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## **Improving the health of adults with autism and their caregivers**

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# Chapter 6

## General discussion

Improvement of the health of autistic adults and autism-caregivers is an urgent matter. However, only a small proportion of the research into autistic adults is dedicated to their physical health. Nevertheless, it is evident that autistic adults' health should be improved, considering their increased mortality risk (Mason et al., 2022). Literature regarding biopsychosocial aspects of caregiver strain in autism-caregivers is also scarce, while their caregiver burden seems to be higher than in other types of caregivers (Bayoumi et al., 2017). This dissertation contributes to the gap in knowledge concerning the mental and physical health(care) of autistic adults and autism-caregivers. Hence, we conducted quantitative research to investigate metabolic syndrome in adults with autistic traits (Chapter 2), gastrointestinal symptoms in autistic adults (Chapter 3), and biopsychosocial aspects of caregiver strain in autism-caregivers (Chapter 4). Furthermore, autistic people often report unmet healthcare needs and barriers in (access to) healthcare, which ask for improvement of their primary care (Mazurek et al., 2020). Therefore, we performed a mixed-method study to explore how primary care providers (PCPs) and autistic adults suggest to improve their primary care (Chapter 5). This general discussion first offers a summary of the main findings of these four studies. Next, methodological considerations, including study limitations, are reviewed. Lastly, implications of these study results for clinicians, policy, future research, autistic adults, and autism-caregivers are formulated.

## Summary

In Chapter 2, we aimed to compare the prevalence of metabolic syndrome, as a measure of cardiovascular risk, and associated biopsychosocial factors between adults with higher and lower levels of autistic traits. In this study, all analysed data from 17,705 included adults came from the Lifelines Cohort, a database covering a general population sample in the Northern Netherlands. The statistical analyses showed that metabolic syndrome is more prevalent in women with higher levels of autistic traits (10.0%) than in women with lower levels of autistic traits (7.5%). In men with higher levels of autistic traits, this is not the case. In these investigated male and female adults with relatively high levels of autistic traits, the presence of metabolic syndrome is associated with lower perceived health, less physical activity, and altered leukocyte levels.

Also based on quantitative results from the Lifelines database, Chapter 3 explored psychological, behavioural, and biological factors associated with gastrointestinal symptoms in adults with an autism diagnosis and in adults with autistic traits. This study displayed that adults with autism ( $n=309$ ) have a higher risk for gastrointestinal symptoms (including constipation, diarrhoea,

heartburn, abdominal pain/discomfort) than adults without autism (n=30,876); the prevalence of one or more gastrointestinal symptom(s) was 1.7 times higher in adults with autism than in adults without autism. An additional insight concerned the 1.3 times higher prevalence of gastrointestinal symptoms in adults with higher levels of autistic traits (n=7783) compared to adults with lower levels of autistic traits (n=7783). Next, multivariable logistic regression showed that psychological factors, including anxiety, depression, stress, and perceived health, were associated with the presence of gastrointestinal symptoms in both adults with autism and adults with higher levels of autistic traits. More specifically, a higher stress score and lower self-perceived health were associated with a higher risk for gastrointestinal symptoms. Next, being less physically active was associated with the presence of gastrointestinal symptoms in adults with higher levels of autistic traits. Furthermore, leukocyte, neutrophil, and lymphocyte counts were positively associated with the presence of gastrointestinal symptoms in adults with higher levels of autistic traits. In summary, both adults with autism and adults with higher levels of autistic traits have an increased risk for gastrointestinal symptoms, which is associated with anxiety, depression, more stress, and worse perceived health.

