. There was also consensus in disagreeing that "treatment as usual" as formulated in the Dutch Multidisciplinary guideline for diagnosis is sufficiently applicable in older adults. No consensus was achieved whether cognitive-behavioral therapy was a useful component of treatment for autistic older adults.

In addition to responding to the statements, the clinical experts made the following comments in addition to the responses to the survey statements.

- The clinical experts commented that the Dutch Multidisciplinary guideline offers "too little certainty to apply 'treatment as usual' (as formulated by the guideline) to older adults because of the necessity of tailoring care and treatment to age-specific characteristics." The clinical experts argue that the topics of importance in caring for older adults differ from the topics in younger adulthood. "Attention should be paid to the changes that typically occur in later life, such as loss of daily occupations, changes in the social role, increasing vulnerability or dependence on others. In addition, specific aging processes play an important role, such as the characteristic way of processing information and the decrease in speed. Also, older adults respond better to more concrete and clear versus abstract language."
- Psychoeducation, in a form adapted to older adults, is considered an indispensable component of treatment. Suggested adaptations are to give additional information about aging processes and to make time to talk about past (positive and negative) experiences in relation to the ASD diagnosis. "Partners and/or children often need support as well." Additionally, behavioral counseling is seen as useful, involving for example home care institutes and informal caregivers who can request a consultation from expert centers in the field of ASD in older adults.
- "An eclectic psychotherapeutic approach, based on the care demand and taking into account co-occurring conditions, adapted to the individual cognitive abilities and potential for change, is preferable. In addition, in older adulthood a sense of purpose is an important issue and attention should be paid to explore activities that are meaningful to the older adult. Older adults who cannot meet with the demands put on them, appear to respond well to psychosocial interventions such as intensive psychiatric home care (from a psychiatric home care nurse) or a relapse prevention plan."
- "Treatment of older people on the autism spectrum with psychopharmaca can help alleviate symptoms, but the clinical experts expressed some reluctance due to interactions, for example in case of polypharmacy."
- Finally, the clinical experts indicated that "generating knowledge, insights and acceptance were the most important treatment goals in order to optimize the quality of life for autistic older people and the people around them."

Aging

In the third round (Table 3 near here) consensus was achieved on only two of the five survey statements. The experts reached consensus on agreeing that the characteristics of ASD change during the aging process. They reached consensus in disagreeing that autistic older adults age in the same way as the general older adults population.

The clinical experts gave the following explanations for their answers

- According to some of the clinical experts, "the entire presentation is often milder because autistic people and/or the people around them have learned to cope with their particularities. Characteristics are also often masked by co-occuring conditions." However, the clinical experts also state that "under stress, characteristics can sometimes be exacerbated, because executive disfunctioning, as well as the ability for planning and keeping an overview, can decline due to the normal aging process."
- They disagree with the survey statement that autistic older adults age in the same way as the general older adults population. They see several differences. For instance, "autistic older adults often have difficulties understanding the consequences of aging, because they have a different coping style. They often experience the transition to older adulthood as unexpected, because they can experience time differently. Increasing problems with memory, planning and maintaining oversight often create feelings of fear, which, in combination with increasing dependence on others, makes aging particularly difficult for this group."
- The clinical experts are unable to reach consensus regarding the "cognitive reserve hypothesis." The differences in cognitive aging can be explained by the fact that "the brains of older people on the autism spectrum are less able to adapt, because the cognitive reserves are already in use." According to the clinical experts, "autistic older adults do not age the same way. Some of the clinical experts find it plausible that normal memory deterioration often results in more problems because memory is a coping mechanism." Other clinical experts propose an alternative theory, the "safeguard hypothesis." This hypothesis assumes that "people on the autism spectrum are so used to compensating for cognitive gaps that they are better equipped to keep compensating for cognitive decline as they enter old age, than the neurotypical older adult population." The majority of the clinical experts make the comment that "too little empirical research has been carried out to be able to make definitive statements on this subject."
- According to the clinical experts there are differences in the ways in which cognitive problems or dementia develop in autistic older adults. "In practice, the characteristics of ASD are sometimes mistaken for early-stage dementia in older adults. A neuropsychological profile does not always sufficiently distinguish ASD from early-stage dementia. Older adults on the autism spectrum can perform poorly on neuropsychological examination as a result of stress, inability to ignore distracting stimuli and a different way of processing information which can influence how instructions are understood. Examiners have to be aware that these factors can interfere. It is difficult to differentiate ASD and early stage dementia based on quantitative results. A thorough history obtained by an informant is crucial to distinct whether problems in executive functioning – for example – are recognized during a lifetime or whether there is a change and decline occurring. Often, the difference between ASD and dementia only becomes clear over time."

