Hamburg University of Applied Sciences

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Associations between the impact of access barriers and healthcare utilization among autistic adults in Germany

Master thesis

Master Health Sciences

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List of Abbreviations

ADHD	Attention deficit hyperactivity disorder
APA	American Psychological Association
ASD	Autism Spectrum Disorder
AUT	Autistic Individual
B	Unstandardized Coefficient
BASS	Barrierefreie Autismus Spektrum Störung
CBT	Cognitive Behavioral Therapy
CDC	Center for Disease Control
CI	Confidence Intervals
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision
ED	Emergency Department
EHIS	European Health Interview Survey
ENT	Ear Nose and Throat Doctor
EQ-5D	European Quality of Life 5 Dimensions
G-BA	Federal Joint Committee
GEDA	Gesundheit in Deutschland aktuell
GERD	Gastroesophageal Reflux Disease
GP	General Practitioner
HCP	Health Care Professional
ICD 10	International Classification of Diseases, Tenth Revision
ID	Intellectual Disability
IQ	Intelligence Quotient
LD	Learning Disability
MCAR	Missing Completely at Random
MI	Multiple Imputations
MMWR	Morbidity and Mortality Weekly Report
NICE	National Institute for Health and Care Excellence
OCD	Obsessive Compulsive Disorder
PDD-NOS	Pervasive Developmental Disorder - Not Otherwise Specified
PKV	Private Health Insurance
RBR	Restricted Repetitive Behavior
SE	Standard Error
SES	Socioeconomic Status
SF-8	Short-Form-8 Health Survey
SHI	Statutory Health Insurance
SPSS	Statistical Package for the Social Sciences
SSRI	Selective Serotonin Reuptake Inhibitors
UKE	University Medical Center Hamburg – Eppendorf
VIF	Variance Inflation Factor
WHODAS	World Health Organization Disability Assessment Schedule
WHO	World Health Organization

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English Abstract:

Background: Autistic adults report barriers to accessing and receiving healthcare, they also experience increased morbidity and mortality. Early planning and continuity of care are often emphasized, in the context of autism healthcare. In Germany, where the public health system is without financial barriers, studies on access to services are lacking. Person-centered interventions and systematic approaches are needed to address barriers at personal, professional, and systemic levels. This study will (1) compare current healthcare use of autistic adults to the general population in Germany, and (2) examine current barriers, clinical and socioeconomic factors affecting access and use of healthcare services, with the aim of informing future strategies for promoting equal care for autistic adults.

Methods: Data from two cross-sectional studies were used, 288 autistic adult population samples were taken from the BarrierfreeASD (BASS) study along with an equal sample of adults from the German general population. Man-Whitney-U tests were calculated to compare the overall healthcare utilization of 5 services (general practitioner, mental health, dental health, ophthalmology, and emergency room visits) between both populations in Germany. Multivariate linear regression analyses were conducted to measure the influence of certain predictors on the healthcare utilization in the autistic population sample.

Results: Autistic adults show significantly higher healthcare use compared to the general population in Germany $U = 8437.500$, $Z = -17.184$, $p < .001$. Autistic adults experience on average 7.9 out of 14 perceived barriers to healthcare access. Multivariate regression analyses showed a significant influence of number of somatic comorbidities, number of mental comorbidities and autism support items (DSM-5) on the overall healthcare utilization ($F\ (10) = 6.805$, $p < 0.001$). The range of R^2 for all the imputations were [0.204- 0.180], adjusted R^2 range is [0.172-0.150].

Conclusion: The findings show that the autistic adult's population is heavily burdened with perceived barriers to healthcare. Despite that, the number of barriers autistic individuals face do not affect their overall use of healthcare services which could signify an unmet need among this population. Further research on the reason why perceived barriers to healthcare have no effect is required. Interventions are needed that, improve the access to care for autistic adults and assure the continuity of high-quality care.

Keywords: Autism spectrum disorder, autistic adults, sociodemographic factors, clinical factors, perceived barriers to healthcare, healthcare service use, healthcare access.

German Abstract:

Hintergrund: Autistische Erwachsene berichten von Barrieren beim Zugang zur gesundheitlichen Versorgung und erhalten oft nicht die notwendige medizinische Begleitung, die sie benötigen würden. Gleichzeitig weisen sie eine erhöhte Morbidität und Mortalität auf. Frühzeitige Planung und Kontinuität besonderer Maßnahmen werden oft im Zusammenhang mit der Gesundheitsversorgung von Menschen mit Autismus betont. Derweil fehlen in Deutschland Studien zur Inanspruchnahme von Gesundheitsangeboten dieser Zielgruppe. Personenzentrierte Interventionen und systematische Ansätze sind jedoch erforderlich, um Barrieren auf persönlicher, beruflicher und systemischer Ebene anzugehen und abzubauen. Diese Studie soll (1) die aktuelle Inanspruchnahme von Gesundheitsleistungen durch autistische Erwachsene mit der allgemeinen Bevölkerung in Deutschland vergleichen und (2) aktuelle Bedürfnisse, Barrieren, klinische und sozioökonomische Faktoren untersuchen, die den Zugang und die Inanspruchnahme von Gesundheitsleistungen beeinflussen.

Methoden: Hierfür wurden jeweils Daten von $N = 288$ autistischen Erwachsenen aus der Studie BarrierefreieASS (BASS) verwendet als sowie Daten von Erwachsenen der deutschen Allgemeinbevölkerung. Man-Whitney-U-Tests wurden angewendet, um die Nutzung gesundheitlicher Leistungen beider Gruppen in Deutschland zu vergleichen. Multivariate lineare Regressionsanalysen wurden durchgeführt, um den Einfluss bestimmter Prädiktoren auf die Inanspruchnahme von Gesundheitsleistungen in der autistischen Stichprobe zu messen.

Ergebnisse: Autistische Erwachsene zeigen im Vergleich zur allgemeinen Bevölkerung in Deutschland eine signifikant höhere Inanspruchnahme von Gesundheitsangeboten ($U = 8437{,}500$, $Z = -17{,}184$, $p < .001$). Autistische Erwachsene sind durchschnittlich mit 7.9 von 14 wahrgenommenen Hindernissen beim Zugang zur Gesundheitsversorgung konfrontiert. Multivariate Regressionsanalysen zeigten einen signifikanten Einfluss der Anzahl somatischer Komorbiditäten, der Anzahl psychische Komorbiditäten und der Autismus Support Elemente (DSM5) auf die Inanspruchnahme von Gesundheitsleistungen ($F(10) = 6.805$, $p < 0.001$). Die Spanne von R^2 für alle Imputationen betrug [0,204-0,180] und die Spanne von adjustiert R^2 liegt bei [0,172-0,150].

Schlussfolgerung: Die Ergebnisse zeigen, dass autistischer Erwachsenen stark durch wahrgenommene Barrieren in der Gesundheitsversorgung belastet sind. Trotz der hohen Anzahl an wahrgenommenen Barrieren, mit denen autistische Personen konfrontiert sind, ist kein signifikante Einfluss auf ihre Gesamtnutzung von Gesundheitsdienstleistungen ist zu beobachten, was auf einen ungedeckten Bedarf in dieser Bevölkerungsgruppe hinweisen könnte. Obwohl ein Teil der Varianz im Model durch klinische Faktoren erklärt wurde, konnte in dieser Studie nicht nachgewiesen werden, dass Barrieren und bestimmte soziodemografische Faktoren die Inanspruchnahme bestimmter Gesundheitsleistungen signifikant beeinflussen. Dies deutet darauf hin, dass es andere Prädiktoren gibt, die sich auf die Inanspruchnahme von Gesundheitsangeboten in dieser Bevölkerungsgruppe auswirken und die noch entdeckt werden müssen.

Schlüsselwörter: Autismus Spektrum Störung, autistische Erwachsene, soziodemografische Faktoren, klinische Faktoren, Barrieren für die Gesundheitsversorgung, Inanspruchnahme von Gesundheitsleistungen, Zugang zur Gesundheitsversorgung.

1. Introduction

Autism Spectrum Disorder (ASD) stands as a profound and enduring neurodevelopmental condition, marked by early onset and the lasting impact it places on autistic individuals and their families throughout their lives (Baird et al., 2006; Lyall et al., 2017). The considerable demands imposed by autism arises from the essential requirement for various highly specialized health, educational, and vocational services (Lord et al., 2018). This necessitates a significant financial investment, rendering autism to be cost-intensive for many parties involved, may that be parents, family members or caregivers of autistic individuals, as they sustain high costs due to productivity loss, loss of work income and possibly loss of leisure time (Rogge & Janssen, 2019). Moreover, as autistic individuals age, the strain on healthcare systems escalates, emphasizing the ongoing challenges and resource implications associated with providing comprehensive support for this population and being able to access it properly as individuals often experience many barriers to service receipt across the lifespan, such as the lack of resources, and inadequate service provider skills (J. K. Y. Lai & Weiss, 2017) .

This master's thesis delves into the examination of the impact of perceived access barriers on healthcare service utilization among autistic adults. The primary objective is to unravel the intricate connections between healthcare service utilization patterns and the obstacles faced by autistic adults in the process. Conducted as part of the "BarrierfreeASS (BASS)" project at the University Medical Center Hamburg-Eppendorf (UKE), this thesis specifically addresses the associations between various demographic and clinical factors, with the needs and barriers in healthcare access and utilization for autistic adults in Germany.

The content of this thesis is structured in eight chapters overall. Following the introduction, an in-depth display of the background of autism spectrum disorder with important information about the etiology, diagnosis, prevalence, comorbidities, and insights into treatment, then healthcare utilization for the German general population along with the healthcare utilization of the autistic adults are explored. After that the barriers hindering the healthcare access for autistic adults are presented and lastly, the topic of healthy aging and aging on the spectrum is briefly touched upon. Afterwards the methodological aspects are contextualized, including information of the BASS project, the comparison data set from the Grupp et al, 2016 study, and the description of the quantitative analyses to be conducted in the framework of this thesis. Subsequently, the result section is divided into three major parts: by descriptive results of the BASS sample and a sample of the comparison population, followed by the comparison results between the BASS sample and the German general population sample, the results of the regression analyses to explore the effects of sociodemographic factors, clinical factors and barriers on healthcare access for autistic adults. The ensuing self-critical discussion presents the achieved results in connection with the recent literature, followed by the clarification of the limitations in this thesis. In conclusion, recommendations for action and future research are given and completed by a brief outlook.

In the last twenty years, a growing body of evidence has emerged regarding the appropriate terminology for discussing autism has emerged. While much of this discourse has centered on the merits of identity-first language versus person-first language, more recently, this debate has expanded to include other autism related terminology (Keating et al., 2023). Person-first approach has been wildly used in the scientific world (Crocker & Smith, 2019), yet some researchers argue that this approach would perpetuate the notion that autism is a defect that must be removed from the individual (and indirectly suggests that disability is inherently bad (Andrews et al., 2019). To date, academic studies have not investigated the language preferences of autistic individuals outside of the United Kingdom or Australia, a recent study from 2023 by Keating et al, explored the linguistic preferences of 654 English speaking autistic adults across the globe and found that certain terminology such as the terms ‘Autism’, ‘Autistic person’, ‘Is autistic’, ‘Neurological/Brain Difference’, ‘Differences’, ‘Challenges’, ‘Difficulties’, ‘Neurotypical people’, and ‘Neurotypicals’ were consistently favored across countries . Therefore, throughout this thesis, ‘autism’ will be the term used when referring to all the conditions on the autism spectrum. And although the appropriate language around autism is recognized as a complex issue (Shakes & Cashin, 2019), In accordance with the prevailing preferences of the majority within the autism community and according to the recent research on this topic, this thesis will employ identity-first language 'autistic adult' rather than person-first language 'adult with autism' (Keating et al., 2023; Kenny et al., 2016).

2. Theoretical Background

In the following chapter, the theoretical background of this master thesis is presented for a better understanding of the importance of the topic. First, autism spectrum disorder is described in more detail including the disorder’s etiology, classifications, diagnosis, comorbidities, treatments and how it evolves into adulthood. Secondly, the healthcare utilization is explored including the various services available for autistic adults with a special focus on Germany, moreover; the research gap is made clear. Last but not least, the barriers to accessing different healthcare services are inspected with a special focus on those barriers facing autistic adults.

2.1 Autism spectrum disorder

Autism spectrum disorder refers to a group of neurodevelopmental disorders which per the ICD-10 encompass "F84.0 childhood autism," "F84.1 atypical autism," and "F84.5 Asperger’s syndrome" (WHO 1992). The previous DSM-IV-TR diagnoses, which included "299.00 Autistic Disorder," "299.10 Childhood Disintegrative Disorder," "299.80 Asperger’s Disorder," and "299.80 Pervasive Developmental Disorder - Not Otherwise Specified" (PDD-NOS) (APA 2002), have been consolidated into a single diagnosis termed "autism spectrum disorder" in the current DSM-5 (APA, 2013). Autism is further classified according to the level of intellectual functioning, which is divided into two groups: no learning/intellectual disability (no LD/ID; IQ ≥ 85) versus an existing learning/intellectual disability (LD/ID; IQ < 85). According to DSM-5, autism diagnosis also involves classifying individuals into three severity levels, providing a measure of the support required by the autistic individual (APA, 2013).

Characterized mainly by impairments in social communication skills and accompanied by restricted and repetitive patterns of interests or behaviors (Green et al., 2019), autism still might present differently with different symptoms in different genders. While everyone is affected by it, it is much more frequently diagnosed in males, females on the other hand are typically diagnosed at a much later stage.(Green et al., 2019) There is, however, growing recognition of the discrepancy between the sexes with regard to autism prevalence rates, symptom presentation, diagnosis, treatment, and outcomes.

For the past 50 years the definition of autism has evolved due to global research interests, changing from the narrowly defined early onset childhood disorder, to a more researched lifelong condition, recognized as fairly common and very heterogeneous (Lord et al., 2018). These advances have come hand in hand with progress in international policies which resulted in increased awareness and advocacy worldwide (Zeidan et al., 2022).

The challenges of autistic people vary and their needs evolve over time. While some autistic adults can live independently, others have severe disabilities and require life-long care and support. Autism often has an impact on many social aspects of one's life like education and employment opportunities (World Health Organization, 2023).

2.1.1 Etiology

While in the majority of cases the exact etiology of autism remains unknown, recent evidence continues to emphasize the multifaceted nature of the condition, with numerous risk factors contributing to its development. These risk factors could fall into three main groups: genetic, neurological and maternal health related factors (Elsabbagh, 2020; Genovese & Butler, 2023). Simply said, genetic risk factors lead to autism by modifying brain development and function making genetic contribution to autism risk significant, with heritability playing a substantial role as demonstrated by family studies(Sandin et al., 2014). Prenatal factors, such as maternal infections, vulnerability of maternal immune system, advanced parental age have been identified as possible contributors to an elevated risk of autism (Conway & Brown, 2019; Jiang et al., 2016) along with maternal mental health showing consistent associations with being a risk factor for a number of health conditions in children (Gentile, 2017). Perinatal risk factors which lead to neurological vulnerability, tend to increase the risk for autism and other neurodevelopmental conditions (Modabbernia et al., 2017).

Combined together, this evidence suggests that autism has no one and only unique cause (Elsabbagh, 2020). These risk factors intertwine into possible causal pathways shared not only within the realm of autism but also with other neurodevelopmental conditions. Ongoing research aims to decipher these intricate pathways, offering insights into potential shared mechanisms and paving the way for more targeted interventions and personalized approaches to diagnosis (Sandin et al., 2016).

2.1.2 Diagnosis

The rise in autism spectrum disorder prevalence has increased demand for diagnostic assessments, however, due to the heterogenous nature, the wide ranging signs and symptoms diversifying the expression of autism and the shared characteristics among other neurodevelopmental disorders, the diagnosis poses many challenges for health care providers

(Huerta & Lord, 2012; Vllasaliu et al., 2016). Because of the lack on any reliable biomarkers, autism diagnosis is solely based on behavioral traits, these behavioral traits share common core characteristics. Firstly, enduring difficulties in initiating and sustaining reciprocal social communication that are not within the expected range of typical functioning given the individuals' age and level of intellectual development. This includes limitations in understanding and responding to both verbal and non-verbal communication of others, the lack of eye contact and facial expressions, and the limited ability to make typical social relationships. Secondly, presenting "restricted, repetitive behavior" (RRB), which could be defined as the presence of restricted interests, difficulties adapting to new experiences, repetitive behaviors, stereotyped movements (e.g., unusual finger movements, problems maintaining eye contact) that lead to cognitive inflexibility and preference for routines, along with interests or activities that are clearly excessive or unusual for the persons age and sociocultural context. Additionally, the onset of the disorder typically occurs in early childhood, although some symptoms may fully manifest later. These symptoms must result in significant impairments in key life areas, including family, social, educational and career aspects (APA, 2013; Rujeedawa & Zaman, 2022; WHO, 2022b).