Our third Lifelines study, with the aim of comparing biopsychosocial aspects of caregiver strain between autism-caregivers (n=722) and non-autism-caregivers (n=2632), was presented in Chapter 4. We found that autism-caregivers have an approximately twofold higher risk for anxiety and depressive disorders compared to non-autism-caregivers. In addition, autism-caregivers reported higher chronic psychological stress levels than non-autism-caregivers. It should be noted that within the group of autism-caregivers, the investigated psychological aspects of caregiver strain were not different between parental and non-parental autism-caregivers. This indicates that not only the parents of autistic children but also the non-parental autism-caregivers experience high psychological strain. Regarding the investigated inflammatory blood markers potentially related to chronic exposure to stress, both lymphocyte and monocyte counts were lower in autism-caregivers than in non-autism-caregivers. Leukocyte responses are part of the gut-brain axis, which can be affected by psychological stress. Thus, autism-caregivers are at higher risk for psychological burden than non-autism-caregivers, which was not associated with just being a parent.

In Chapter 5, the aim of the Delphi-study was to explore how primary care for autistic people could be improved according to Dutch PCPs and autistic adults. In order to reach this main goal, the Delphi-study first increased insight into the barriers specifically experienced in Dutch primary care for people with autism. Selection of the investigated barriers was based on previous literature, 11 initial semi-structured interviews with autistic adults and healthcare providers, and the input of our project team members. These barriers are related to

healthcare providers, autistic people, and the organization of general practice. The Delphi-study showed that the 20 investigated barriers were recognized by both the participants with autism and the primary care providers. Markedly, the autistic participants assessed the negative impact of most barriers relatively higher than the primary care providers. Next, a set of 22 recommendations for improvement of primary care for autistic people, focusing on healthcare providers, autistic people, and the organization of general practice, were all assessed as very useful by PCPs and autistic adults. Based on the assessment of feasibility, these 22 recommendations were categorized into less or more feasible. Examples of useful and feasible recommendations for improvement are education for PCPs, enhancement of autistic adults' preparation for a GP-appointment, and planning more time for a GP-consultation.

### Methodological considerations

#### *General considerations*

In this dissertation, both quantitative measures, semi-structured interviews, and a Delphi-study were conducted to explore biopsychosocial factors and healthcare barriers relevant for improvement of the health and care for autistic adults. To incorporate the perspectives of autistic people, we consulted several autistic adults during the conceptualization of our study designs and interpretation of study results, as participatory research is encouraged (Poulsen et al., 2022). However, since our collaboration did not come without difficulties experienced by both the researchers and autistic project team members, it is advised for future researchers and autistic people to be thoroughly informed about participatory research (Fletcher-Watson et al., 2019; Pickard et al., 2022). Moreover, from our project team experiences, we learned that it is vital to clarify all team members' roles, competencies, expectations, and responsibilities up-front. This could increase internal collaboration and maximize all team members' input.

Next, it is important to note that autistic adults with an intellectual disability were not represented in the studies of this dissertation. Also, selection bias regarding autistic people working together with researchers in participatory research should be taken into consideration. In participatory research, most of the time, verbally strong or high-functioning people with autism are joining participatory research, which could lead to a biased perspective. In addition, in both the Lifelines studies and Delphi-study the cultural and ethnic diversity of participants was low. Lifelines is a cohort in the Northern Netherlands, which resulted in the inclusion of mainly adults with an Eastern or Western European background. Therefore, our Lifelines results cannot be generalized to autistic adults with other backgrounds than Eastern or Western European, possibly having different genetics, socioeconomic status, or lifestyles. In the Delphi-study, we aimed to include participants with different ethnic and cultural

backgrounds. However, this was very difficult, despite the use of the AWA's widespread network, and we were not able to get in contact with a lot of adults with autism with varying ethnic or cultural backgrounds.

### *Lifelines studies*

The main strength of the quantitative studies in this dissertation entails the analysis of data based on both physical measurements (weight, length, waist circumference, immunological variables), self-report (stress, perceived health), and semi-structured interviews (MINI: anxiety and depression) in adults with autistic traits and autism-caregivers from the large general population sample, the Lifelines Cohort. In our Lifelines Study concerning the autism-caregivers, we were able to use the prospective design of the Lifelines Cohort by investigating biopsychosocial aspects of caregiver strain in a period after the start of being a caregiver. However, when using retrospectively collected data, not all variables of interest are available. For example, in our study regarding gastrointestinal symptoms, it could have been valuable also to take dietary habits into account, as these could be different in autistic people, considering restrictive or selective patterns.