Discussion

This Delphi study focused on diagnostic and therapeutic aspects of ASD in late life and relating them to the adaptive strategies and the aging process by questioning a range of clinical experts in the field. They responded to survey statements on the topics of diagnostics, treatment and aging and added comments to explain their responses.

Regarding diagnostics, the clinical experts agreed that age-specific characteristics for older adults should be added to the DSM-5 criteria, that criteria and diagnostic steps are applicable and that there are specific co-morbid diagnoses. Also, measures used in adults are thought to have limited applicability. The AQ for instance is developed as a screening tool (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) and as such has limited diagnostic properties; the experts reflect in their opinion that this is certainly the case with older adults because age-specific factors are not taken into account. The experts made suggestions for age-specific characteristics for instance by more explicitly relating presentation to the stage of life and the aging process. In addition, they call for more awareness of co-occurring physical and mental health conditions, age-related differential diagnosis (such as cognitive deterioration), the influence of cognitive aging on compensating strategies and they call for thorough assessment using multiple sources. There is no agreement within the clinical expert panel regarding the choice of measurement instruments. This is probably due to the fact that there is a lack of psychometric research into ASD in older adults., ADOS, or ADI-R, are also administered to older adults but, at the time of this study, there was no research whether responses were influenced by age. After this Delphi study had been conducted, a few psychometric studies have been published, showing that the questionnaires, used in these studies, the HAP (Informant version of a Personality Questionnaire, Barendse & Thissen, 2006; Heijnen-Kohl et al., 2017) and the BRIEF (Davids et al., 2016; Roth et al., 2013; Geurts, Pol, Lobbestael, & Simons, 2020), can have an additional value in detecting ASD features and behaviors in older adults.

Regarding treatment, the clinical experts agreed that adaptations are necessary in therapy of older adults. There is consensus regarding helpful components in the treatment of autistic older adults (psychoeducation, family therapy or couples therapy, behavioral counseling, and medication). However, it is unclear what specific adjustments need to be made to cognitive behavioral or eclectic interventions in order to study its effectiveness. Psychopharmaceuticals are also deemed a useful component of treatment but can entail risks and precautions.

The age-related issues that call for adaptation according to the experts are changes that typically occur in later life. Knowledge of aging processes is important and attention is needed for a narrative element, to talk about past (positive and negative) experiences in relation to the ASD diagnosis. Partners and/or children often need support as well as professional caregivers that may be involved. Increasing insight and acceptance is very important (Crompton, Michael, Dawson, & Fletcher-Watson, 2020). Specific psychoeducation has been developed that is focused on older adults on the autism spectrum; research is currently in progress into the effectiveness and added value of this adapted form of regular psychoeducation (van Heijst & Geurts, 2015). Regarding psychopharmaca, clinical experts indicate that with older adults interactionsfor example, in case of polypharmacy, have to be taken into account.