Notably, the difficulties of diagnosing autism are not just because of the nature of the condition itself, but due to other aspects affecting the process, firstly, the gender differences among diagnosis, female autism is often missed with the currently available diagnostic tools, in order to solve this problem, many researchers have investigated ways of identifying autistic females, such as by looking at camouflaging, which is a common reason behind missed diagnosis (Driver & Chester, 2021). Another factor playing an important role in the diagnosis is the previously briefly mentioned 'camouflaging' which is when some people tend to employ different strategies and behaviors in order to cope or adapt within their everyday social world, thereby camouflaging their autistic differences and difficulties but the underlying autistic profile remains unaffected, yielding a mismatch between external observable features and the internal lived experience of autism (Cook et al., 2021; McQuaid et al., 2022). Although both autistic males and females camouflage, those designated the female sex at birth, demonstrate higher camouflaging relative to autistic males, as for autistic adults with non-binary gender expressions, camouflaging has been also demonstrated, although these adults did not significantly differ in comparison to autistic cisgender females or males, respectively and not many studies have explored the interactions between diverse gender and camouflaging (Beck et al., 2020; Hull, Lai, et al., 2020). The surrounding environment also has an important role, in which symptoms happen to be tamed in supportive settings, yet they become more apparent in stressful situations and circumstances (Hull et al., 2017).

Diagnosis of autism can have an immense impact on an individual (Rujeedawa & Zaman, 2022), Undiagnosed autistic individuals have often face being misunderstood and negatively labeled. Having a proper diagnosis enables professionals to offer necessary assistance, validate their needs, and address issues they are facing effectively. Additionally, it opens avenues for support such as disability benefits and inclusion opportunities in the workforce (Fusar-Poli et al., 2022). Research has indicated that diagnosis contributes to fostering a positive self-identity in women (Bargiela et al., 2016). Additionally, a diagnosis offers a rationale for previous behaviors and helps counter societal criticisms, thus reducing blame. Furthermore, it provides an explanation for past experiences, aiding individuals in making sense of their lives (Eckerd, 2020; Rujeedawa & Zaman, 2022).

Aligned with international policy recommendations, the evidence behind the significance of incorporating early identification tools into regular services, such as country-level developmental surveillance, maternal and child health programs is growing (WHO, 2013). These programs provide optimal platforms for leveraging existing expertise and capacity in the realm of child development. Moreover, the data would also serve as valuable input for different areas of research, addressing existing knowledge gaps concerning how social determinants influence help-seeking behavior, access to care, clinical presentation, and outcomes. This, in turn, enhances early identification within communities (Elsabbagh, 2020).

2.1.3 Prevalence

In 1944, Asperger described autism as a rare childhood disorder. However, for the past 50 years the definition of autism has evolved perhaps in part due the advancements in diagnostic criteria and diseases classification systems, which led to a shift in global research interests, changing the definition from the narrowly defined early onset childhood disorder, to a more researched lifelong condition, recognized as fairly common and very heterogeneous. (Lord et al., 2018)

A systematic review from 2012 estimated that the global prevalence of ASD was about 1 % (Elsabbagh et al., 2012). In developed countries, the prevalence of ASD was estimated to be around 1.5 % (Lyall et al., 2017). The number of autistic individuals has increased in the past decades. For example, recent prevalence data from the United States Center for Disease Control and Prevention's (CDC) Morbidity and Mortality Weekly Report (MMWR) estimates have increased from 1 in 150 children aged 8 years in the year 2000 to 1 in 44 children in the year 2018. To 2020 where the prevalence was 1 in 36 children aged 8 years and was 3.8 times as prevalent among boys as among girls (Maenner, 2023). In Germany, there is limited data on the prevalence percentages, the only available study to date, researching the prevalence of autism in Germany is estimated to be about 0.25% in 0- to 24-year-olds in 2009 (Bachmann et al., 2013). According to systematic reviews published earlier, the variations in prevalence estimates over time are not likely attributed to an actual increase in prevalence, but instead, these differences appear to be linked to changes and enhancements in diagnostic categories, research methodologies, and research quality. Factors contributing to these variations include improved access to diagnostic and intervention services, heightened awareness of autism within communities, and the acknowledgment that autism can coexist with other developmental disorders (Elsabbagh et al., 2012; Zeidan et al., 2022). The populations surveyed are usually children, however Zeidan et al reports of two studies specifically focused on the epidemiology of autism in adults, one of which reports a combined prevalence of autism to be around 1% (Brugha et al., 2016), while the other reports a significant increase in the prevalence rate among Medicaid adults with an autism diagnosis from 2.66 per 1000 in 2006, till 3.25 per 1000 in 2007, and reaching 3.66 per 1000 in 2008 over the 3-year study period, which mirrors the increasing prevalence trends observed among children over the past few years (Jariwala-Parikh et al., 2019)

2.1.4 Comorbidities and treatment

Autism manifests with a diverse array of accompanying comorbidities, encompassing physical features such as macrocephaly, or physical conditions such as gastrointestinal disorders which may involve gastroesophageal reflux (GERD), constipation, diarrhea, food allergies, colitis, ulcers, and inflammatory bowel disease (Buie et al., 2010), obesity and sleep issues, along with mental conditions including anxiety, epilepsy, depression, attention deficit hyperactivity disorder (ADHD) as well as difficulty sleeping and self-injury tendencies (World Health Organization, 2023). The symptoms of comorbidities in autism may be atypical and can often be difficult to recognize (Belardinelli et al., 2016). Communication challenges stand out as a significant factor contributing to these diagnostic complexities, since within autism, a substantial proportion, ranging from 25% to 50%, experience difficulties with verbal communication (Patten et al., 2013). Another study also reported that many individuals with autism are also incapable of pointing to the source of their discomfort, and usually find it difficult to attend to or detect bodily sensations (DuBois et al., 2016)

Around 40% to 60% of autistic children and adolescents have two or more co-occurring disorders, and as many as 24% of autistic children and adolescents have three or more co-occurring disorders (Simonoff et al., 2008). That percentage was much higher for adults with a study from 2014 in the USA reporting almost 73% - 81% of the autistic adults who they researched, meet criteria for at least one current co-occurring psychiatric disorder (Buck et al., 2014). According to a more recent meta-analysis, the most frequent autism associated psychiatric disorder in all ages are: ADHD, anxiety disorder, sleep-wake disturbances, disruptive behaviors, impulse-control, and conduct disorder, depressive disorder, obsessive-compulsive disorder (OCD), bipolar disorder and those disorders within the schizophrenia spectrum (M.-C. Lai et al., 2019).

Autistic individuals are at a higher risk of experiencing mental health issues compared to their neurotypical adult counterparts, as the autistic individuals often meet the criteria for at least one cooccurring psychiatric disorder (Rosen et al., 2018). These co-occurring psychiatric disorders have high clinical implications for individuals on the autism spectrum, since the presence of one or more disorders could potentially mask the expression of autism symptoms, confuse it with other chronic disorder and thus result in a delay in the diagnosis until a later age (Mazefsky et al., 2012). Furthermore, these co-occurring conditions could affect or in some cases worsen the autism symptoms, or result in an increase in the number of treatments one needs. Evidence from other studies also suggest that adults have higher rates of co-occurring physical health conditions including: hypertension, cardiovascular diseases, diabetes, pulmonary conditions, and obesity than the general population (Croen et al., 2015; Davignon et al., 2018; Hand et al., 2020). However, it is worthy to note, that poorer health is not always inevitable consequence of autism but instead could reflect important health inequities experienced by autistic individuals that exist internationally (Bishop-Fitzpatrick & Kind, 2017).

Most of the interventions focus on children since the signs and symptoms of autism usually manifest at the very young age of 2 to 3 years. Very few studies have investigated behavioral treatments in adults and more research is needed to show effects of treatment for this target group (Lord et al., 2018). Moreover, the profound heterogeneity of autism, usually makes it difficult to create a one fits all design of treatment plan. Recently, there has been a concerted effort to develop individualized treatment plans from primary care providers (Brice et al., 2021). These plans are crafted based on expert consensus, particularly for addressing various co-occurring conditions. Including various intervention strategies encompassing behavioral, developmental, and social approaches to alleviate symptoms and impairments caused by autism (Lord et al., 2018; NICE, 2021; Rosen et al., 2016). Examples include cognitive behavioral therapy (CBT) (Bemmer et al., 2021; Rosen et al., 2018) and pharmacological treatment to treat the co-occurring disorders with autism and not the autism itself (Joshi et al., 2010). Although research on their use is still limited, antipsychotics and selective serotonin reuptake inhibitors (SSRIs) are often prescribed for the treatment of co-occurring anxiety, aggression, irritability, and self-injury in autistic individuals (Buck et al., 2014; Mosner et al., 2019). In the realm of medical treatment, some factors appear to play a role in deciding on the care plan for the comorbidities; age, gender, and the existence of an ID. A recent study from Spain characterizing the physical and mental health profile of children, adolescents and adults with autism in Spain, found that psychiatric polypharmacy was significantly higher in autistic individuals with ID, as well as in the women and elderly subgroups (Vidriales-Fernández et al., 2023).

2.1.5 Autistic Adults

An essential part of growing older is independence, which from one perspective could include graduating from school, pursuing further education or getting some kind of job and from another perspective, could include moving out of the parental home, developing sustainable relationships and partnerships outside the family bubble, in order to have an autonomous everyday life. For autistic individuals transitioning into adulthood, all of these developmental tasks are either only achieved with delay or, more often, not achieved at all due to limitations in the areas of social skills, action planning and everyday practical skills. Therefore, a successful transition to care in adulthood is of central importance (Freitag et al., 2020). As autism is a lifelong condition, the demand for ongoing support remains constant during the transition from childhood to adulthood. This has been highlighted by publications stressing the importance of early planning, continuity of care and the need to consider developmental needs rather than simply defining an age cut-off healthcare transfer (NICE, 2016). However, most specialized services for autism have predominantly been centered on catering to autistic children or autistic adults who also have an intellectual disability (ID) with an IQ below 70, neglecting to adequately address the needs of autistic adults who do not have an ID (Postorino et al., 2016; Shattuck et al., 2012). A significant portion, ranging from half to two-thirds, of autistic adults fall into the latter category without an intellectual disability (Maenner, 2020).

Additionally, the intersection between autism and healthcare utilization unveils disparities in access to preventive care services, emergency room use, and overall satisfaction with healthcare experiences compared to their non-autistic counterparts (Nicolaidis et al., 2012; Nicolaidis & Raymaker, 2013). Understanding the healthcare needs of autistic adults is paramount for the development of effective, person-centered interventions (Mazurek et al., 2021). Similarly, the need for specialized comprehensive healthcare services becomes increasingly vital (Epping-Jordan et al., 2004), yet the journey through the healthcare system poses distinctive hurdles. Research indicates that healthcare utilization among autistic adults is marked by various barriers, spanning from the nature of autism to societal, systemic and professional factors (Bishop-Fitzpatrick & Kind, 2017). The following sections aim to shed light on the healthcare utilization and barriers faced by autistic adults in accessing appropriate healthcare services, providing an understanding the specific needs of this population and laying the foundation for discussions on potential solutions and improvements in healthcare delivery for this population.

2.2 Healthcare Utilization

Providing healthcare for autistic individuals is often complex (Ames et al., 2021), requiring dynamic organization among multiple healthcare providers within complementary disciplines to support social, behavioral, mental and physical vulnerabilities (Hand et al., 2021). Specific needs often include integration of medication management, consultation with subspecialists across physical and mental health disciplines, and coordination of services for frequently co-occurring mental health conditions (Underwood et al., 2023). Given the well-recognized constellation of co-occurring conditions among autistic individuals presented in the previous subchapter, it is critical that organizations and providers ensure accessible and responsive longitudinal healthcare experiences and that caregivers can anticipate the extent of care and care coordination that might be needed (Clarke et al., 2017).

Autism is connected with high healthcare utilization rates and frequency from very young ages, for example Cummings et al. (2016) reported that autistic children were more likely to have at least one pediatric visit, more overall visits to the pediatrician, specialty care visits, such as speech therapy, occupational or social skills therapy, physical therapy, psychotherapy, and neurology, within a 1-year period than neurotypical children. The study also reported that autistic children were more likely to be hospitalized, and have at least one ED visit, and be involved as an outpatient in hospital care (Cummings et al., 2016). Until now, there is no multi perspective systematic review evidence on overall healthcare access for autistic adults on the level of healthcare where barriers and facilitators are present. This being alarming given the levels of increased prevalence of comorbid health conditions and the incidence of preventable health problems experienced by autistic adults (Calleja et al., 2020). The recent systematic review by Gilmore et al. (2022) sheds light on the healthcare utilization patterns of autistic adults among five important healthcare services separately which included: primary care, preventive services, outpatient mental health, the emergency department and hospitalization rates and compared them to populations of neurotypical adults. All the studies considered employed cross-sectional designs. Data was predominantly collected at the state or national level, with a couple of studies collecting data via interview or survey. ED use was examined in 12 studies, hospitalization was examined in 8 studies, mental healthcare visits in 5 studies, preventive services in 3 studies, and primary care visits in 2 studies. In 11 studies health service use was compared between only an autism and neurotypical population comparison group, and in 3 studies, the autistic individual's group was compared with more than one comparison group (e.g. ADHD and general population). There was significant variability among studies regarding participant demographic characteristics. For instance, 10 studies did not provide the mean age of either autistic or neurotypical adults. Among those that did report the mean age of autistic adults, it ranged from 14 to 37 years. The proportion of males in the samples of autistic adults varied between 41% and 85%. Additionally, studies that disclosed geographic location indicated that autistic adults predominantly resided in urban areas rather than rural settings, this systematic review revealed mostly equal or higher use of certain services but also a concerning reliance on emergency department visits and high hospitalization rates. Which prompts the need for further research with a focus on identifying specific targets to enhance healthcare access for autistic adults and mitigate the frequent use of emergency departments and hospitalizations (Gilmore et al., 2022).

2.2.1 Healthcare utilization in the German general population

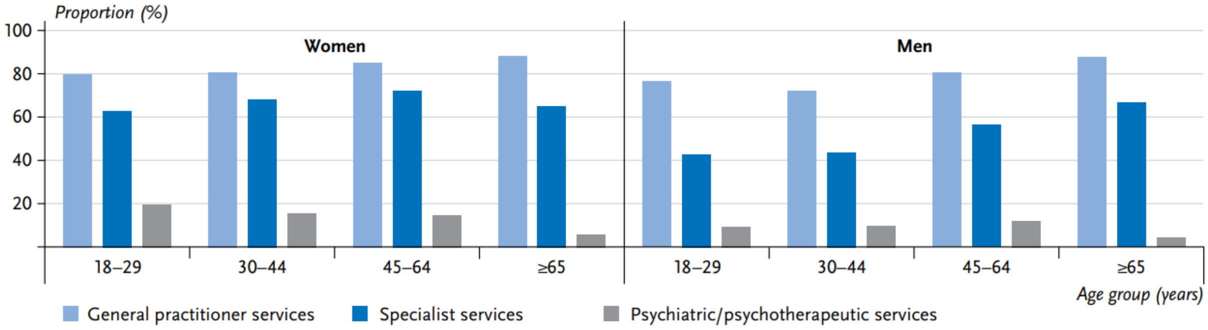
Outpatient health care plays a central role in identifying health problems and treating them worldwide. The largest area of services being outpatient medical care and psychotherapy (Prütz et al., 2021). In Germany, these healthcare services are mainly provided by clinic-based physicians and psychotherapists. These healthcare practitioners are usually the first point of entry to the German health care system, they assess the need for and provide treatment, carry out examinations, and, when necessary, arrange for the provision of further healthcare and social services (RKI, 2015). Around 90% of adults in Germany utilize outpatient medical or psychotherapeutic services each year (Prütz & Rommel, 2017). Healthcare also includes aspects of preventive care, which includes vaccinations, important medical checkups (e.g. blood pressure monitoring, cholesterol, blood sugar tests) and cancer screening. Another essential part of healthcare is medication intake (Prütz et al., 2021) and management (G-BA, 2020). The costs for such services are covered by the statutory health insurers, and the utilization of such services is voluntary (Busse et al., 2017; G-BA, 2020) .

Obtaining comprehensive information on the utilization and costs of all health services at an individual level in Germany poses challenges due to the complex nature of the health care system. With multiple payers, such as statutory health insurance covering physician visits and hospital stays, and separate financing for rehabilitation by statutory pension insurance. The use of outpatient health care provided in medical practices can be analyzed using data from official statistics, service providers, and statutory health insurance as well as from population-representative health surveys. However, since the invoicing modalities changed in Germany in

2008, accounting data can only be used to calculate the number of cases per quarter that were treated at a specific doctor’s practice, not the contact frequencies during a quarter. In addition, accounting data from health insurances often refer only to specific groups of insured people (Kurth et al., 2009; Schubert et al., 2008). In contrast, survey data enable to analyze the utilization of outpatient medical care from the patient’s perspective and to identify associations with social determinants and other influencing factors (Ohlmeier et al., 2014).

In GEDA 2019/2020-EHIS which is a study about the health and living conditions of people aged 15 years and older for the German Health Update, where between April 2019 and September 2020, 23,001 respondents answered various questions. The study used a questionnaire based on the third wave of the European Health Interview Survey (EHIS), which was carried out in all EU member states. Age, gender and education were taken into account as determinants of healthcare utilization. The analyses revealed a tendency towards differences by gender in the sense of higher utilization of health services by women as you can see in the Figure 1. The use of many services was also increased with increasing age, along with educational background differences being observed for some of the indicators.

Figure 1: *The difference in healthcare use of various health services among women and men.*



(Source: Robert Koch Institute, 2017)

Another German population representative study by (Grupp et al., 2016) where healthcare utilization was also stratified by age and gender over the period of 6 months reported similar results. Almost 95% of all respondents had at least one contact with an outpatient physician during the 6 months period. Important differences between men and women were found. Overall, women had higher utilization rates and mean outpatient physician visits for both general practitioners, specialists. The findings also reported that women had more mental health providers visits than men. However, an age and gender related pattern was also visible: For men, utilization of healthcare services and the mean number of contacts with outpatient physicians increased steadily with age. In women, a similar pattern regarding utilization rates and mean contacts with GPs was reported. However, utilization rates and mean contacts with specialists seemed to be highest among women aged 30–59. Utilization of and mean contacts with mental health providers seemed to decrease in both genders at the age of 70. The study also researched the costs for healthcare utilization and found similar patterns with costs being related to gender and age and the types of services.