The statistical associations reported in the quantitative Lifelines studies in this dissertation do not prove causality between the investigated biopsychosocial factors and outcome measures (N.B. metabolic syndrome, gastrointestinal symptoms, autism-caregiver-strain). Therefore, these results might not lead to the direct implementation of clinical interventions since such interventions should first be developed and analysed on effectiveness.

The studies in this dissertation are limited to the inclusion of participants based on a self-reported autism diagnosis. However, 99.1% of the Lifelines participants who reported to have autism also added the year of diagnosis. This increases the validity of these self-reported autism diagnoses. Also, in our Lifelines studies, the self-reported autism diagnoses were complemented with AQ-10 data. One can debate autistic people's self-report skills, which could be affected by their reflective abilities. However, in autistic adults, self-report skills, specifically regarding autistic traits, have not been investigated yet. The predictive value of the AQ-10 with respect to having an autism diagnosis has been investigated. However, in the Lifelines studies in this dissertation, the aim of using the AQ-10 was not to predict an autism diagnosis, but to roughly quantify the degree of autistic traits in a large general population sample.

### *Delphi-study*

The main strength of the Delphi-method is the inclusion of a panel consisting of both autistic adults and PCPs, in order to reach higher levels of consensus, using controlled feedback (Niederberger & Spranger, 2020). This method leads to concrete study outcomes and corresponding recommendations for general

practice. Furthermore, the Delphi-method gives all participants an equal anonymous voice, which might not be the case in, for example, focus groups (Taylor, 2020). Moreover, we prepared this Delphi-study with both an orientating literature search, semi-structured interviews, and input from autistic people with lived experience. This resulted in a substantiated list of 20 barriers investigated in the Delphi-study. For our Delphi-study, it was chosen to perform digital surveys, instead of physical Delphi-rounds, as this was a more feasible study design during the COVID-19 pandemic. One can debate if other types of study designs would have been suitable as well. For example, a quantitative survey study using a larger sample of respondents might include more different types of autistic adults and PCPs. Considering that specifically the autism spectrum has a wide range, selection bias of high-functioning autistic people could be the case in our Delphi-panel. However, to reduce selection bias in our Delphi-study, we aimed to include autistic adults with experience in speaking on behalf of a broader range of people on the autism spectrum. These participants were selected using our project team members' professional network. Lastly, for example, a study design using concept mapping could also have been useful for our research question. In concept mapping, a group brainstorm on topic statements is followed by individual ratings of these statements. Next, multivariate analyses of these ratings result in a visually presented concept map, which is then interpreted by the group of participants (Rosas & Kane, 2011). For our Delphi research question, concept mapping could have added more insight into how our participants interpreted the rating results of the barriers and recommendations, possibly leading to more in-depth implementation suggestions for general practice.

### Implications

This dissertation resulted in several implications for clinicians, policy, future research, autistic adults, and autism-caregivers, which will be described below and summarized in Figure 1. These implications mainly concern future steps leading to the improvement of healthcare for adults with autism and autism-caregivers, as the reduction of their health risks is urgent. Many of these future steps could possibly be catalysed by more integrated psychiatric and somatic care for autistic adults and their caregivers. Such steps meet the aims of the Dutch Integrated Care Agreement (Integraal Zorgakkoord, version 1.0, September, 2022), the Dutch Health Advisory Board (Gezondheidsraad, *Integrale zorg voor mensen met lichamelijke en psychische aandoeningen*, 27 May 2020), and the Integrated Health Services Department of the World Health Organization (<https://www.who.int/teams/integrated-health-services/about>).



## Implications for clinicians

The hypothesis that underlying autistic traits are associated with an increased risk for metabolic syndrome and gastrointestinal symptoms is firstly supported by the finding that women from the general population with higher levels of autistic traits have an increased risk for metabolic syndrome. Secondly, this hypothesis is supported by the finding that adults with higher levels of autistic traits experience gastrointestinal symptoms more often. This means that clinicians, such as general practitioners and psychiatrists, should be aware of this higher risk when they see people who have autistic traits, but do not have an autism diagnosis (yet). This awareness could help clinicians with earlier recognition of cardiovascular risk factors or gastrointestinal symptoms in individual adult patients with autistic traits, possibly leading to the reduction of chronic diseases.