Finally, the clinical experts only reached consensus regarding aging that autistic older adults age differently and that ASD characteristics change with age. There was no consensus on whether autistic older adults have more or less ability to adapt, whether they develop problems at the same rate or not or whether the neuropsychological profile of autism is sufficiently differentiated from co-morbid dementia processes. Several studies of ASD and aging have been published since the data for this Delphi study were collected. This raises the question of whether the clinical experts would have given different answers nowadays, in light of the results of the studies regarding ASD and cognitive aging. Nevertheless, this research area is still in its infancy and we are as yet unable to formulate unequivocal answers (Bowler, Geurts, & Howlin, 2019). For instance, it is uncertain whether autistic older adults have a greater or smaller chance of developing dementia or Parkinson's disease. Recent epidemiological studies (Bishop-Fitzpatrick, Minshew, Mazefsky, & Eack, 2017; Croen et al., 2015) demonstrate that there is an increased chance of both dementia and Parkinson's disease in people on the autism spectrum which is consistent with earlier research

(Starkstein, Gellar, Parlier, Payne, & Piven, 2015) showing indications of an increased chance of Parkinson's disease but conflicts with findings of other research (Oberman & Pascual-Leone, 2014). In the Netherlands extensive research has been conducted on the topic of ASD and cognitive aging. These cross-sectional cognitive studies between neurotypical older adults and autistic older adults (with no intellectual disability) give no indications that there are larger age-related differences for cognitive problems in people on the autism spectrum (Lever & Geurts, 2015; Lever, Werkle-Bergner, Brandmaier, Ridderinkhof, & Geurts, 2015), although autistic older adults do report cognitive symptoms more frequently than neurotypical older adults (Davids et al., 2016). A possible explanation could be that problems in executive functioning in ASD might not wane with age and lead subjectively to increasing limitations as age-related incapacities come on top of this. However, there is too little research and clinical experience to provide clear consultation for clinical practice. Presumably, various subgroups could be distinguished within the larger group of autistic (older) adults. Maybe some individuals on the autism spectrum are susceptible to developing dementia.

There are several limitations to our Delphi study. Even though response rate is high (91–100%) the size of the expert panel is small, the panel's international range is narrow and there is an imbalance between Dutch (n = 10) and Belgian (n = 1) clinical experts. The criteria for inclusion were very strictly formulated, as the reliability of a Delphi study depends on the participants' expertise of the topics of the statements about which opinions were given. Only a small number of clinical experts met these criteria. Moreover, we did not include a group of autistic older adults even though they especially can offer unique insights on the subject of this Delphi study (Hickey et al., 2017; Michael, 2016).

We have chosen to utilize a Delphi study procedure with three structured rounds of surveys, each covering a subtopic. In this Delphi study, the iterative character to reach consensus after feedback rounds was subordinate to charting the expert viewpoints. Nevertheless, consensus was reached on most of the survey statements (12 out of 17; especially on diagnosis and treatment). Despite the limited scientific evidential value of the Delphi method, in this study we have decided to allow the clinical experts to give extensive explanations for each statement. Further scientific research, input from autistic older adults and their environment and cross-validation of the results of this Delphi study in other countries is needed. Increasing scientific knowledge on this topic will bring improvement to the quality of treatment for autistic older adults within reach.

Clinical implications

- Clinicians should be mindful of the possibility of an ASD diagnosis in an older adult population and the importance of providing treatment to autistic older adults.
- This Delphi study provides practice-based knowledge based on which adaptations to diagnostics and treatment of ASD in older adults can be made.
- The effects of ASD on aging (and vice versa) are not clear yet.

Notes

1. Note: the Dutch *Multidisciplinary guideline for diagnosis and treatment of autism spectrum disorders in adults* was made in close collaboration with the British National Collaborating Center for Mental Health (NCCMH) in developing the original *NICE guideline Autism Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum* (National Institute for Health and Clinical Excellence, 2012, National Clinical Guideline Number 142, last updated August 2016). There is a great resemblance between both guidelines. Regrettably in both guidelines there is very little content specifically about ASD and aging, because of the lack of research, which is why any research is so important.

Acknowledgments

We thank the clinicians for contributing to this study and sharing their experiences.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The author(s) reported there is no funding associated with the work featured in this article.

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Data availability

Data can be obtained from Reinier van Arkel (the Netherlands) by B. Hitzert

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