The German healthcare system, distinguished by its dedication to universal coverage and comprehensive care, operates on the principle of solidarity, ensuring access to high-quality medical services for all residents. Universal coverage is a cornerstone, encompassing citizens, permanent, and temporary residents, with the principle of shared financing collectively shouldered by the population. Health insurance, primarily statutory health insurance (German title “Die gesetzliche Krankenversicherung”, acronym “GKV”) for the majority, is obligatory for those below a specific income threshold, with contributions shared between employers and employees. Private health insurance (German title “Private Krankenversicherung”, acronym “PKV”) provides an alternative for higher-income individuals, offering additional benefits and personalized coverage. The healthcare delivery system is decentralized and multi-tiered, involving general practitioners as primary caregivers and various hospitals providing diverse services. Patients have the freedom to choose their primary care physician and access specialists directly. Quality assurance and regulation, overseen by institutions like the Federal Joint Committee (German title “Der Gemeinsame Bundesausschuss”, acronym “G-BA” ,which is the highest decision-making body of the joint self-government of physicians, dentists, hospitals and health insurance funds in Germany, uphold high standards, emphasizing the collaborative nature of outpatient and inpatient care (G-BA, 2020; IQWiG, 2018; Obermann et al., 2013).

However, obtaining comprehensive information on the utilization and costs of all health services at an individual level in Germany poses challenges due to the complex nature of the health care system (OECD, 2019). With multiple payers, such as statutory health insurance (SHI) covering physician visits and hospital stays, and separate financing for rehabilitation by statutory pension insurance (OECD, 2023), data linkage is intricate. Claims data limitations, including a lack of detailed information and the exclusion of some services, further complicate a comprehensive assessment (Grupp et al., 2016). Consequently, referring to population surveys becomes essential (Grupp et al., 2016), despite the associated challenges of being time intensive, and potentially biased (Groves, 2006). And while survey data may result in imprecise cost estimates compared to claims data, it allows for direct collection of information aligned with research questions, facilitating integration with existing datasets. In this context, a population survey by Grupp et al, 2016 was conducted to provide gender and age specific reference values for medical and non-medical health care utilization, as well as direct and indirect costs, offering crucial insights for disease-specific excess cost calculations and healthcare utilization patterns from the adult population in Germany.

2.2.2 Healthcare utilization in autistic adults

Autistic adults often require a wide range of support services, ranging from the need for special diagnostic and therapeutic health services (Jobski et al., 2017) to needing special educational support (Bürki et al., 2021) , more social services (Fortuna et al., 2016) and supported employment (Vogeley et al., 2013). This extensive service use yields significant costs on both caregivers and society alike. Most of these papers stem from the USA or other countries. For Germany, there is only a cost-of-illness model for autistic individuals without an intellectual disability, which found that amongst inpatient services, mental healthcare was used most frequently, while dentists, general practitioners, and pediatricians were the most frequently consulted outpatient services in that respective order. Service use distinctly differed by sex, with females incurring higher costs than males (4864 EUR vs. 2936 EUR) (Höfer et al., 2022).

When reviewing the systemic review by (Gilmore et al., 2022) previously mentioned, one concludes that for the area of the emergency departments (ED) visits, most of the studies included category six of good evidence studies,(according to the LEGEND (Clark et al., 2009) critical appraisal tools used). No statistically significant difference was found in the ED use between autistic adults and general population comparison groups (Ames et al., 2021; Hand et al., 2019; Zerbo et al., 2019). As for hospital admissions, most of the studies reported, found that autistic adults had a greater odds of hospitalization or were equally hospitalized as often as the comparison groups (Ames et al., 2021; Nicolaidis et al., 2013; Zerbo et al., 2019). For outpatient care services, all studies that compared autistic adults' use of mental health services to that of the comparison groups were determined to be of good evidence, and consistently found that autistic adults had greater use of such services (Ames et al., 2021; Maddox et al., 2018; Zerbo et al., 2019). Lastly, for the primary care services, two studies reported that autistic adults had a significantly higher odds of use of primary care services when compared to comparison groups. As such, patterns of healthcare use of some services were less thoroughly characterized than others, although still managed to provide an overview of what the existing literature knows about autistic adults' use of several important services predominantly in the US healthcare system.

The existing literature so far presented has predominantly focused on specific services and has often been derived from studies conducted in the US and other countries. While these studies provide valuable insights, the gap in the research lies in the comprehensive understanding of the overall healthcare use of autistic adults in Germany. Despite the recent study by Höfer et al. (2022) shedding light on specific aspects of healthcare utilization, such as inpatient and outpatient services, there remains a shortage of information that holistically examines the overall healthcare use patterns of autistic adults in the German context. In order to address this gap, the first research question of the present thesis seeks to provide a comprehensive comparison of the total healthcare use between autistic and neurotypical adults in Germany.

2.3 Barriers to healthcare utilization for autistic adults

Transition refers to the purposeful, planned process that addresses the needs of young people in a holistic way as they move from a child-centered to an adult-oriented health care systems (Blum et al., 1993). In contrast, a transfer in healthcare is defined as the singular event when medical care of a young person is moved from children to adult services/ service provider. Autistic adults face several barriers to accessing physical and mental healthcare services (Doherty et al., 2022; Mason et al., 2019). And due to the complex nature of healthcare needs, the persisting comorbidities, limited access to well informed healthcare professionals (Ghanouni et al., 2021; McCormack et al., 2020; Nicolaidis et al., 2015) along with multiple sensory and auditory sensitivities, autistic individuals may experience challenges in higher rates compared with people who have other types of conditions when trying to access various healthcare services (Raymaker et al., 2017; Weiss et al., 2018).

We must understand that bad health is not an inherent outcome of autism; it rather highlights the significant health disparities which face autistic individuals on a global level (Bishop-Fitzpatrick & Kind, 2017). Autistic adults usually report having greater unmet healthcare requirements, lower satisfaction with their healthcare, and a greater number of barriers to healthcare than neurotypical adults (Nicolaidis et al., 2013). With older age, they often lose the structure of health services or family support, requiring them to learn how to independently self-manage their health (Kuo et al., 2018). They must find a primary care practitioner who will take them as a patient and help navigate the healthcare system, which poses many challenges in various aspects (Nicolaidis et al., 2015).

In recent history, efforts have been made in order to develop an understanding of autism-specific barriers, in 2015 Nicolaidis et al, felt the need to develop instruments that can evaluate and assess both autism specific and general barriers to healthcare, the team wanted to move on from national surveys which tended to focus on access barriers to healthcare for people with disabilities in general without including autism specific items and considering the specific challenged autism proposes. The team was successful and ended up with developing both a long form and a short form of the barriers to healthcare checklist.

Now turning our attention to practical application, the Short Form version serves as a valuable guide for use in clinical or research settings. The main themes presented in the questionnaire can be arranged into semantically related categories: (1) emotional, (2) executive function, (3) healthcare navigation, (4) provider attitudes, (5) patient-provider communication, (6) sensory, (7) socio-economic, (8) support, and lastly (9) waiting. Before delving into further details, let's take a closer look at the items included in the short form, as presented in Table 1.

Table 1: *Structure of the previously experienced barriers.*

Categories of healthcare access barriers	**Raymaker questionnaire short form items**
Emotional	1. Fear, anxiety, embarrassment, or frustration keeps me from getting primary care.
Executive function	2. I have trouble following up on care (e.g. going to pharmacy, taking prescribed drugs at the right time, or making a follow-up appointment). 3. I have difficulty understanding how to translate medical information into concrete steps that I can take to improve my health.
Healthcare navigation	4. I don’t understand the healthcare system. 5. It is too difficult to make appointments. 6. I have problems filling out paperwork.
Provider attitudes	7. My behaviors are misinterpreted by my provider or the staff. 8. My providers or the staff do not take my communications seriously. 9. I cannot find a healthcare provider who will accommodate my needs.

	10.My providers or the staff do not include me in discussions about my health.
Patient-provider communication	11. Communication with my healthcare provider or the staff is too difficult. 12. When I experience pain and/or other physical symptoms, I have difficulties identifying them and reporting them to my healthcare provider.
Sensory	13.Sensory discomforts (e.g. the lights, smells, or sounds) get in the way of my healthcare
Socioeconomic	14. Concerns about cost or insurance coverage keep me from getting primary care 15. I do not have a way to get to my doctor’s office
Support	16.I have inadequate social, family, or caregiver support
Waiting and Examination Room	17.I find it hard to handle the waiting room

It is well established that autistic individuals encounter numerous barriers when attempting to access appropriate healthcare. Recent research, echoing the findings of Nicolaides et al. 2015, categorizes these barriers into three main levels: personal barriers, professional barriers, and systemic barriers. At the personal level, challenges include sensory sensitivity, making it difficult for individuals to navigate new or stimulating healthcare settings, and communication difficulties that complicate symptom identification and engagement with healthcare providers. Barriers at the professional level often stem from a lack of provider knowledge and skills related to autism, hindering their ability to tailor care and understand the unique experiences and needs of autistic patients. In some cases, autistic individuals find themselves still cared for in child and adolescent psychiatry well into young adulthood. Some may remain untreated altogether (Freitag et al., 2020). Furthermore, seeking treatment from adult institutions can result in irritation and termination of treatment due to excessive demands from specialists (Freitag et al., 2020). Systematic barriers, finally, encompass a lack of continuity in care or collaboration among healthcare providers, time and resource constraints affecting the delivery of high-quality care, and financial or insurance issues that can impede access to necessary care and preventative services

(Calleja et al., 2020; David et al., 2022; Dückert et al., 2023; Mason et al., 2019; Raymaker et al., 2017; Walsh et al., 2020, 2023) The use of previously developed tools that help autistic individuals in self-reporting on barriers faced in healthcare settings, can aid relevant stakeholders in determining the most frequent or most severe barriers impacting care access within a certain organization or setting. This could allow prioritization and evaluation of intervention strategies which would likely address these specific barriers and ease proper access (Nicolaidis et al., 2016; Raymaker et al., 2017; Walsh et al., 2023).

In Summary, shifting our focus to recent years, progress has been in identifying the main barriers autistic adults are faced with as they try to navigate the adult healthcare system; knowledge that continues to be critical in informing the relevant stakeholders and shaping global public health policy actions. Nevertheless, much evidence is still needed to substantiate the effects these barriers might reflect healthcare access patterns. Additionally, more evidence is still needed to further address how social demographic predictors and clinical factors affect autistic adults help-seeking behavior and access to care and to what effect do these barriers hinder this access. This knowledge would play a key role in reducing disparities and shaping future strategies (Calleja et al., 2020; Malik-Soni et al., 2022; Walsh et al., 2020).

2.4 Aging on the autism spectrum

Aging is an unmodifiable risk factor for comorbidity that makes apparent the need for comprehensive health care targeting multiple conditions (Casanova et al., 2020). In contemporary times, extended life expectancy offers many individuals the opportunity for active engagement in society for numerous years beyond child-bearing and retirement. A fundamental requirement for this is that these additional years are enjoyed with good health and well-being. As individuals age, the likelihood of chronic illnesses and multimorbidity tends to rise. Elderly individuals experiencing multimorbidity, age-related cognitive decline, and significant physical limitations often require assistance with daily activities and face an increased risk of eventually requiring long-term care (McMaughan et al., 2020; RKI, 2012; Rudnicka et al., 2020). Thus, it is crucial to provide support and healthcare services for older adults grappling with health issues and declining physical function. The objective is to facilitate their ability to maintain independence for as long as possible and actively participate not only in basic everyday activities but rather participate in social activities that are enjoyable to them. The topic of healthy aging is of great importance to the German society considering the tremendous segment of the German population according to the latest population projection from 2022 by the Federal Statistical Office indicating that the proportion of elderly people (aged 65 and older) in the population is around 22% and will continue to rise (Federal Statistical Office, 2022). As part of its ongoing health surveillance efforts, the Robert Koch Institute systematically gathers comprehensive data on the health status of older individuals residing in their own homes, understanding the factors associated with healthy aging and tracking trends over time within Germany. Key indicators in this realm encompass various facets, including levels of physical and cognitive functioning, the prevalence and nature of chronic ailments, and markers of frailty (e.g., frequent falls, weight loss, decreased mobility). Additionally, factors such as health-related limitations in daily activities and levels of social engagement are taken into account. Furthermore, age-specific dimensions of healthcare quality are also examined, including patterns of medication use such as polypharmacy (Buttery et al., 2015; Fuchs et al., 2013; Holzhausen et al., 2011; RKI, 2015).

Unfortunately, recent research suggests that autistic adults consistently have poorer physical and mental health (Croen et al., 2015; Weiss et al., 2018), alongside an increased risk of premature mortality (Bishop-Fitzpatrick et al., 2018; Hirvikoski et al., 2016; Smith DaWalt et al., 2019), and greater annual healthcare expenditure than neurotypical adults overall and across nearly all specific areas of healthcare. These healthcare areas include outpatient care, primary care, emergency care, mental healthcare services, neurology, home healthcare, prescription drug claims, and skilled nursing assistance (Vohra et al., 2017; Weiss et al., 2018; Zerbo et al., 2019). Yet to our knowledge, the monitoring of the same indicators nor the planning for a healthy aging process specifically designed for autistic adults in Germany is nonexistent, thus portraying the depth of need of health research in that area.

In the context of this thesis, the presented literature was used as an orientation for the selection of predictors included in the analyses. The research objectives, hypotheses, as well as the research questions that are investigated in this thesis and the research methods are described in the following chapters.

3. Objectives and Research Questions

Based on the presented literature and theoretical background, this thesis deals with three research questions and objectives.

The first objective deals with the description of the overall healthcare service utilization of autistic adults in Germany and the comparison with the German general population. Certain healthcare services will be considered in the definition of overall healthcare utilization based on the previous literature: general practitioner (GP), mental healthcare services, dental healthcare services, ophthalmologist healthcare services and emergency department visits (ED), those services that are usually paid for/reimbursed by health insurance companies. To meet this objective, the following research question will be investigated:

> How is the overall use of defined healthcare services among an adult autistic sample compared to the general population in Germany?

- ➔ H0: The overall use of healthcare services among an adult autistic sample does not differ from the German general population.
- ➔ H1: The overall use of healthcare services among an adult autistic sample does differ from the German general population.

The second objective of this thesis deals with the inclusion of sociodemographic factors and clinical characteristics of autistic adults as predictors for healthcare utilization.

> Do sociodemographic or clinical variables explain variance in the contacts to healthcare services among autistic adults?

- ➔ H0: Sociodemographic (gender, age, education, income, relationship status, employment) or clinical variables (DSM-5, somatic comorbidities, mental comorbidities) do not explain variance regarding the contacts to healthcare services.
- ➔ H1: Sociodemographic (gender, age, education, income, relationship status, employment) or clinical variables (DSM-5, somatic comorbidities, mental comorbidities) do explain variance regarding the contacts to healthcare services.

The third objective of this thesis is to determine effects of previously experienced barriers to healthcare access by autistic adults on healthcare utilization. To answer this, the following research question will be answered:

> Do previously experienced barriers to healthcare access explain variance in overall healthcare utilization among autistic adults in Germany?

- ➔ H0: Previously experienced barriers to healthcare access do not explain the variance in global healthcare utilization among autistic adults in Germany.
- ➔ H1: Previously experienced barriers to healthcare access explain the variance in global healthcare utilization among autistic adults in Germany.

The methods that are used to meet these objectives are described in the following chapter.

4. Methods

In this chapter, a detailed description of the methods conducted in this thesis is provided. Firstly, the data collection procedure is explained in the context of the project BarrierfreeASD (German title “BarrierefreieASS”, acronym “BASS”) and a description of the questionnaire used for this thesis is provided in the Appendix I. The comparison data set is also presented with some of the main information needed from it for the analyses and the questionnaire will be attached in the Appendix I. The following sections of this thesis will describe the relevant variables that are included in the analyses and how they were operationalized and later on assessed. Then, the planned statistical analyses to answer the research questions are explained. The ethical considerations for the BASS study are presented. Finally, an important disclaimer, the handling and the recording of source data on CD/USB stick is not possible due to the scientific-in-confidence rating of such data by their owner, the UKE.

4.1 Project Design

The project BarrierfreeASD, from now on referred to as BASS focuses primarily on assessing the existing healthcare provisions for autistic adults without intellectual disability in the domains of diagnosis and therapy, and contributing to optimized healthcare for autistic adults in Germany by reducing existing barriers while building enabling factors. The Project started in 2020 and was carried out for three years at the Department of Medical Psychology at the University Medical Center Hamburg Eppendorf (UKE) (David et al., 2022). The study was conducted as a cooperation project between the Institute and Polyclinic for Medical Psychology at the University Hospital Hamburg-Eppendorf (UKE), the special outpatient clinic for autism and ADHD (UKE), the Institute for Health Economics and Health Services Research (UKE), the special outpatient clinic for autism in adults (Clinic and Polyclinic for Psychiatry and Psychotherapy, Cologne University Hospital). It was supported by the following cooperation partners: Prof. Dr. Dr. Kai Vogeley (Special Outpatient Autism in Adults), Autism Research Collaboration, Federal Association of Autism Germany eV, Autism Parents Association Hamburg eV, Hamburg Autism Institute, Aida Knabe psychotherapy practice, autSocial eV, Autism Institute Lübeck, and Autism Strategy Forum Bavaria.