Increased knowledge and awareness are helpful steps towards improved health for autistic adults, as also supported by the participants from our Delphi-study. For example, healthcare providers could be educated about the increased health risks in adults with autistic traits, associated biopsychosocial factors, and barriers and recommendations for improvement of primary care. This education could be developed for PCPs, but also for medical students, psychiatrists, and residents in general practice and psychiatry. Moreover, accredited courses for medical specialists or other specialists, organized by healthcare providers with autism expertise and autistic people with lived experience can be helpful.

The above-mentioned topics for education could also be an important subject of patient-doctor conversations, contributing to a mutual understanding. However, it is known that most patients also want to receive appropriate referrals and diagnostics for their symptoms, besides being informed about underlying biopsychosocial mechanisms. These steps are important for timely diagnosis or exclusion of medical conditions and for the patient's feeling of being taken seriously (Federatie Medisch Specialisten, Richtlijn SOLK en somatoforme stoornissen). The latter, the feeling of being misunderstood, was a barrier that three-quarters of the autistic adults in our Delphi-study experienced as having a very negative impact on their primary care. Possibly, stigmatization or communication barriers might be interrelated with the feeling of being misunderstood and with insufficient diagnostic step-by-step workups.

Furthermore, clinical guidelines, for example including psychiatric autism spectrum disorder guidelines and gastrointestinal or cardiovascular risk management guidelines, should be enriched with our study results and those of previous studies (e.g., Micai et al., 2023) concerning somatic comorbidities and related biopsychosocial factors in autistic people. In the Netherlands, one can also think of a general practice guideline on autism, because current Dutch general practice guidelines (*Nederlands Huisartsen Genootschap (NHG)*

*richtlijnen*) include ADHD, anxiety, depression, but not autism. Moreover, a revision of Chapter 4 of the Dutch GGZ *Standaard Autisme*, regarding diagnostics and psychological and somatic monitoring of people with autism, is necessary (available on <https://www.ggzstandaarden.nl/zorgstandaarden/autisme>).

Despite the fact that the associations demonstrated between various factors of the biopsychosocial model and metabolic syndrome and gastrointestinal symptoms do not imply causality, these associations can be an important starting point for tailored interventions. One could think of specifically incorporating interventions for the reduction of stress, anxiety, and depression in healthcare for adults with autistic traits. Information regarding the relationships between these psychological aspects in autism could for example be integrated into standard psychoeducation modules for people who are diagnosed with autism.

Many people with autism have a caregiver in everyday life. As autism is a life-long condition, these autism-caregivers often provide long-term care for their child, family member, or acquaintance. Furthermore, caregiver-strain is related to increased mortality (Fairthorne et al., 2014; Schulz & Beach, 1999). Clinicians should also be aware that being an autism-caregiver is associated with higher stress levels, more anxiety, and depression compared to being another type of informal caregiver. So, autism-caregivers should not be overlooked, as their psychological caregiver strain is increased as well. Timely assessment of caregiver-strain and specifically reduction of stress, anxiety, and depression in autism-caregivers is indicated. Both psychiatrists and general practitioners should question the families of autistic people more about their experienced caregiver strain.

Lastly, our Delphi-study specifically investigated recommendations for improvement of primary care. Thus, it is advised that PCPs discuss the presence of healthcare barriers with colleagues and with autistic patients. Next, PCPs have the responsibility to assess which specific improvements are feasible in their own clinical practice, as experienced barriers could possibly vary between individual healthcare providers. Based on our Delphi-study, it is not possible to directly generalize the investigated recommendations to other types of healthcare for autistic adults. However, it is imaginable that some of the barriers and related recommendations to reduce these barriers can also be applicable in other types of healthcare for autistic people, rather than just in primary care. Thus, clinicians from other medical specialties could possibly learn from these study outcomes as well. For example, education about autism could be helpful for other types of healthcare providers who treat people with autism relatively often, such as neurologists, physiotherapists, dentists, surgeons, or internal medicine specialists. However, the latter might ask for more qualitative research aiming to translate our study outcomes to other

types of clinical settings, making these results more relatable and easier to implement in different clinical practices.