The project had 3 main goals: First, current mental healthcare needs for autistic adults were assessed at three levels (individual, structural and professional) and from three perspectives (autistic adults, relatives and healthcare providers). Second, an improved healthcare structure and service concept for autistic adults was developed. Third, the newly proposed concept was evaluated again by the relevant stakeholders (autistic adults, family caregivers and healthcare providers) along with having conducted feasibility of implementation and cost-effectiveness analyses (David et al., 2022). This study had a three phased mixed-methods design in order to achieve each of the project's main goals. The key activities that took place in each phase of the project timeline are represented below in Figure 2.

The first phase consisted of 3 main parts with the aim of collecting information on current mental healthcare for autistic adults from the three perspectives mentioned before. Qualitative data was collected through interviews with autistic adults and through focus groups conducted with their family members, caregivers, and healthcare providers. The quantitative data was obtained through large-scale online surveys each specifically designed to fit the target group it was appointed for. Furthermore, service utilization and related costs were estimated. In the second phase, the development of a future healthcare model was derived based on data collected from phase one, and a literature search considering the heterogeneous and complex needs within the autism spectrum. The third phase consisted of performing the second round of data collection (both quantitative and qualitative). With the focus of assessing and putting into action the recommendations already devised for shaping a future healthcare model.

Finally, based on the results of the analysis, the developed recommendations and model for improving healthcare for autistic adults was reviewed and adjusted accordingly (Figure3). As of December 2023, the project was completed. As this care concept was developed, it is now awaiting to be tested in practice. In this regard, an application for a follow-up project was submitted to the Innovation Fund of the Federal Joint Committee (G-BA) in a two-stage selection process. The project received a positive first answer, now the second stage of the application is underway. Since this thesis is mainly interested in the perspectives of the autistic adults themselves, only their survey will be considered. More details on the data collection process, and other data sources used for this master thesis are explained in the following sections.

Figure 2: *BASS timeline highlights (own representation).*

(Continued)

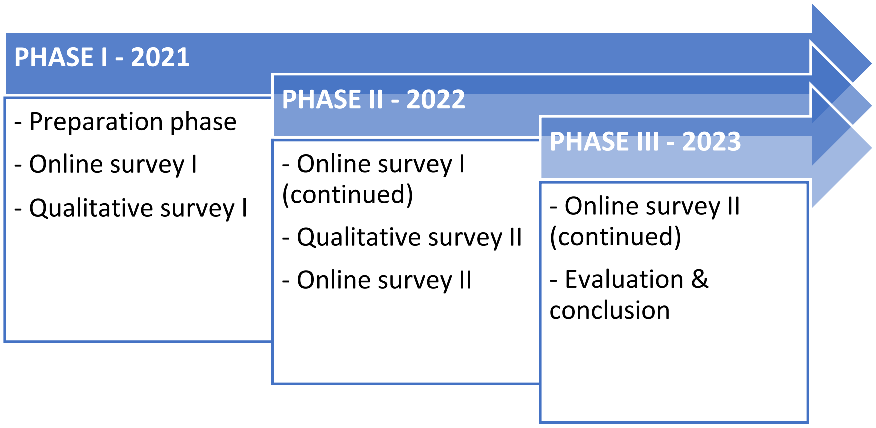
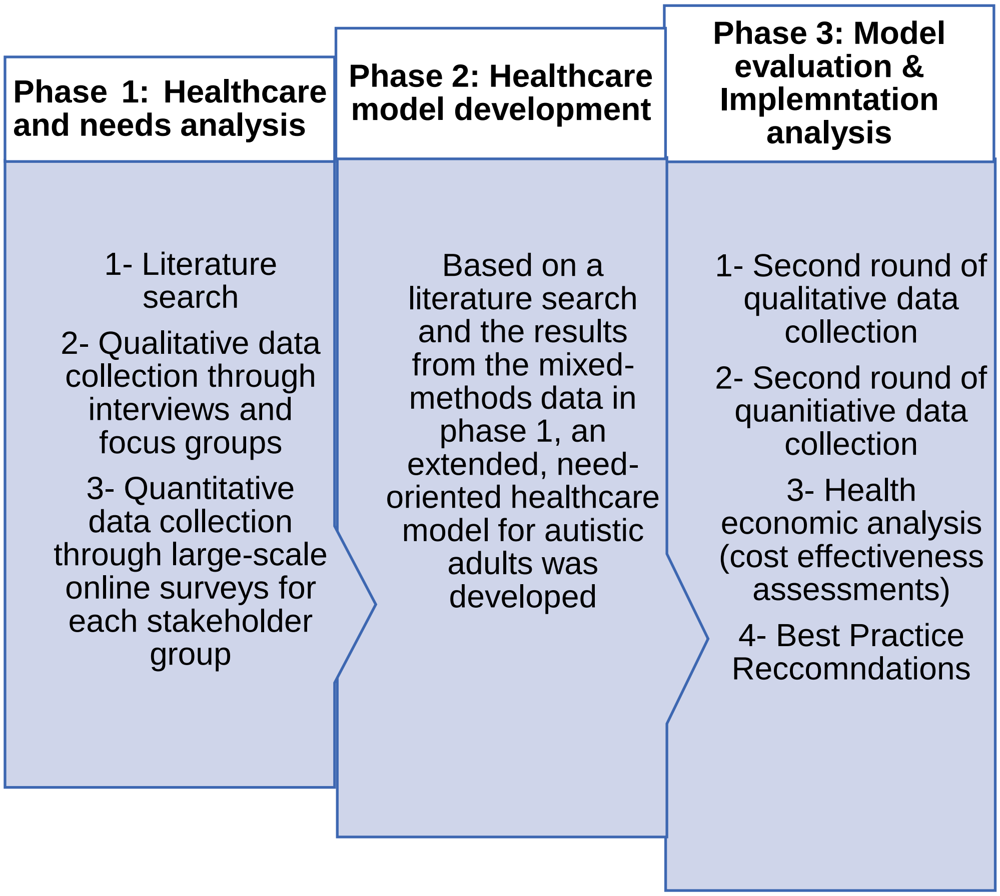


Figure 3: *Overview of the three phases of the BASS project (own representation)*



4.2 Data Collection

This master thesis involves a secondary analysis of data collected from the first online questionnaire for the BASS project. The first questionnaire was an online scale that was active from December 2021 to February 2022. The BASS project took place within a German wide mixed methods study conducted using a cross-sectional, voluntary, and anonymous 60-minute online survey in the German language. It was implemented in the online survey tool Lime Survey (Limesurvey GmbH, 2022). The target sample encompassed three points: autistic adults, family caregivers and all healthcare professionals in all relevant fields across Germany.

The questionnaire had three main parts (Table 2): the first one targeted previous experience of medical-therapeutic care and need assessment, which involved care indicators with questions about diagnosis health seeking behavior, and previously experienced healthcare barriers (e.g. type of autism diagnosis, age at the time of diagnosis, place of the diagnosis, autism severity (DSM-5), Raymaker barriers to healthcare questionnaire, etc.). Many of the questionnaire items were either a five-point Likert scale format ranging from highly agree to highly disagree or were a multiple-choice option with a list of options to choose from. Some of the questions had the extra option to be answered qualitatively within a text field. The second part inquired information about the individuals including sociodemographic, occupational and clinical questions (e.g. age, gender, health insurance type, familial status, somatic comorbidities, mental comorbidities, education level, employment status, information on healthcare use patterns and frequency, etc.). Followed by a component about general health and possible impairments, which was designed to capture respondents' own assessment of health and attitudes towards their own impairment status using EQ-5D and the SF8 tools as means to measure health-related quality of life. The relevant information from the questionnaire of BASS used in this thesis is attached in the Appendix I.

Participants met inclusion criteria if they were adults (18 years and older) with a confirmed diagnosis of an autism spectrum disorder: early childhood autism (according to ICD-10: F84.0), atypical autism (according to ICD-10: F84.1), Asperger syndrome (according to ICD-10: F84.5), or another autism diagnosis which participants were allowed to fill in freely in a text field. They also met the inclusion criteria if they were without cognitive/intellectual limitations (i.e. diagnosis of intelligence impairment) and without a diagnosed intelligence quotient (IQ) of less than 70. Relatives or partners (18 years and older) of autistic adults and professionals from relevant healthcare professions (general medicine, psychiatry, psychotherapy, pediatrics, social pedagogy, social work, occupational therapy, speech therapy, etc.) were included. Sufficient German language skills were required since the questionnaire was only available in that language. The survey was anonymous and could be canceled at any time without giving justification. The duration of completing the survey varied between 25 and 60 minutes. All respondents participated voluntarily, without any incentives offered by the study team/center.

4.2.1 BASS dataset

A structured awareness survey was circulated online between December 2021 to February 2022. Data collection was performed based on a cross-sectional design. The participating autistic adults out of the general population were selected through a purposive sampling approach by announcing the study on the official study website, in university clinics and other partner organizations. Informed consent was collected online prior to the participation during the beginning of the questionnaire. All participant's data was pseudonymized through the generation of a participant ID. Data entry was conducted by the study team using the electronic data capture tool REDCap, hosted on secured servers of the UKE. The database included branching logic to ensure correct data entry, as questions are partly conditioned for specific respondent groups.

The first online questionnaire reached overall 408 autistics adults across Germany. Observations were checked for plausibility. During the process of plausibility check and data cleaning, (N=97) participants withdrew earlier from the study by not completing the questionnaire, thus excluded from the analysis. (N=2) participants filled the questionnaire more than once which also resulted in excluding them. Moreover, (N=19) participants were excluded for filling one of the central questions for the analysis "Have you ever been to healthcare professional in the past 6 months" with a "yes", but in the questions that branch out from it, they chose none of the healthcare provider options that were listed for them to pick from in the questionnaire. The free text fields for this question were not used in the analysis to build new categories as they were too little in number of answers to build new corresponding categories and be involved in the analysis. The answers were reassigned to other pre-existing categories if they were fit. This left (N= 287) representatives of the BASS study data set for analysis. Most of the questions in the questionnaire were to be answered voluntarily and only few items required an obligatory answer, which led to having missing data, information on how this data was dealt with follows in the next sections.

Table 2: *Overview of the BASS questionnaire for autistic adults (own representation).*

BASS questionnaire	**Variables included**
Part 1: previous experience of medical-therapeutic care and need assessment	Autism diagnosis DSM 5 Barriers to healthcare
Part 2: sociodemographic and clinical information	Sociodemographic data Co-occurring health conditions Patterns of healthcare utilization
Part 3: general health and possible impairments	EQ-5D SF-8 WHODAS 2.0

4.2.2 General population data set

In order to compare the autistic adult's healthcare utilization rates with the German general population, data from the "Health care utilization and costs in the general population in Germany" study (henceforth called the German general population study) were used. The German general population study by Grupp et al, was conducted in 2016 by a group of researchers at the University Medical Center Hamburg Eppendorf. The study was conceptualized in order to develop reference values of both medical and non-medical healthcare utilization costs. The study also had the important aim to report healthcare costs in Germany from a societal perspective. This study included a total of (N=5007) telephone interviews conducted among German speaking individuals aged 18 years and older. All conducted interviews were based on the study questionnaire that was developed in cooperation with USUMA (Independent Service for Surveys, Methods and Analysis), which is a German market and social research institute, based in Berlin (USUMA, 2023). This study was funded by the German Federal Ministry of Education and Research (grant number 01EH1101B) (Grupp et al., 2016).

Participants were chosen through easy sampling method, in order to assure a random number of households was picked. This sampling method comprises registered and generated telephone numbers according to the area network system of the federal network agency. Numbers were drawn proportional to the regional structure of residents at the federal state level, stratified for the known city size classes of administrative districts and communities (ADM e.V., 2013). The data from this study was provided by Prof. Dr. Alexander Konnopka who is a head of working group at the center for psychosocial Medicine (UKE) and is a member of the BASS project team, via email.

During these interviews participants could provide their informed consent over the phone. Participants were inquired about their utilization of medical and non-medical healthcare services over the past 6 months. Additionally, they provided information on their sociodemographic information, employment status, lifestyle, medical history and co-occurring somatic and mental health conditions. The economic value of recourse utilization was assessed and data subjected to analysis using various statistical techniques including descriptive statistics and generalized linear models or two-part models (Grupp et al., 2016). Table 3 summarizes the key parts from the study questionnaire of the comparison group.

Table 3: *Overview of the study questionnaire for German general population (own representation).*

General population questionnaire	**Variables included**
Part 1: general health and possible impairments	EQ-5D
	Co-occurring health conditions
	Patterns of healthcare utilization
	Use of outpatient services
	Hospitalization and use of care services
	Impairment level (personal estimation)
	Wellbeing level (personal estimation)
Part 2: sociodemographic and clinical information	Sociodemographic data
	General lifestyle

4.3 Procedures, Variables and Instruments

Different analyses are conducted which include multiple variables in the context of this thesis. In this section, the relevant variables for the analyses and the way they were assessed is explained. This includes the description of instruments that were used and the explanation why certain variables were included. The assessment of the outcome, and the predictors included in the analyses will be explained.

4.3.1 Overall healthcare utilization assessment

To measure the main outcome, “overall healthcare utilization”, the contacts to different healthcare professionals were used. The contacts included the following main areas of healthcare services based on the healthcare services mostly used by autistic adults in the previously presented literature: general medicine, dentistry, ophthalmology, mental healthcare, and the use of emergency room services. First the number of visits for each person was recoded into a binary from of yes/no visit to each of the services. For the category GP, ‘yes’ answers to both house doctor and kids’ doctor were collapsed into one for the bigger category of GP, same was done for the category mental healthcare services as ‘yes’ answers to a visit to psychiatrists or psychologists for either private of group therapy sessions for both adults and kids, were also collapsed into the main category of mental healthcare. Then a total score of utilization was built and demonstrated in a scale range of zero to five with a minimum score: 0 = no visits to healthcare professionals, and a maximum score: 5 = maximum visits to healthcare professionals. This was done for both datasets (BASS and the Grupp et al, study) as this variable was not only needed for the comparison between both groups but also needed for the regression analyses later on.

4.3.2 Included predictors

In the BASS questionnaire, the variables age, gender, familial status, school leaving qualification and employment status are part of the section Sociodemographic Data. Age is assessed by asking for the age as a numerical input and gender by asking whether the participant identifies as male, female or diverse. For the statistical analyses the response category “diverse” is collided with the response category “male” because of the limited number of participants (n= 27) stated to have a gender different from male or female. For the regression analysis the variable was coded with the dummy coding 0= not female gender and 1= female gender.

Familial status is measured by categories of marital status in the questionnaire. These categories are “single”, “married (spouse, registered partner) or permanent partnership”, “married (living in separation)”, “divorced**”,** and “widowed”. For the regression analysis the variable was coded into a dummy variable with the reference 0=not in a relationship and 1=in a relationship.

Income is estimated by categories of net household income. These categories are “less than €500”, “from €500 till below €750”, “from €1,000 till below €1,250”, “from €1,250 till below €1,500”, “from €1,500 till below €2,000”, “from €2,000 till below €2,500”, “from €2,500 till below €3,000”, “from €3,000 till below €3,500”, “from €3,500 till below €4,000” and “€4,000 or more”. For the regression analysis the variable was coded into a dummy variable depending on the median split of the data with the reference 0=less than €2,000 and 1=more than €2,000.

The highest school qualification is evaluated by categories of highest school-leaving qualification. These categories are “Student”, “Without qualification”, “Promotional/special school leaving certificate”, “Elementary school certificate”, “Intermediate school leaving certificate”, “High school diploma” and “Other”. For the regression analysis the items were collided into a new variable which was coded into a dummy coding depending on the acquiring of a high school diploma or not (German name “Abitur”, which is the qualification needed in order to start university) with the reference 0=with no Abitur and 1= with Abitur.

Employment status is determined by categories of employment. These categories are “Full-time employed”, “Part-time employed”, “Marginally employed (450 €-; mini-; one-euro-job)”, “In vocational training/apprenticeship or retraining”, “Unemployed”, and “Not applicable”. For the regression analysis the variable was coded into a dummy variable with the reference 0=not employed and 1=employed.

Number of somatic comorbidities, number of mental comorbidities and the items of autism support are part of the section clinical factors data. The number of comorbidities were collected each by the following questions “Have you used any health care services or visited a doctor's office in the last 6 months for any of the following physical conditions?” for somatic comorbidities and “Have you used any health care services or visited a doctor's office for any of the following mental illnesses in the last 6 months?” for mental comorbidities, participants were allowed to pick from a list of conditions, multiple answers were possible. Table 4 summarizes the comorbidities listed in the questionnaire. The answers were on scale of 0-10, with (0 = no co-occurring health conditions, and 10 = maximum number of co-occurring health conditions). Among the answers for the mental comorbidities, were the options “None of the physical/mental illnesses mentioned” and “not applicable”, both of which were considered as an indication of no comorbidities present and were given the amount 0 and therefore not included in the sum calculation.

Table 4*: List of comorbidities included in the BASS questionnaire.*

Somatic Comorbidities	Mental Comorbidities
• Lung disease, e.g. asthma, chron. bronchitis • Joint disease, e.g. rheumatism, arthrosis, arthritis • Metabolic disorders, e.g. high cholesterol, thyroid disease • Diabetes • Chronic pain, e.g. headaches, back pain • Diseases of the digestive tract, e.g. stomach/intestinal ulcer, appendicitis, liver disease, gallbladder disease • Cancer • Cardiovascular diseases, e.g. heart attack, cardiac insufficiency, stroke, high blood pressure, arteriosclerosis • Osteoporosis • Epilepsy	• Addiction, e.g. due to alcohol, drugs or medication • Psychosis, e.g. schizophrenia, schizoaffective disorder, "drug psychosis" • Affective disorder, e.g. depression or bipolar disorder • Anxiety disorder, e.g. panic disorder, social phobia, generalized anxiety disorder • Obsessive compulsive disorder • Posttraumatic stress disorder • Somatoform disorder (e.g. also pain disorder) or psychosomatic body complaints • Eating disorder • ADHD (attention deficit hyperactivity disorder) • Personality disorder • None of the mental illnesses mentioned

To measure the degree of autism severity, a proxy, was developed by the BASS study team with two items analogous to the diagnostic and statistical manual of mental disorders' (DSM-5) (APA, 2013) definition of severity or required support for the two principal diagnostic criteria. Principle A: persistent deficits in social communication and social interaction, and Principle B: restricted, repetitive patterns of behavior, interests, or activities. Thus, was done because there was no standardized, validated self-report measure for autistic adults in the German language at the time of data collection for the study. This newly created proxy allowed quantification of subjective autism severity. Participants could answer the respective items on a 5-point Likert scale (1=none to 5=very). First item was “How much do you require support due to difficulties in interpersonal communication and social interactions?” and the second item being “How much do you require support because you are holding on to behavioral habits, routines, or interests that are important to you (e.g. difficulties in self-organization or dealing with change).” Later on, a mean score for both items was calculated in order to minimize the number of predictors included in the regression analyses.

To measure the perceived barriers to healthcare, the Access Barriers Checklist Short Form (Raymaker et al., 2017) was used, that is translated by Peth et al. in their ongoing research. The checklist was specifically developed for autistic individuals to assess barriers they often experience in clinical settings and showed both good content and construct validity in clinical setting use (Raymaker et al., 2017). The main themes covered in the questionnaire are related to different categories; emotional, executive function, healthcare navigation, provider attitudes, patient-provider communication, sensory, socio-economic, support, and lastly waiting (Table 3). The Short Form includes 17 items rated “yes” (=1) or “no” (=0), added up to a sum score of 17 (minimum score: 0 = no barriers experienced at all, maximum score: 17 = barriers experienced in every aspect).

Table 5 below presents an overview of all variables included as predictors, grouped by the appropriate clusters of what they measure, the original data level and the final data level after operationalization are shown. In order to keep a low number of predictors, certain categorical variables regarding gender, employment status, highest level of education, income and familial status were collapsed and coded as binary variables. For variables with the outcomes “yes”, “no” and “I don’t know”, the outcomes “no” and “I don’t know” are collapsed into one outcome. For the variables gender, employment, highest level of school education, familial status, ‘‘female’’, ‘‘employed’’, ‘‘with Abitur’’, ‘‘more than 2.000 euros per month’’ and ‘‘in a relationship’’ are the reference categories respectively. For the measure of the proxy item of autism support needed via the DSM5 items, a mean value is calculated and the mean item is used as the predictor. For the variables somatic and mental comorbidities, a sum of the number of comorbidities experienced by the person is calculated for each variable independently. Barriers to healthcare are also presented as a total score range from 0-17.

Table 5: *Overview of the Included predictors.*

Predictors	Variables	Original Data Level	Final Data Level
Dependent Variable	Overall use of healthcare	Nominal	Number of services used from 0-5
Sociodemographic Factors	Age	Metric	Age in numbers
	Gender	Nominal	Binary coding Female –1 Not Female –0
	Employment	Nominal	Binary coding Employed --1 Not Employed --0
	Highest level of education	Nominal	Binary coding: With Abitur---1 Without Abitur—0
	Income	Nominal	Binary coding (median split) More than 2.000 euros per month--1 Less than 2.000 euros per month-- 0
	Familial status	Nominal	Binary coding In a relationship --1 Not in a relationship –0
Clinical Factors	DSM 5 item 1 & 2 mean	Scale	Score from 1-5 for each item -> mean calculation
	Somatic comorbidities	Nominal	Number of comorbidities 0-10
	Clinical comorbidities	Nominal	Number of comorbidities 0-10
Perceived barriers to healthcare	Barriers to healthcare questionnaire	Scale	Score from 0-17

4.3.3 Statistical Analysis

In order to answer the three research questions of this thesis, different statistical analyses are used which are described in this chapter. All statistical analyses are conducted using the statistical software IBM Statistical Package for the Social Sciences (SPSS) version 27. An overview of the syntax of commands used for the analyses can be found in the Appendix II. A significance level of $p < 0.05$ was used for all analyses to detect statistically significant results. Before the statistical analyses were carried out, a power calculation was conducted with G*power 3.1.9.7, which is a free power analysis program for a variety of statistical tests (Faul et al., 2007). For a statistical power of 0.8 and a significance level of $\alpha = .05$, a coefficient of determination of $R^2 = .055$, with 10 predictors, a sample size of $N = 114$ would be required for a significant overall model. An initial data cleaning, extracting all incomplete and double answers from the dataset and checking for any systematically missing values, was performed and non-conformities were excluded from the analysis.

4.3.3.1 Descriptive analysis of BASS sample

At first, the sample of autistic adults is described by different sociodemographic variables which include age, gender, familial status, school education level, employment status and income. Relevant clinical variables are also reported which include a proxy item for autism severity level (DSM-5 items), number of comorbid somatic disorders, number of comorbid mental disorders and the number of perceived barriers to healthcare. All variables of interest will be first analyzed and described descriptively. Categorical variables will also be analyzed by calculating absolute frequencies and frequencies in percentages. For the metric variables, the mean (M), standard deviations (SD) and minimum - maximum values as a range are calculated. For further analyses, the metric variables will also be tested for normal distribution with the Kolmogorov-Smirnov and Shapiro Wilkens tests. In addition, their distribution in histograms are shown in Appendix III (Field, 2013).

4.3.3.2 Comparison between BASS sample and general population

To answer the first research question of this thesis, the overall healthcare utilization, measured with the total score of contacts to specific healthcare services, is described and compared to the general population in Germany. The specific healthcare services included in this analysis have been chosen based on the presented literature and the healthcare services included in both questionnaires, these items include: general practitioner (house doctor and kids' doctor), dentist, ophthalmologist, mental healthcare professionals (psychologist and psychiatrist) and lastly emergency room services. Data of the general population is taken from a study by Grupp et al. (2016). In the study, representative data of the German population, is based on a cross sectional survey commissioned by the University Medical Center Hamburg Eppendorf in cooperation with the German market research institute USUMA GmbH. The population for the data was represented by all people aged 18, and N = 5.007 participants were interviewed. Using data from the study by Grupp et al. (2016), the mean of the outcome variable calculated “overall healthcare utilization”, will be compared descriptively to the mean of the general population data. In order to be able to compare the data between the BASS sample and the general population sample properly together, a matching of the datasets was conducted. For the matching process, the technique case control matching was used, which is a useful technique to reduce selection bias when running certain statistical calculations and to ensure that the cases and controls are similar in certain characteristics and that any effect is not because of the different characteristics (Setia, 2016). The case control matching for this analysis was done on the basis of age and gender.

To test if there is a statistically significant difference between the overall healthcare utilization of autistic adults and the general population, an independent sample t-test will be calculated. The assumptions for the t-test will be checked first which includes that the samples are independent, the dependent variable is a nominal variable and normally distributed and that the variances are equal (Field, 2013). To check for normal distribution of the outcome variable, a Shapiro-Wilk, Kolmogorov-Smirnoff tests will be calculated for both samples. In addition, histograms and QQ-plots will be examined. In the case that the data is not normally distributed, a Mann-Whitney-U test will be conducted to compare the rank of the means of the different samples. To check for variance homogeneity, a Levene test will be calculated in SPSS. Depending on whether the variances are equal or unequal, a different formula is used to calculate the t-value (Ruxton, 2006). If the assumption of equal variances is fulfilled, the formula for an independent t-test with pooled variances is used.

4.3.3.3 Bivariate analysis

Bivariate analyses are going to be conducted to investigate the correlations between the predictors and therefore to check for one of the linear regression requirements, multicollinearity. To test correlation effects in every direction, two-tailed tests are carried out. The tests which are to be used for the bivariate analyses depend on the data level of the variables. For investigating the correlation between normally distributed metric variables, Pearson’s correlation coefficient (r) is adequate. If the Kolmogorov-Smirnov or the descriptive analysis shows that the metric variables are not normally distributed, Spearman’s rank correlation coefficient (rs) is used instead. Correlations between dichotomous nominal variables and metric variables are calculated with the point biserial correlation which is also done with the Pearson’s correlation coefficient (r)(Field, 2013). For the interpretation of the correlation coefficients, the guidance by Cohen (1988) is used as an orientation. According to Cohen, correlation coefficients between the values $r = 0.1$ and r =

0.3 can be interpreted as a weak correlation, correlations between the values r = 0.3 and r = 0.5 are moderate and correlations above r = 0.5 are to be interpreted as strong correlations (Cohen, 1988).

4.3.3.4 Multiple linear regression analysis

To answer the second and third research questions of this thesis which are to find out which predictors have an influence on the overall use of healthcare services among autistic adults and to see if the sociodemographic factors, clinical factors or barriers to healthcare access explain the variance of healthcare use, a multiple linear regression model will be calculated. The dependent variable (DV) of all models intended is the overall use of healthcare services. At first, the requirements for a linear regression are tested. This approach is aligned with the recommendations from the author and statistician Andy Field (Field, 2013). Consequently, the addition of multiple independent variables (IV) necessitates a sufficiently big sample size. A widely accepted rule of thumb suggests that a minimum of 10 data cases per predictor variable should be present in the model (Field, 2013).

Six key assumptions will be assessed to determine the appropriateness of this model prior to the calculation. First, the assumption of linearity to confirm that the relationships between the DV (overall use of healthcare services) and each IV are approximately linear. Independence of the residuals, and existence of outliers will be checked and dealt with. Homoscedasticity, will be assessed using residual plots. Additionally, the normal distribution of residuals will be examined through statistical tests and diagnostic plots (Field, 2013).

In the planned regression model, all previously defined predictors that are shown in Table 3 will be included in it. This is done to calculate how much variance can be explained. As a measure for the goodness of fit of the models, R2 and adjusted R2 are reported to estimate if the model can be generalized (Field, 2013). The effect size of the predictors on the outcome will be given by the unstandardized coefficient (B) and its standard error (SE), indicating the increase of the outcome by a one-unit change of the predictor. To compare influences of several predictors, the standardized coefficient (β) is reported. Significance is given by the p-values of the t-statistics. To consider multicollinearity, the correlations between the predictors in the bivariate analyses should be below r = 0.9. The variance inflation factor (VIF) and the tolerance statistic are analyzed. VIF values above VIF = 10 and tolerance values below r = 0.2 indicate a problematic multicollinearity (Field, 2013).

For interpreting the correlation coefficients, the classification by Cohen (1988) is used as orientation. According to Cohen, correlation coefficients between r = 0.1 and r = 0.3 can be interpreted as a weak correlation, correlations between r = 0.3 and r = 0.5 are moderate and correlations above r = 0.5 can be interpreted as strong correlations (Cohen, 1988)

4.3.3.4 Missing Value Analysis and Multiple Imputation in SPSS

For the predictors with missing values, multiple imputation (MI) was chosen in order to replace the missing cases. MI is a statistical technique for handling missing data, which has become increasingly popular due to its generality and developments. The main idea of MI relies in using the distribution of observed data to estimate a set of plausible values for those missing. Multiple data sets are created and then analyzed individually but identically to obtain a set of parameter estimates (White et al., 2011). According to White et al, (2011), that the number of imputations should be at least equal to the percentage of missing item values. Since the data we have has an amount of almost 9.9% missing data, 10 was the chosen number of imputations for running the MI. First the Little’s missing completely at random (MCAR) test was done to check if the data missing at random. Little's MCAR test: Chi-Square = 3.393, DF = 3, Sig. = .335, then multiple imputation was conducted. In Table 6, you can find an overview of the variables included in the MI analysis and get an overview of the missing data present in the BASS dataset.

Table 6 *: Overview of variables included in the MI analysis.*

Variables	**N**	**Missing**	
		Count	Percent
Alter	287	0	.0
numberofkom2	286	1	.3
numberofkom1	286	1	.3
Ray_Summe	287	0	.0
DSM5_mean	287	0	.0
Income_Median	262	25	8.7
total_use_HC_new	287	0	.0
job_binary	286	1	.3
sex_binary	287	0	.0
famstatus_binary	287	0	.0
school_binary	286	1	.3

4.4 Ethical Consideration

The mixed method study ‘’BarrierFreeASD’’ was approved by the Local Psychological Ethics Commission of the Center for Psychosocial Medicine at the University Medical Center Hamburg-Eppendorf (LPEK-0227). The findings of the study were disseminated via multiple scientific meetings and peer-reviewed journals. Over the course of the study, cooperating partners and associations were and continue to be informed about the study’s course and findings by regular newsletters, meetings and the study website (David et al., 2022). In the following chapter, the results of the described analyses are presented.

5. Results

The results of the analyses done for the purpose of this thesis are presented in this chapter. Firstly, the results of the descriptive analyses are provided for the BASS sample and for the general population matched sample. Secondly, the results of comparison are of the overall healthcare use of the German general population and the BASS sample. Lastly, the results of the multiple linear regression analyses are presented. Attached in the appendix III & IV, the supplementary output from SPSS for the analyses is provided in addition to the tables and graphs presented in the text.

5.1 Sample description

The sample of autistic adults is described by using different sociodemographic variables and the distribution of the relevant variables is given, a sample description of the general population is also provided.

5.1.1 BASS sample description

The sample includes a total of N = 287 autistic adults. Participants who did not meet all inclusion criteria were excluded from the analysis. The participants are on average 38.34 years old (SD = 11.337) ranging between 18 to 65 years. Half of the participants were female (54.7 %). Most of the participants stated having Aspergers syndrome (85.4%) and that they were on average 32.00 years old (SD=13.02) when they received their autism diagnosis. Two thirds of the participants revealed being single (65.2 %). As for the level of education, 69.0 % of the respondents disclosed having a university entrance qualification (with Abitur) and (54.8%) reported being employed which included either a full-time, part-time, or marginal employment as well as those in vocational training or concluding an apprenticeship. Since the study was a nationwide study, there were varying numbers of participants depending on the region, as shown in Figure 4. An almost equal number of participants were recruited from Northern, Southern, and Western Germany.

The detailed information about the sociodemographic data before multiple imputations and pooling process of the sample is presented in Table 7.

Figure 4 : *Distribution of participants by regions in Germany.*

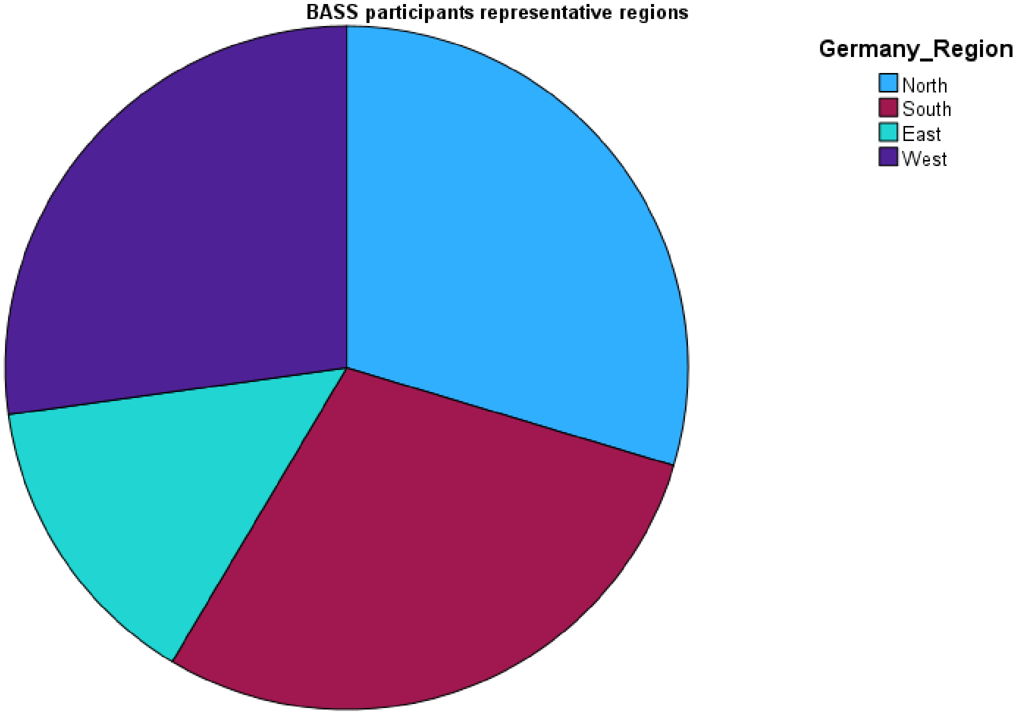


Table 7: *Sample description of autistic adults (N = 287).*

	N	N % / M (SD)
Age	287	38.34 (11.33)
Gender	287	
-Male		104(36.2)
-Female		157 (54.7)
-Diverse		26(9.1)
Type of ASS diagnosis	287	
-Early childhood autism		12(4.2)
-Atypical Autism		19(6.6)
-Asperger Syndrome		245(85.4)
-Other		11(3.8)

Familial status	287	
-Single		187(65.2)
-Married / stable partnership		69 (24.0)
-Married (separated)		8 (2.8)
-Divorced		22 (7.7)
-Widowed		1 (0.3)
Highest school degree	287	
-Student		9(3.1)
-Without qualification		2(0.7)
-Promotional/special school leaving certificate		2(0.7)
- Elementary school certificate		13(4.5)
-Intermediate school leaving certificate		62(21.6)
-High school diploma		198(69.0)
-Other		1(0.3)
Monthly Net income of the household*	262	
- until under 500 €		35(12.2)
- from 500 to under 750 €		21(7.3)
- from 750 to under 1.000 €		39(13.6)
- from 1.000 to under 1.250 €		20(7.0)
- from 1.250 to under 1.500 €		17(5.9)
- from 1.500 to under 2.000 €		28(9.8)
- from 2.000 to under 2.500 €		33(11.5)
- from 2.500 to under 3.000 €		20(7.0)
- from 3.000 to under 3.500 €		11(3.8)
- from 3.500 to under 4.000 €		10(3.5)
- 4,000 € and more		28(9.8)
-Missing		25(8.7)
Employment status*	287	
- Full-time employed		63(22.0)
- Part-time employed		55(19.2)
- Marginally employed (450 €-; mini-; one-euro-job)		23(8.0)
- In vocational training/apprenticeship or retraining		16(5.6)
- Unemployed		121(42.2)
- Not applicable		24(8.4)
Use of outpatient healthcare services in the past 6 months	287	
- Yes		261(90.9)
- No		26(9.1)

Note: n = number of participants; M = mean; SD = standard deviation; * In some variables multiple answers were permitted that's why the N is not consistent among all categories.