### Implications for policy

The results of this dissertation suggest that policymakers should facilitate more integrated psychiatric and somatic care for autistic adults and their caregivers, which is in line with the biopsychosocial model (Deter et al., 2018). This psychiatric and somatic integrated care could for example be a collaboration between hospital-specialists, mental care providers, and PCPs (Leue et al., 2020). Moreover, somatic monitoring of autistic adults in out- or inpatient psychiatric clinics could be helpful. This was for example done in the ‘Monitoring Outcomes of Psychiatric Pharmacotherapy (MOPHAR)’ study, in which metabolic syndrome was detected in an outpatient bipolar population (Simoons et al., 2019). However, at what scale (locally or nationally) and which other medical specialties should be involved to facilitate widely-available integrated psychiatric and somatic care for autistic adults and their caregivers, should still be defined. Future policy changes on integrated care should also lead to revisions of clinical guidelines, such as Chapter 8 of the Dutch GGZ *Standaard Autisme* regarding Organization of care (available at <https://www.ggzstandaarden.nl/zorgstandaarden/autisme>).

It can be advocated that integrated psychiatric and somatic care should not only be incorporated for autistic people, but for the broader population of psychiatric patients, having an increased risk for different somatic comorbidities. An example of a national Dutch initiative is the combined lifestyle intervention program (*gecombineerde leefstijlinterventie, GLI*). In this program, people with obesity are coached to improve their lifestyle guided by both medical specialists and primary care providers. The development of more locally integrated psychiatric and somatic care in the Netherlands fits within the Dutch Integrated Care Agreement published in 2022 and created by the Dutch government, Dutch mental healthcare, and the Dutch Federation of Medical Specialists (*Integraal Zorgakkoord*, version 1.0, September, 2022). *Nota Bene*, one of the statements in this Dutch Integrated Care Agreement involves the improvement of appropriate care for people with higher health risks by constructing more integrated care.

Lastly, several recommendations that resulted from our Delphi-study implicate changes in organization of general practice, which could possibly result in more autism-friendly practices (Johnson et al., 2020). For example, in Dutch general practice, it has already been made possible to use double consultation times for people with autism, as this will be covered by insurance policies. All in all, the knowledge gained in this dissertation contributes to a better understanding of the neurodiverse population. As a consequence, policymakers should invest in both stigma-reducing national campaigns and

in the widespread development of neurodiverse-accommodating logistics and design of healthcare. However, in order to also facilitate adequate integrated psychiatric and somatic care, such changes are also needed in other types of healthcare for autistic people.

### Implications for future research

A first lead for future research could be to investigate which specific autistic traits seem to be most associated with the increased health risks in adults with autistic traits. It could for example be useful to investigate associations between specific traits or clusters of autistic traits and physical health problems using the AQ-10 in adults from the general population and in adults with autism. This could delineate underlying pathways and identify subgroups of adults with autistic traits (also in the general population) who are more at risk for certain physical symptoms. Next, longitudinal research exploring causal pathways needs to be performed to gain a better understanding of the relationship between autism and increased health risks. Additionally, it could be relevant for example to investigate the cardiovascular risk in autistic adults with intellectual disabilities and with different types of ethnic backgrounds, as cardiovascular risk could be affected by both variables. All in all, those outcomes could be helpful knowledge for revisions of clinical guidelines regarding for example more person-centred primary care, psychiatric care, and cardiovascular risk management.