Table 8 presents the categorical variables after the multiple imputation procedure with the collapsed binary answers version that was further used for the various analyses of this thesis.

Table 8: *Descriptive statistics of the categorical variables from after multiple imputations.*

	N	**N% / M (SD)**
Age	287	38.37(11.33)
Gender	287	
-Female		157(54.7%)
-Not female		130(45.3%)
Familial status	287	
-Single		187(65.2%)
-In a Relationship		100(34.8%)
University entrance qualification (Abitur)	287	
-With qualification		198(68.9%)
-Without qualification		89(31.0%)
Monthly Net income of the household	287	
-Until under 2000 €		175(60.9%)
-From 2000 €		112(39.0%)
Employment status	287	
-Employed (full, part-time, marginal, internship/apprenticeship)		154(53.6%)
-Not employed		133(46.3%)

N = number of participants; M = mean; SD = standard deviation.

Table 9, shows the descriptive results for the outcome variable, overall use of healthcare, and the metric predictors age, subjective autism severity, number of experienced barriers to healthcare, the number of somatic and mental comorbidities. The participants on average had (m= 1.13) somatic comorbidities, (m= 1.51) mental comorbidities, and they visited at least (n= 2) healthcare providers from different fields in the past 6 months. In addition, the variables were tested for normal distribution with the Kolmogorov-Smirnov and Shapiro Wilkens tests. Based on the results of the tests and the examining of the QQ plots, none of our variables are normally distributed since the both tests shows significant results. Therefore, the H0-hypothesis cannot be accepted that the data is normally distributed (Field, 2013). For the other variables, age (D(286) = 0.071; p = 0.001), the perceived barriers sum score (D(286) = 0.079; p < 0.001), the number of somatic comorbidities (D(286) = 0.242; p < 0.001), the number of mental comorbidities (D(286) = 0.203;

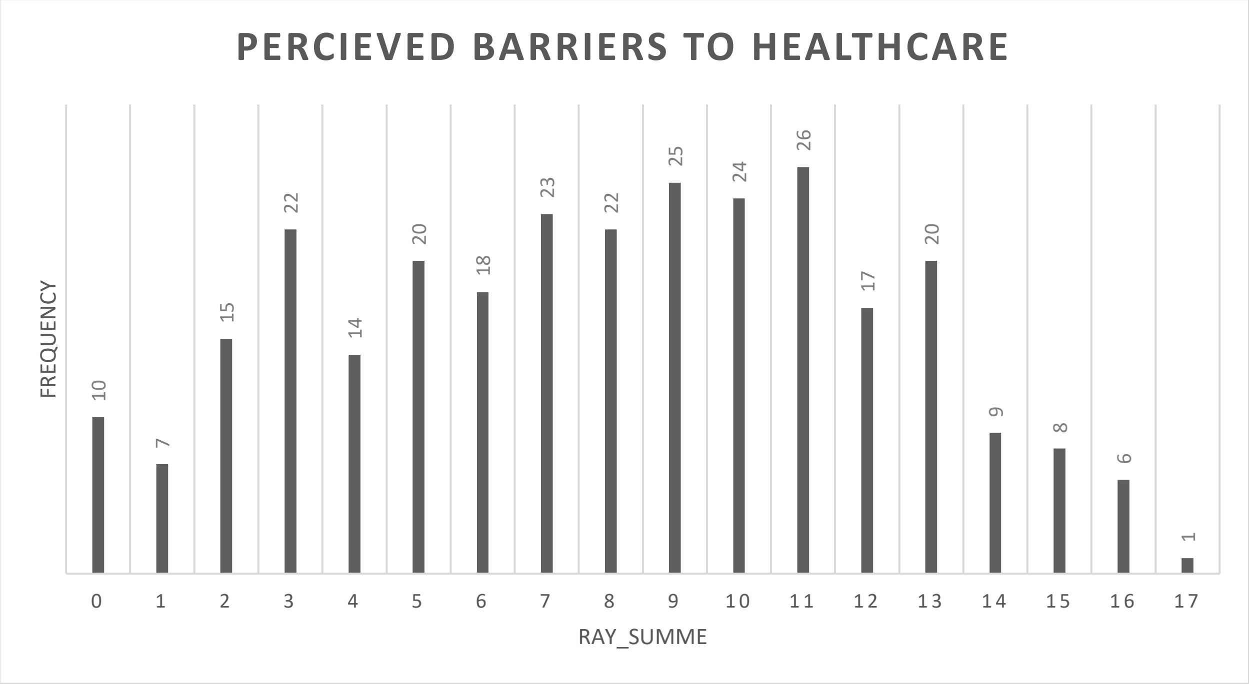
$p < 0.01$) and the overall use of healthcare ($D(286) = 0.177$; $p < 0.001$). The distribution of the variables in graphs indicates the same results. The histograms for the metric variables are presented in appendix VI.

Table 9*: Descriptive statistics for metric variables.*

Variable	N	M	SD	Min-Max
Age	287	38.37	11.33	18-65
Age at time of diagnosis	287	32.00	13.02	4-62
Barriers to healthcare	287	7.93	4.13	0-17
Number of somatic comorbidities	287	1.13	1.32	0-6
Number of mental comorbidities	287	1.51	1.50	0-7
DSM 5 items mean	287	3.41	0.96	1-5
Overall use of healthcare	287	2.24	1.21	0-5

N = number of participants; M = mean; SD = standard deviation; Min = Minimum; Max = Maximum

Figure 5: *Perceived barriers to healthcare in the BASS population.*



While studying Figure 5, we can see that the majority of the autistic population reports facing multiple barriers, they generally report facing 8 barriers, no conclusions from the figure can be drawn as to which of the 9 categories of barriers this population mostly faces. Only 10 participants reported that the list of perceived barriers inquired about in the healthcare system did not apply to their experience.

5.1.2 The German general population sample description

In the general population study by Grupp et al, a total of 5005 persons were interviewed, 2417 of whom were men and 2588 women in Germany. The participants ages ranged from 18-65, the mean age was 51 years and was higher in women 52 years (SD=19) than in men 49 years (SD=18). In their sample, women tended to have a lower degree of education along with a lower degree of qualifications and that they worked part-time more often. After matching the data based on age and gender, 288 cases were left and those were used for the statistical tests. First, the sample characteristics of the matched population are presented then the results of the comparison of are provided. The average age of participants was 38.37 ± 11.33 years. In most cases, the mean number of somatic or mental comorbidities for the matched sample of the general population was (m=0.64) and (m=0.12) respectively, and the mean number of their overall healthcare service use was (m=0.39).

Table 10*: Descriptive statistics of the matched German general population sample.*

	N	**N % / M (SD)**
Age	288	38.37(11.33)
Gender	288	
-Not Female		130(45.1%)
-Female		158(54.9%)
Familial status	288	
-Single		153(53.1%)
-In a Relationship		135(46.9%)
University entrance qualification (Abitur)	288	
-With qualification		171(59.4%)
-Without qualification		117(40.6%)
Monthly Net income of the household*	288	
-Until under 2000 €		89(30.9%)
-From 2000 €		156(54.2%)
-Missing		43(14.9%)

Employment status	288	
-Employed (full, part-time, marginal, internship/apprenticeship)		219(76.0%)
-Not employed		67(23.3%)
-Missing		2(0.7%)

In Table 10, the descriptive results are shown for the outcome variable, overall use of healthcare, and the metric predictors age and the number of somatic and mental comorbidities. On average, the mean number of somatic or mental comorbidities for the matched population was (m=0.64) and (m=0.12), respectively. And the mean number of overall healthcare service use was (m=0.39). Table 11 depicts the descriptive statistics for the metric variables included in the analysis. For the creation of the variable number of somatic, mental comorbidities, and to ensure a fair comparison between both groups, a new variable was built including only the co-occurring conditions mentioned in both questionnaires. This process resulted in the exclusion of the following comorbidities from the analysis: personality disorder, ADHD, obsessive-compulsive disorder, epilepsy.

Table 11: *Descriptive statistics for metric variables of matched population.*

Variable	N	M	SD	Min-Max
Age	287	31.33	11.33	18-65
Number of somatic comorbidities	284	0.64	0.84	0-5
Number of mental comorbidities	284	0.12	0.53	0-5
Overall use of healthcare	287	0.39	0.54	0-4

N = number of participants; M = mean; SD = standard deviation; Min = Minimum; Max = Maximum

5.2 Comparison between BASS and General population sample

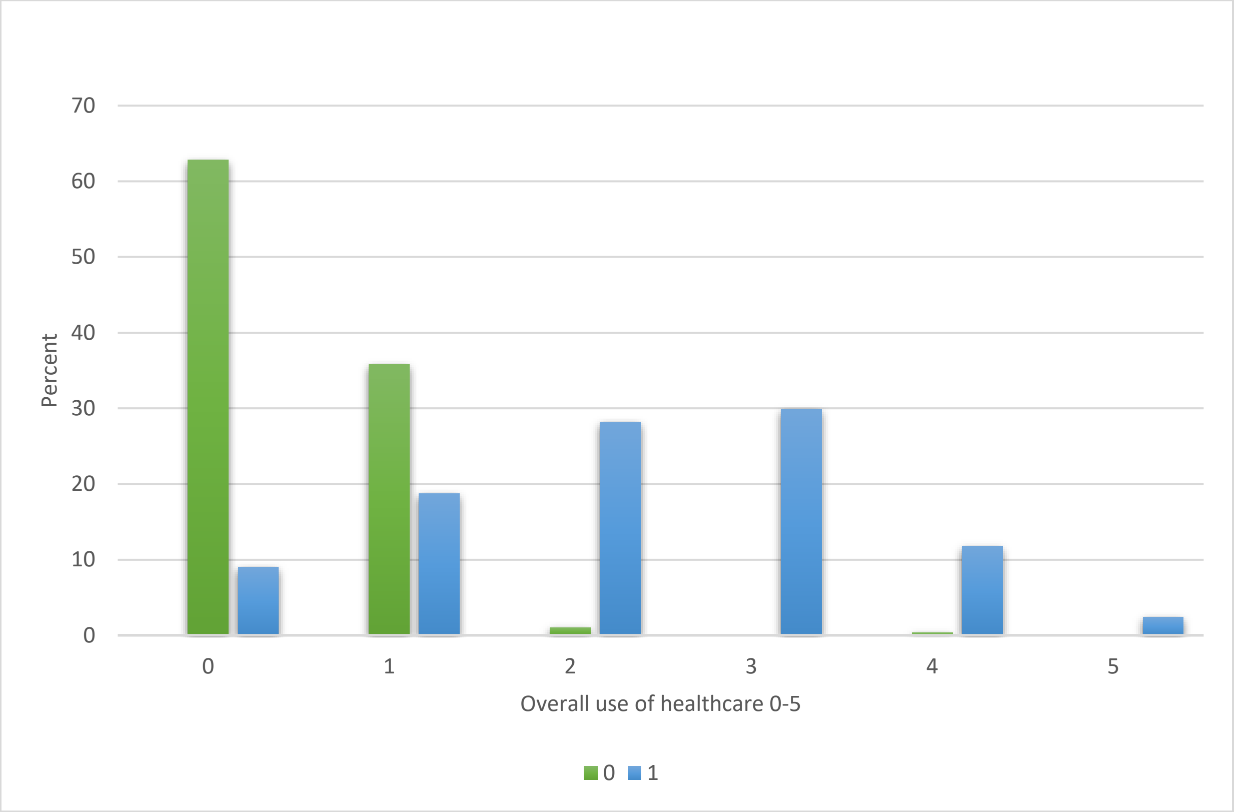
To test if the found difference is statistically significant, an independent sample t-test was planned. First, the assumption was checked if the outcome variable ‘overall healthcare service use’ is normally distributed. The Kolmogorov-Smirnov test for normal distribution showed difference in the overall use of healthcare for the autistic adults between both groups, Kolmogorov-Smirnov *p*<.05. Therefore, the H0-hypothesis was rejected that the variable is normally distributed (Field, 2013). In addition, the graphical assessment of the QQ-plot and the histogram further indicated a non-normal distribution (Appendix V). So, instead, a Mann-Whitney-U test was conducted in order to compare the data, since it does not assume specific distributions for the data. Although it is considered to have less power than the t-test, it still represents a valuable tool for skewed distributions analysis. A significant result means that the two groups differ from each other in a statistically significant manner and that the mean ranks of the variable differ from each other for the two groups, the values of mean ranks and sum of ranks can be found in Table 12 (Divine et al., 2018). The Mann-Whitney-U test was calculated to determine if there were differences in the overall use of healthcare between autistic adults and the general population sample. There was a statistically significant difference in the overall use of healthcare between both groups, $U = 8437.500$, $Z = -17.184$, $p < .001$.

Table 12: *Overview of sum of rank differences between both groups.*

	Grouping variable	**N**	**Mean Rank**	**Sum of Ranks**
Overall use of healthcare score from 0-5	0 (general population)	288	173.80	50053.50
	1 (BASS)	288	403.20	116122.50
	Total	576		

Descriptively, according to Figure 6, it is clear that there is a difference between both samples, from the use patterns of both populations. From the illustrated utilization, we can notice the difference between the two samples, with almost more than 60% of the general populations sample having had zero visits to healthcare professionals during the past 6 months. The rest of the sample ~35% having visited at least one healthcare provider in the past 6 months. On the contrary to the autistic adults' population, which show a consistency in consulting with healthcare providers except for almost 9%. This group reported having had no outpatient service use during the past 6 months.

Figure 6 *: Overall use of healthcare of General population sample & BASS sample populations in 5 selected healthcare services during the past 6 months.*



0 = general population sample, 1 = BASS population sample

By taking a closer look at those use patterns that are presented in Figures 7 and 8, and conducting a descriptive frequency analysis on the visit types in both samples have reflected the emergence of striking differences. Notably, within the general population sample, the predominant contacts within the preceding six months were with their general practitioner or dental healthcare specialist. Conversely, the BASS sample exhibited nearly equivalent interactions with their general practitioner and mental healthcare specialist, relegating the dental healthcare specialist to a third-place position. Remarkably, another difference that we can see from both figures is that the general population sample reported no use of mental healthcare services during the past 6 months at all.

Figure 7: *Display multiple choice frequently used healthcare services in general population (own visualization)*

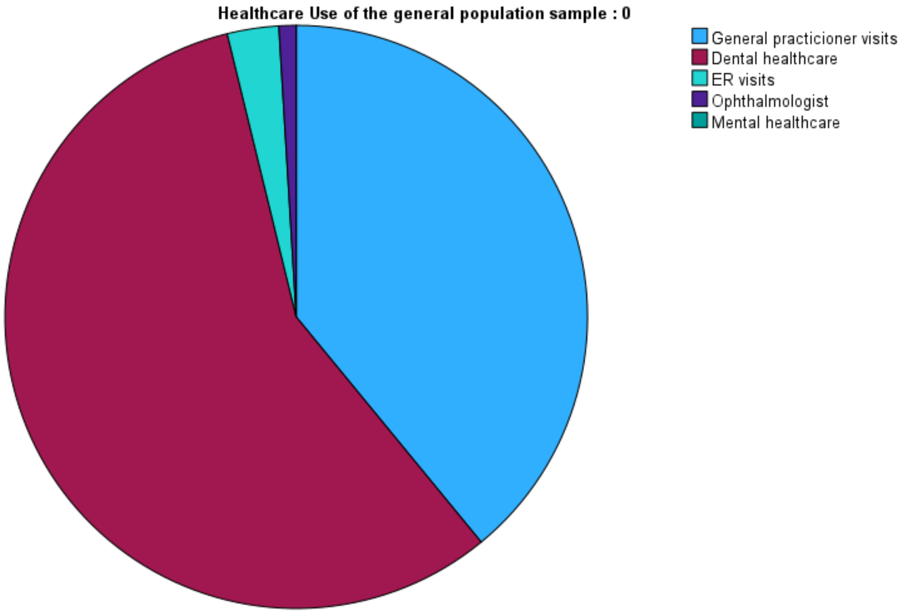
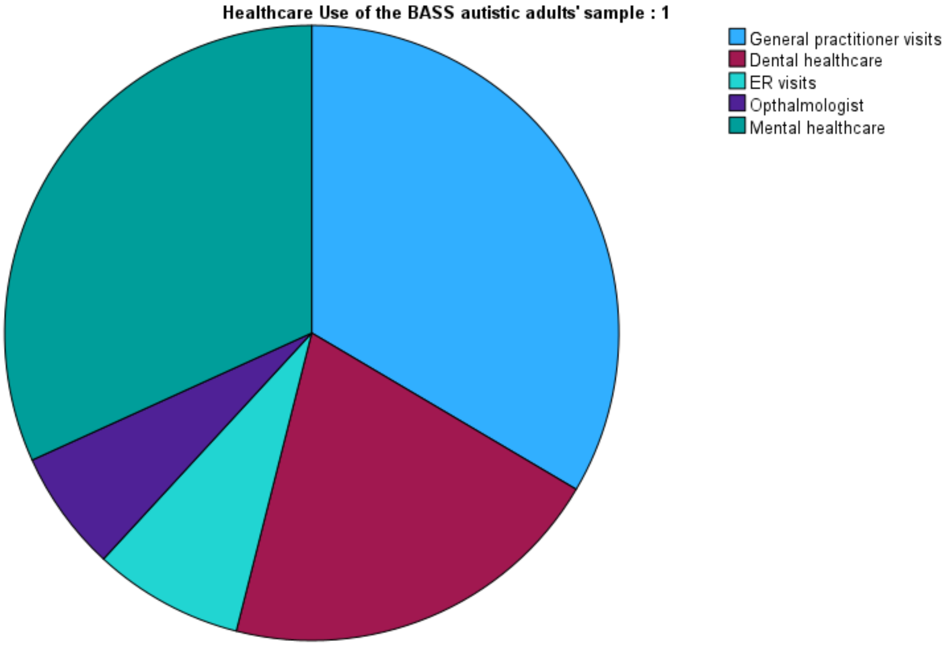


Figure 8: *Display multiple choice frequently used healthcare services in BASS population (own visualization)*



Therefore, the first research question of this thesis can be answered by these results that the utilization does indeed differ among both populations and the healthcare utilization of autistic adults is statistically higher compared to the general population in Germany.

5.3 Bivariate analysis

The results of the bivariate analyses show the correlations between the predictors and are presented in the correlation matrix in Tables 13 & 14. Some significant correlations between the predictors were found in the bivariate analyses. A moderate correlation was found between the degree of autism severity DSM5 and the barrier sum score age ($r = 0.275$, $p < 0.01$). Furthermore, gender correlated with the relationship status (rs = -.151, p = 0.05) and the number of somatic comorbidities (rs = .144, p = 0.05). Relationship status also correlated with income (rs = -.313, $p < 0.01$) and with the number of somatic comorbidities (rs = -.159 $p < 0.01$). Both coefficients can be interpreted as a medium and weak negative correlation respectively (Cohen, 1988). The employment status significantly correlated with education level (rs = .126, p = 0.05) and the income level (rs = .247 $p < 0.01$). It also correlated with the number of somatic comorbidities (rs = -.129, p = 0.05) and the number of mental comorbidities (rs = -.171, p = 0.01). Income correlated with mental comorbidities (rs = -.146, p = 0.05). These correlations can be interpreted as negative, weak correlations (Cohen, 1988) . Number of Somatic and mental comorbidities correlated with each other (rs = .327, p = 0.01). All statistically significant correlations can be interpreted as weak to moderate correlations. Therefore, no high correlations were found between the predictors and no multicollinearity between the predictors can be assumed (Field, 2013).

Table 13: *Correlation between metric variables.*

		Ray_Summe
DSM5 item 1 and 2 mean	Pearson Correlation	.275**
	Sig. (2-tailed)	<.001
	N	287
Age	Pearson Correlation	.072
	Sig. (2-tailed)	.223
	N	287

**. Correlation is significant at the 0.01 level (2-tailed).

Table 14: *Correlation matrix of the ordinal variables.*

Variables	**1.**	**2.**	**3.**	**4.**	**5.**	**6.**
1. Gender	**-**					
2. Relationship status	-.151*					
3. Education	.091	-.039				
4. Employment status	.000	.022	.126*			
5. Income	-.004	-.313**	.075	.247**		
6. Somatic comorbidities	.144*	-.159**	.037	-.129*	-.014	
7. Mental comorbidities	-.008	-.006	.038	-.171**	-.146*	.327**

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

5.4 Regression analysis

In this section, the results of the multiple linear regression analyses are presented. First the assumptions of the regression analysis are checked and then the results of analyses are provided.

As with most statistical analyses, multiple linear regression necessitates certain requirements to be met so that we can interpret the results. The six requirements which were tested are presented in Table 15.

Table 15: *Requirements testing of the multiple linear regression model.*

Requirements	**Fulfillment**
Linearity of the relationships	Yes
No outliers	Yes
Independence of the residuals	Yes
No multicollinearity	Yes
Homoscedasticity	Yes
Normal distribution of residuals	Yes

Outliers measurements were evaluated using Leverage values (LEV), the highest LEV in the current data sample was (lev= 0.13927) which according to Huber (1981) is below the recommended cut-off value of 0.2. Cook distance was also examined, and the highest value of 0.04569 which is far away from the cut-off criterion of 1 thus, confirming the no outliers assumption (Huber, 1981). In order to check the independence of the residuals, the Durbin-Watson statistic in the Model Summary was used. The Durbin-Watson statistic had a range of 0.43 – 0.39, indicating that there was no autocorrelation in the residuals. Multicollinearity was checked in two different ways: firstly, using the bivariate analysis of correlations between variables themselves (refer to the section before for further detailed information). Secondly by using the tolerance / VIF (variance influence factor) value. For the correlations, no Pearson correlation values were greater than 0.7, and no tolerance values below 0.1 or VIF value was greater than 10. Normal distribution was checked visually through the histogram and PP plot.

Four independent regression models were calculated, to check each of the different hypotheses independently, in this respective order: sociodemographic factors, clinical factors, barriers to healthcare. Overall healthcare services use was the dependent variable. Lastly the final regression model was calculated with all of these different predictors combined together. Independent variables were all entered simultaneously in the regression model. Table 16 portrays the results of each of the models before the MI process.

Table 16: *Results of regression models of original data predicting the use of overall healthcare use.*

Regression model	R square	Adjusted R square	P
1: Sociodemographic variables only	0.035	0.012	0.157
2: Clinical factors only	0.14	0.131	< 0.001
3: Barriers to healthcare only	0.009	0.005	0.118
4: All factors combined	0.204	0.172	< 0.001

The results of the regression model including the clinical factors only are shown the Table 17. Since there was no missing data in the included variables of this regression model, all 10 imputations showed the same results. The results of the ANOVA show a significant model (F (10) = 6.805, p < 0.001). The $R^2 = 0.140$ (adjusted $R^2 = 0.131$), which means that this model can be interpreted as such; using the adjusted R^2, that around 14% of the variation in overall healthcare utilization is explained by the predictors in this model. This is indicative of a medium/moderate goodness-of-fit according to Cohen (1988). The clinical predictors, proxy item for autism severity, number of somatic and number mental comorbidities statistically significantly predict the criterion overall use of healthcare services, $F(3, 282) = 15.35$, $p < .001$.

Table 17: *Results of clinical factors multiple linear regression model.*

	Unstandardized Coefficients		Standardized Coefficients			95% confidence interval for B	
Model	**B**	**SE**	**Beta***	**t**	**Sig**	**Lower bound**	**Higher bound**
Constant	1.390	.251	-	5.537	<.001	.896	1.884
DSM 5 mean	.111	.071	.263	1.555	.120	.135	.344
Number of somatic comorbidities	.240	.053	.167	4.518	**<.001**	.040	.235
Number of mental comorbidities	.138	.049	.089	2.788	**.005**	-.030	.252

The results of the regression model including all predictors combined after MI process are shown the Table 18. The results of the ANOVA show a significant model (F (10) = 6.805, p < 0.001). The range of R^2 for all the imputations were [0.204- 0.180], adjusted R^2 range is [0.172-0.150], which means that this model can be interpreted as such; using the adjusted R^2, that around 15-17.2% of the variation is explained by the predictors in this model. This is indicative of a medium goodness-of-fit according to Cohen (1988). The socio demographic predictors age, gender, employment status, education level, familial status, income level, along with barriers to healthcare access do not predict the outcome variable. On the other hand, the variables; clinical predictors autism severity, number of somatic, mental comorbidities statistically significantly predict the criterion overall use of healthcare services, *F* (10, 275) = 6.664*, *p* < .001. (*this number was calculated by hand from the average of the F values presented for all 10 imputations as no pooled value was readily calculated from SPSS, the ranges from the F values were: [5.927- 6.373]

Table 18: *Results of pooled multiple linear regression model.*

	Unstandardized Coefficients		Standardized Coefficients			95% confidence interval for B	
Model	**B**	**SE**	**Beta***	**t**	**Sig**	**Lower bound**	**Higher bound**
Constant	.987	.472	-	2.092	.036	.062	1.911
Age	-.010	.006	-.095 – (-.097)	-1.581	.114	-.023	.002

Sex	.073	.138	.035 - .029	.530	.596	-.197	.342
Employment status	-.044	.142	-.019 – (-.17)	-.310	.756	-.321	.233
School qualification	.273	.148	.091 – .111	1.844	.065	-.017	.562
Income	.279	.153	.119 - .108	1.819	.069	-.022	.580
Familial status	.232	.158	.094 – .089	1.463	.143	-.079	.542
DSM 5 mean	.148	.074	.121 - .114	1.998	**.046**	.003	.293
Number of somatic comorbidities	.277	.056	.302 - .303	4.938	**<.001**	.167	.387
Number of mental comorbidities	.141	.052	.172 - .171	2.719	**.007**	.039	.242
Ray sum	-.015	.018	-.058 – (-0.48)	-.825	.409	-.051	.021

Dependent Variable: AUT use of healthcare including participants with no use of ambulant services in the past 6 months. *Data for the standardized coefficients (Beta) is represented by the value ranges from the 10 multiple imputations

Table 18 shows the results from the regression model with all ten predictors, the analysis reveals that not every predictor is significant. Mostly clinical factors which are represented by the autism support items (DSM-5 mean), number of somatic comorbidities and the number of mental comorbidities represent significant predictors of the healthcare use score by autistic adults when all the other variables in the model are held constant. School qualification and income level are almost significant with p = 0.065 and p= 0.069 respectively. Looking at the unstandardized coefficients B for the significant predictors, one can conclude that having a higher number of somatic comorbidities, would lead to a 0.277 increase in the overall healthcare utilization. Same goes for mental co-occurring conditions with each score point of comorbid conditions leading to a 0.141 increase in the overall healthcare utilization of autistic adults and vice versa. Also, the higher the mean need of support due to various difficulties in interpersonal exchange and cooperation or because of holding on to habits, routines or interests, the overall use of healthcare utilization is increased by 0.148. Due to the fact the multiple data imputation was done, the standardized coefficients Beta for the predictors were unable to be produced by SPSS for the pooled version, but where only presented for each imputation case alone. The 95% confidence intervals (CI) for the significant predictors do not show a problem because they do not include 0 and therefore are clearly in a positive or negative direction.

Therefore, the second research question of this thesis can be answered by these results that there are certain predictors that explain the variance of the healthcare utilization of autistic adults in Germany. Those predictors from the included models were number of somatic and number of mental comorbidities and the DSM-5. In the next chapter, the discussion of the data and results is presented. To properly interpret the presented results and formulate conclusions, this study will address its limitations and strengths.

6. Discussion

The main goals of this study were first to provide an elaborate picture of overall healthcare utilization patterns in a sample of autistic adults without intellectual disability from Germany and compare it to a sample of the general population in Germany. Secondly, to identify which predictors mostly affect the overall healthcare use of various services for autistic adults. In the context of the study, it was significant not only to explore the possible perceived barriers but also to be able to depict additional influences on the utilization of certain outpatient healthcare services through the inquiry of individual sociodemographic and clinical factors and characteristics of the utilization behavior.

The reported healthcare use is significantly different among both populations, with autistic adults having higher utilization rates compared to the German general population. The results from the regression analyses reveal that only the number of comorbidities an individual has, whether somatic or mental health related, and the autism severity (DSM-5), could be identified as significant predictors of healthcare utilization among autistic adults in the final multivariate regression analysis. Unexpectedly, the other included predictors and especially surprising, the perceived barriers to healthcare did not contribute significantly into explaining the model of utilization patterns. One potential explanation for that, could be the interaction of the different variables together, which for the purposes of this thesis has not been tested.

6.1 Discussion of original BASS dataset

The data for this study were collected through a secondary analysis of structured surveys administered to participants, ensuring standardized data collection procedures across all respondents. This method facilitated the acquisition of comprehensive and detailed information regarding various aspects of healthcare among which the utilization patterns of autistic adults without intellectual disability. However, despite the robustness of the data collection approach, several challenges were encountered during subsequent data analysis process. One notable challenge pertained to the secondary analysis, particularly in structuring the research questions based on the readily available information within the questionnaire. Additionally, due to the sensitive nature of the topic, potential reluctance or internalized stigmatization among participants to disclose personal healthcare experiences poses a challenge to data collection efforts visible through the level of incomplete questionnaires and the level of missing data in some variables (Pearson & Rose, 2021).

To mitigate this challenge, measures such as ensuring confidentiality and anonymity were implemented to create a safe and non-judgmental environment for participants to share their experiences openly. Despite efforts to maximize response rates and minimize missing data through clear instructions and user-friendly survey design, some participants may have omitted certain responses or provided incomplete information. To address this challenge in the scope of the thesis, an imputation technique called multiple imputations was employed. First LCAR's test was done to estimate missing value percentages, then data was replaced through MI, thereby minimizing the impact of missing data on the integrity and validity of the presented findings.

6.2 Discussion of descriptive statistics

Key descriptive findings echo other previous studies that have consistently shown that autistic individuals have more medical and mental health issues compared to the general population and are more likely to use healthcare services than other groups (Cummings et al., 2016; Gilmore et al., 2022; Vohra et al., 2017). These findings align with responses from autistic adults who report about having two co-occurring mental and somatic health diagnoses on average, including major depression, anxiety disorders, or PTSD as the most often mentioned conditions. They also have one other somatic diagnosis on average, including either chronic pain, diseases of the gastrointestinal tract, or metabolism disorders, or other bodily problems. Many of the respondents were receiving an average of 2 mental or behavioral or emergency health services on average during the past 6 months.

6.2.1 Sex differences

The descriptive findings showed that females usually obtained a more delayed autism diagnosis than the male gender (m= 33 years for females vs. m= 30 years for not females). This is in line with the notion of the existence of a female autism phenotype, which has been thoroughly discussed by experts over the last few years. The female autism phenotype consists in a slightly different presentation of the core and associated autistic characteristics related to the typical male features, which may not be fully explained by the diagnostic criteria and tools (Hull, Petrides, et al., 2020). Another reason to which this delay in diagnosis can be attributed to, is that autistic females, especially those with no intellectual disabilities (such as the female population included in the BASS sample), have developed more effective strategies to camouflage the difficulties they might face in social situations leading them to a risk of going undiagnosed (Bargiela et al., 2016; Cook et al., 2021). Notably, in the BASS sample no big difference between female vs not female autistic people were detected in the number of comorbidities, or the overall use of healthcare.

These sex differences have been studied based solely on descriptive statistics (Appendix IV), as we did not statistically compare the female and not female data due to the small sample sizes.

6.2.2 Healthcare use differences

Almost all of the autistic adults in the BASS sample reported that they had a healthcare contact in the last 6 months and, for the majority, the contacts that were considered in this thesis were only certain outpatient treatments and ER admissions. The findings that autistic adult generally use healthcare services to a greater degree than other comparison groups fall into alignment with what is currently known about this population's health status. Specifically, since this group is usually faced with a higher number of mental and somatic co-occurring conditions (Croen et al., 2015; Hand et al., 2021). This frequent use of services may indicate several problems. For instance, the high use demonstrates not only the high need this population has, but rather the inadequate care they receive when they need to manage or treat these co-occurring conditions. This could be due to the lack of knowledge about/experience with autism, or the unwillingness to tailor autism specific adaptations by healthcare providers, or other sensory or communication issues they are faced with in clinics. All of which does not stop the frequent use of certain outpatient healthcare services (Lipinski et al., 2022; McCormack et al., 2020; Schott et al., 2021), or the hunt for healthcare providers who are willing to listen to their needs, adapt their approaches and respect the way autistic adults communicate with them and most importantly want to be communicated with (Nicolaidis et al., 2015). Importantly to note, however, not all healthcare services were analyzed, only the main services were investigated as those were the only ones included in the questionnaire. Furthermore, the number of visits to each of the services were considered for analyses in the scope of this thesis.