Furthermore, this dissertation asks for future research with a similar biopsychosocial approach investigating other types of stress-/lifestyle-related chronic physical conditions in adults with autistic traits. For example, it raises questions about cancer risk in adults with autistic traits and associated biopsychosocial factors. In future research, these biopsychosocial factors could also be complemented with more contextual (e.g., life events) and environmental factors (e.g., living circumstances, local resources). Moreover, we investigated immunological markers in autistic adults and adults with autistic traits. This asks for more research into the presence and effects of chronic low-grade inflammatory status in autistic adults, since the innate immune memory plays an important role in the development of atherosclerotic cardiovascular disease (Bahar et al., 2024).

Alongside the above-mentioned research aims focusing on a better understanding of somatic risk profiles in adults with autistic traits, future research should focus more on the effective implementation of integrated clinical guidelines, and on the organizational steps that need to be taken to facilitate integrated and somatic care. The latter is relevant as organizational changes often cost time and money, which can become available with supporting research outcomes. Lastly, considering the different needs of autistic people and the barriers they experience in healthcare, it should be investigated if the

current national cardiovascular risk management programs are effective and tailored enough for the autistic population.

### Implications for autistic adults and autism-caregivers

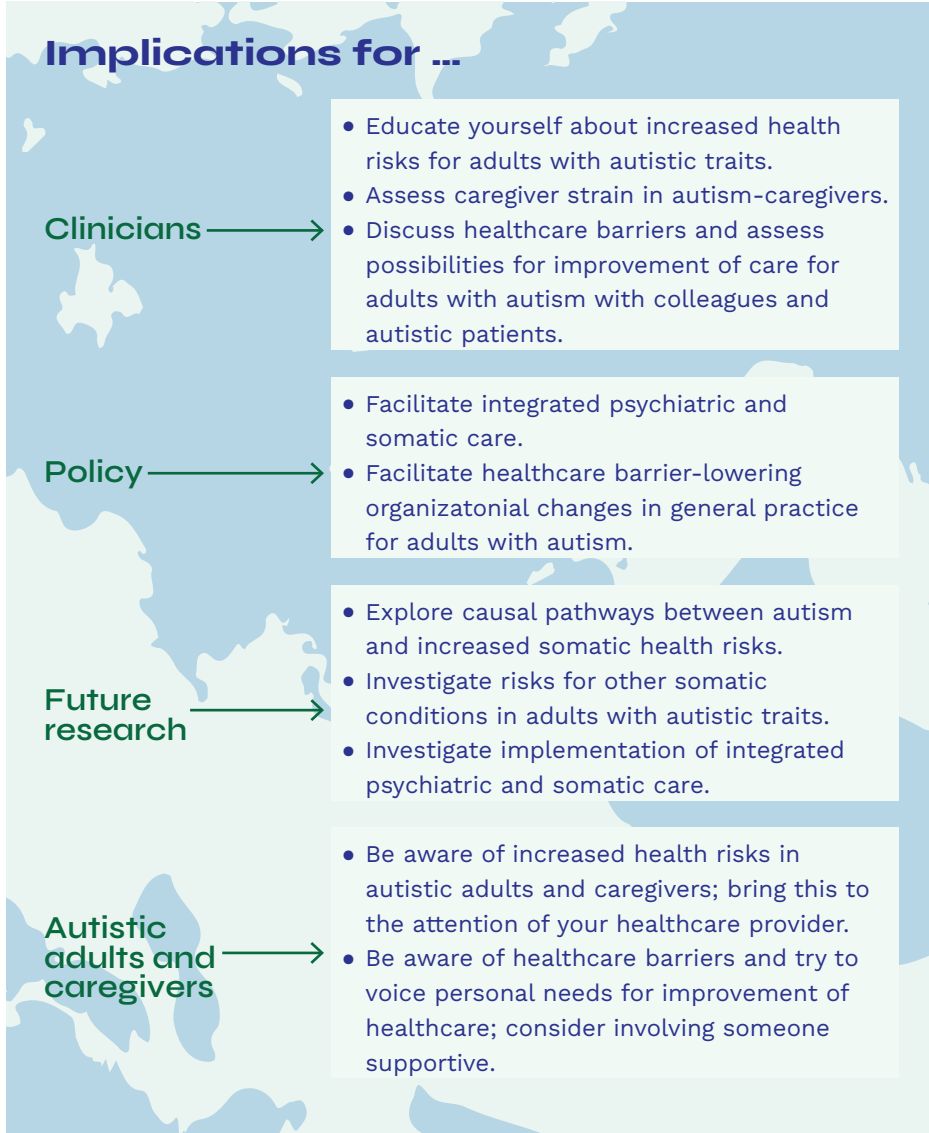
Both our Lifelines studies and our Delphi-study implicate that autistic adults and autism-caregivers need improved healthcare to prevent somatic symptoms, chronic diseases, and caregiver strain. Knowledge of these increased health risks should be accessible for autistic adult and autism-caregivers through for example (online) factsheets/flyers or informative websites. Our AWA project-team, for example, published a factsheet summarizing the outcomes of our Lifelines study regarding gastrointestinal symptoms (see Appendices). This type of factsheet could be used to educate both autistic adults, autism-caregivers, and healthcare providers. Autistic adults who are willing and able to, could take action in their own hands and notify their healthcare providers (PCPs, psychiatrists, etc.) about the increased health risks in autistic adults, to enhance prevention or early recognition of for example gastrointestinal symptoms and metabolic syndrome. However, educating healthcare providers is not the responsibility of autistic adults themselves, particularly because not all autistic adults are capable to adequately verbalise their rights and needs. Hence, based on our Delphi-study, it is advised to consider involving someone from the social support system when autistic people experience barriers in healthcare. In the end, clinicians and policymakers are primarily the parties that should prioritize the improvement of the health and healthcare for autistic adults with more effective prevention and treatment of comorbidities.

Despite that improvement of primary care should mostly come from PCPs and policymakers, it is important that autistic adults themselves are aware of possible healthcare barriers as well. Awareness of these barriers might empower some autistic adults to discuss these barriers with their PCPs. To spread knowledge and awareness, our AWA project team created a summarizing flyer in Dutch about the Delphi-study outcomes regarding barriers and recommendations for improvement of primary care (see Appendices).

Lastly, the results in this dissertation regarding autism-caregiver strain might increase the personal validation of experiencing chronic stress, anxiety, or depression for autism-caregivers in daily life. Validation is important in being able to cope with these psychological aspects of caregiver-strain, as it may result in a feeling of being understood. The outcomes of this dissertation might also give autism-caregivers the opportunity to take their own health more into account, considering the strain that comes with taking care for someone with autism. However, currently, there still is a gap between scientific results, such as the outcomes in this dissertation, and the daily lives of autism-caregivers. Thus, a first step should involve the dissemination of scientific results combined with lived experiences. This could be achieved in collaboration with

for example peer support platforms, bringing autism-caregivers together (e.g., in the Netherlands: <https://www.mamavita.nl/>).

Figure 1. Implications for...



## Conclusion

Taken together, this dissertation is a call to place the health of adults with autistic traits and autism-caregivers higher on the agenda of clinicians, researchers, policymakers, and autistic adults and autism-caregivers themselves. Primarily, clinicians should be educated about the increased health risks in autistic adults and autism-caregivers, in order to be able to prevent or recognize these comorbidities timely. This is relevant because of the higher prevalence of both metabolic syndrome and gastrointestinal symptoms in adults from the general population with higher levels of autistic traits, as shown in this dissertation. The associations we found between biopsychosocial factors and respectively metabolic syndrome and gastrointestinal symptoms ask for more psychiatric and somatic integrated care for autistic adults. With this, a hypothetically chronic hyper-stimulation of the HPA-axis through increased chronic stress and immunological alterations in autistic adults should be considered for more in-depth research. Since it is evident that autistic adults have an increased risk for physical health problems and mortality, future research could use the associations we found between the biopsychosocial model and autistic traits to develop preventive interventions specifically targeted for adults with autism (or higher levels of autistic traits). To make sure future preventive measures and the treatment of physical health problems are effective for this target population to improve their health, barriers in the healthcare for autistic people should be reduced. Therefore, this dissertation also offers recommendations for improvement of primary care, the gatekeeper of adequate healthcare for autistic adults.

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