The high use of primary healthcare services among the autistic population could also be attributed to the fact that many kinds of preventive services are routinely provided during primary care visits. The use of such services has been shown to extensively reduce the use of tertiary healthcare services mainly, hospitalizations among various populations (CDC, 2023) . It is encouraging that recent literature found that autistic adults were more likely to receive most preventive services including different screening tests and vaccinations (Ames et al., 2021; Nicolaidis et al., 2013; Zerbo et al., 2019). Nevertheless, it must be stated that these studies focused only on certain types of preventive services and that the purpose of outpatient service use in our population was not inquired about in the questionnaire. As such, we have no clear information of autistic adults' preventive care use within our sample in Germany, thus no conclusions can be made in this regard.

Therefore, in order to draw more conclusions on why this high use of total healthcare services exists among the autistic adult's population, this study should be replicated in bigger samples including more healthcare provider options, and the number of visits to each medical provider and even location of this providers to try to conclude any concrete patterns of use. It is also important that future studies examine the purpose of those healthcare visits and whether an urgent issue, regular check, or a preventive service were the reason for the frequent consults. In addition, the formulation of the items could be revised in a way to minimize the recall bias and no answer bias of such questionnaire items.

6.3 Discussion of comparison between both samples

For hypothesis H1, which assumed that the overall use of healthcare services among an adult autistic sample does not differ from the German general population, a statistically significant difference was found between both samples in their overall utilization of several healthcare services. The results from Mann Whitney-U test, show that there is a significant difference in the mean rank of the healthcare use among the autistic adult's population and the general population sample which is corroborated by the previously presented literature in this thesis (Gilmore et al., 2022).

Based on Figure 3, depicting the use patters for both populations among 5 different healthcare services during the past 6 months, we can conclude that autistic individuals have a higher percentage of healthcare visits than the general population. Descriptively, almost 60% from the general population sample reported having had no healthcare contacts in the past 6 months, these results contradict with the findings of the previously presented research. This has been reported by Grupp et al in 2016, that almost 95% of Germans had at least one visit to a health practitioner each year. However, this could be due to the fact that only a small sample of the general population was considered in this comparison due to the case control matching process which has reduced the number of participants from (n = 5007) to (n = 288) for comparison purposes . Therefore, this information should be cautiously interpreted. Another reason for that could be, the recall bias, since the study used a six-month recall period that is for specific for capturing rare events while minimizing the level of the recall bias. Yet, researchers still say, it is not possible to know which recall period is optimal for such studies (Bhandari & Wagner, 2006). Among further inspection of the samples, according to the descriptive information in Figure 4, the

10% of the general sample population mostly had contacts to a general practitioner or to dental healthcare services. Moreover, in comparison to the BASS sample, as depicted in Figure 5, the main visited areas for the autistic adult's population were general healthcare services (which includes both GP and kid's doctors), mental healthcare services followed by dental services in the third spot. This supports findings of previous literature showing the extensive use of mental health services among the autistic population compared to the general population (Ames et al., 2021; Maddox et al., 2018; Zerbo et al., 2019). Since the samples were small no further calculations on healthcare utilization differences among gender could be extrapolated in both samples and are therefore not researched in this thesis.

6.4 Discussion of regression analysis

In total, four regression models were calculated. Each model included one set of predictors only, 1) sociodemographic factors, 2) clinical factors, 3) perceived barriers to healthcare, and the last one 4) included all of the different areas of predictors combined. The model with only sociodemographic predictors showed non-significant results, and the same goes for the model with the perceived barriers to healthcare. However, the model with the clinical factors was significant offering almost 14% variance explanation. Lastly the combined categories regression model was also significant offering around 17% variance explanation, mainly due to the fact that the clinical factors were included in it with very minimal noticeable enhancement in the level of variance explained once combining all of the different categories.

For hypothesis H2, which assumed that sociodemographic data and clinical factors influence the contacts to healthcare services, a statistically significant association was only found between the number of somatic comorbidities, the number of mental comorbidities and the autism severity items (DSM-5) to the contacts to healthcare services. This is logical as individuals with high comorbidities tend to visit the doctors more often to get treatment and the higher their need for support is, the more likely they are to reach out for support (Vohra et al., 2017). In the context of autistic adults, it is common that they have higher prevalence of physical and mental health co-occurring conditions (Bishop-Fitzpatrick & Rubenstein, 2019). Another sociodemographic factor that might affect the contacts to healthcare services, is the status of health insurance a person has. According to a study reviewing of inequality of opportunity in therapy seeking , it is concluded that self-payers and privately insured individuals obtain outpatient therapy slots more quickly than those insured under statutory health insurance (Strauss, 2015). The issue with unequal healthcare access due to financial barriers is much more prominent in other countries such as the USA. And even having health insurance coverage does not necessarily mean this coverage is adequate or that it isn't associated with burdensome issues (National Academies of Sciences et al., 2018). The question of whether access to healthcare utilization was perceived as easy or difficult for the participants due to differences in healthcare insurance status in the sample under investigation remains unanswered.

Although the barriers were perceived as generally medium (m = 7.93) in the sample examined here, none of the questions from the short form touches upon the topic of health insurance. The status of individuals' insurance was queried but was not included in the regression analysis, so it is unclear whether the individuals were self-payers or covered by statutory health insurance, making the insurance status a potential confounding variable. Another recent research has highlighted how provider biases can exacerbate disparities in healthcare access (specifically for mental healthcare access purposes) for individuals with low socioeconomic status and other demographic characteristics. While the impact of sociodemographic characteristics observed in their study was somewhat limited, recognizing the link between SES and the availability of therapy appointments could prompt practitioners to reconsider their own criteria for selecting patients (Niemeyer & Knaevelsrud, 2023). A study from 2018 by Dudley et al., investigated the importance of living situations on the healthcare of autistic adults. They had adjusted for several demographic factors known to influence service utilization and requirements. The authors interestingly, found that living situation emerged as a noteworthy predictor of service utilization, access, and barriers to services. Specifically, autistic adults who resided alone or with family members exhibited lower service utilization, greater unmet needs, and encountered more obstacles in accessing services. These findings are in fact rather unsurprising, that autistic adults who lived in supported residential settings such as supervised housing or group homes, received more services and this was attributed to the given array of services offered and delivered through their supported living facility (Dudley et al., 2019). This aspect was not included as a predictor in the current thesis due to the fact that this has not been presented as a very strong factor among various literature resources.

As for hypothesis H3, which assumed that the perceived barriers to the healthcare system access explain the variance in overall healthcare utilization among autistic adults in Germany, the examined model of only perceived barriers did not show a statistically significant correlation between the predictors and the overall healthcare utilization. This finding is inconsistent with what has been established in the literature. For instance, autistic adults face higher rates of barriers to specialized care due to various challenges they face, including sensory problems, emotional or communication problems (Raymaker et al., 2017). All these challenges combined could contribute to a reduced satisfaction with care, higher ER visits, and reduced self-efficacy (Nicolaidis et al., 2013, 2015; Vogan et al., 2017). It has also been thought that given the immense challenges of receiving these services, autistic adults may require a vast amount of endurance to overcome the burden of seeking their necessary healthcare services. Participants further indicated that seeking and not receiving healthcare made them feel hopeless and helpless (Ghanouni et al., 2021).

A longitudinal study from Ontario by Vogan et al from 2016 about tracking service rates and experiences (barriers and satisfaction) of autistic adults without ID revealed that, individuals facing medical issues encountered notably more obstacles in accessing services compared to those without such concerns. Moreover, individuals dealing with both medical and mental health issues expressed lower levels of satisfaction with the services received. However what's surprising about the regression results, is that the literature has established over the years, that the perceived barriers to healthcare play a very important role in how the autistic adults are using the healthcare system (Weir et al., 2022) , as these barriers tend to sometimes stop them from reaching out to health providers thus limiting their access to healthcare, yet from the calculated results, we find out that it is in fact insignificant in the specific context we tested. Despite the fact that participants in the questionnaire did not have an intellectual disability, there was an observed remark suggesting that when perceived barriers were high, there was also a relatively high utilization of healthcare services. This observation might imply that individuals perceiving significant healthcare barriers tended to have lower levels of resilience and were more inclined to seek professional help for severe symptoms or a more pronounced illness trajectory compared to others. However, the correlations between the predictors were not tested so there might have been a missed connection there which would better explain the results.

6.5 Aging on the autism spectrum: Implications in Discussion

Although this study does not include persons above the age of 65 it is important to consider the health of autistic individuals as they age. Older adults use far more healthcare services than the younger generation (Institute of Medicine (US) Committee on the Future Health Care Workforce for Older Americans, 2008), because the older they get the higher the chance of them falling ill is (RKI, 2012). Healthy aging, also referred to as successful aging (McLaughlin, 2017), a concept is defined by the World Health Organization as "the process of developing and maintaining functional ability that enables well-being in older age." (Rudnicka et al., 2020). According to the WHO, there is no such thing as a typical older person. Some 80-year-olds have physical and mental capacities similar to many 30-year-olds. Other people experience significant declines in capacities at much younger ages (WHO, 2022a). This concept encompasses both the physical and mental capacities of older adults at any given time (Beard et al., 2016), as well as the resources and support they access and utilize. Key elements of healthy aging include disease and disability prevention and management, the maintenance of good physical and cognitive functionality, and engagement in active lifestyles and healthful behaviors (McLaughlin et al., 2012).

Achieving healthy aging is a fundamental objective of modern medicine, particularly in the context of geriatric care. It is crucial to recognize that healthy aging and health in old age are integral aspects of health-policy planning and measures. These principles are reflected in national health targets, such as those established by the cooperation network gesundheitsziele.de, which is funded by the German federal government (RKI, 2012). Yet, despite efforts to promote healthy aging as the norm for any individual getting older (Jin, 2017), subsets of the aging population face multiple challenges that result in inequities in resource distribution, disparities in healthcare access thus resulting in tremendous negative consequences on health outcomes (McMaughan et al., 2020). There is sparse literature available on the topic of aging on the autism spectrum. A recent study from Australia examined the applicability of the popular gerontology concept of “aging well” to autistic adults and found that a very small proportion of autistic adults were found to be aging well. The study also found that significantly fewer autistic adults were maintaining physical and cognitive functioning and actively engaging with life in comparison to controls, however they found that the current dominant model of “aging well” is limited for examining autistic individuals (Hwang et al., 2020). For the BASS sample, no information about the lifestyle, (e.g. physical activity, diet, social participation) were considered when creating the questionnaire, therefore no deductions can be made on how healthy these individuals are outside of the number of comorbidities they have. Which is regrettable since growing healthy is not only linked with comorbidities and the recent literature have made the concept of healthy aging a corner stone to reflect national health targets. Therefore, it's important to consider the healthy aging of autistic adults within the German health framework and involve more aspects about healthy ageing, recognizing that they may face unique challenges and require tailored support to achieve optimal well-being as they age by developing a proxy item that help researchers quantify this term and involve it in future research.

In summary, no statistically significant correlation between sociodemographic factors, perceived barriers to care, and the utilization of healthcare services could be confirmed in the present thesis, which is why the second null hypothesis was partially retained and the third null hypothesis was fully retained. However, the absence of a statistically significant correlation does not rule out the possibility that one actually exists. It is important to interpret and discuss the findings presented so far with caution. The study had a small sample size, leading to the execution of four multiple regression analyses with three thematically grouped predictors each and one final regression analysis with all predictor groups together. While this approach addressed the issue of the small sample size, it also carries the risk of overestimating or failing to detect effects. Nonetheless, it is important to note that the results are specific to the model used, and the findings may change significantly when adjusting for other variables. In the following chapter, light will be shed on some of the most important advantages and limitations for this study.

7. Strengths and Limitations

7.1 Strengths of BASS sample and study

A major strength of the BASS study is the participatory approach, which ensured involvement of autistic peer researchers, relatives and service providers at all stages. Participation was further maximized in the study by offering several methodological participation modes to autistic adults by the use of interviews for the drafting of the questionnaire items during phase one of the project, and also by allowing the participants to answer the questionnaire online which gave them enough time, allowed them to be in a familiar area for them to be able to be as comfortable as possible while answering these items. To our knowledge, this is the first comprehensive study with a specific interest in gathering holistic perspectives of various stakeholders, autistic adults and family relatives. The study also has another great advantage over previous work, in that it is the largest and first known survey of autistic individuals without ID in Germany, providing crucial information to policymakers, researchers, and public interest groups on the current unmet needs and services received by this group. Findings provide actionable information on what health services are most needed, which will assist in policy and program planning within the German healthcare system and across other service systems, including the social system. Limitations of the BASS and German general population studies will be described below.

7.2 Limitations of BASS sample and study

Although this thesis offered a selection of interesting findings, some limitations should be acknowledged. First, while respondents represented a wide geographic area across Germany, the survey targeted mainly the German speaking population and does not necessarily reflect trends one would find in migrants, descendants of migrants and ethnic minorities or other non-German speaking communities. Nevertheless, it is a nationwide survey with good representation from autistic individuals, caregivers and healthcare providers. With the amount of emerging evidence that migration and the ethnic minority status are associated with the risks of autism spectrum disorder due to various reasons (e.g. lack of access to healthcare services, lack of awareness about autism, fear of stigma among their communities, cultural barriers, and most importantly language barriers) or certain healthcare disparities (e.g. difficulties in understanding the meaning of culturally shaped symptoms and communication problem) (Morinaga et al., 2021) it has become increasingly important to make sure this sort of studies is essential, which should also reach everyone in the community so that the improvements are overarching and benefit everyone. Other studies from the USA also have examined the disparities in healthcare due to race and ethnicity. The researchers have found that differences in prevalence of certain health conditions among certain populations and patterns of hospitalizations that could be markers of differential adequacy of outpatient care for the co-occurring conditions in autistic adults (Rast et al., 2023; Schott et al., 2022). This evidence suggests that outcomes could potentially vary when examining that particular segment of the German population.

Additionally, It is also important to note that self-reported responses to the survey may have been affected by recall bias (Bhandari & Wagner, 2006). This information was collected from autistic individuals about their healthcare use patterns during the past 6 months, although many comorbidities, healthcare providers and services were already listed for them to choose from. Yet, we are not sure that participants have managed to remember everything and give the exact correct information for all of their healthcare visits and needs. Nor were all the possible healthcare services listed in the questionnaire to choose from (e.g. gynecologists, cardiologists, ear-nose and throat doctors (ENT), etc.).

Another issue that arises with online questionnaires, is that inclusion and exclusion criteria have no way of being verified, and there is no way of telling if the individuals answering are doing so truthfully. Another important limitation to self-reported responses is that many of the questions inside the questionnaire were not obligatory. This resulted in non-response bias and having missing data. In consequence, this led to the exclusion of people (n= 118) from the questionnaire and the valuable inputs they might have provided in other parts of the questionnaire. This also led to the exclusion of certain variables where many missing data was present and the variables would not have been able to be assessed properly. Nevertheless, obtaining the perspective of autistic individuals from self-reported information is a key step in identifying the needs of individuals in Germany. Furthermore, sufficient responses powered the study to conduct the analyses needed to investigate the research questions of this thesis.

Due to the small sample size, the number of predictors included in the final regression model was limited in order to achieve sufficient statistical power (Sham & Purcell, 2014). It was not possible to consider investigating smaller subgroups for (e.g. residents of northern Germany, southern, eastern, and western, or residents of rural areas vs residents of cities). Gender differences (male, female and diverse) could not also be examined within the framework of these analyses, as the sample of diverse individuals would have been too small. Only 9.1 % (n=26) of the diverse participants were present in this sample which is why no analyses split by gender could be done.

7.3 Limitations of comparison sample and study

Moving on the population comparison, the German general population study also has certain limitations, which primarily resulted from the telephone interview approach. This might have caused selection bias by excluding the most severely ill people as they wouldn't be the ones talking on the phone and answering the interview questions, another limitation was also the 6-month recall bias (Grupp et al., 2016) which was also present in the BASS sample. Another limitation specifically presenting itself for the comparison between the sample population and the general population was the fact that the study included only the female and male gender. This did not allow a proper gender comparison among the two populations. Nonetheless, this was overcome by colliding the diverse and male samples together and creating the new dummy variables (female vs not-female), and followed by running descriptive statistics analyses on the samples to compare them together. Moreover, for certain items in the phone interview guide/questionnaire used by Grupp et al., there was no exact matching item in the BASS questionnaire. This led to some variables being modified accordingly to fit each other in order to use them for the comparison analysis among the two populations (e.g. the number of somatic and mental comorbidities).

The formulation of the three hypothesis was dependent on the various literature already presented in the theoretical background. This could be considered a limitation for not relying on a well-established healthcare use model that is already acclaimed and verified and then trying to expand on it. Despite incorporating a comprehensive network of predictors into the regression model, the variables included in the last multivariate regression model explained about 17 % of the variance. This is considered a medium goodness of fit (Cohen, 1988), a significant portion of the variance remains unexplained. This suggests the presence of additional, unidentified factors influencing healthcare utilization in autism.

Additionally, the measurement of some variables included in this study needs to be discussed. For example, the perceived barriers to healthcare, were examined using the Raymaker short form survey. This is a validated, standardized instrument but with only 17 items. Nevertheless, for obtaining more precise insights into previously encountered barriers to healthcare, an alternative approach could involve utilizing a different instrument to assess this, such as the extended version of the same questionnaire containing 36 items. Another example would be the outcome variable, the overall healthcare utilization which was measured with only including 5 healthcare services only available in the survey depending on the literature which usually portrayers them as the most highly used healthcare services by autistic adults, which were all coded to a binary variable which could have led to imprecise information. Therefore, it can only be stated whether or not the responder has visited one of these services during the past 6 months but not the number nor frequency of the visits. More detailed information would be helpful to measure the full use of healthcare and explore the purpose of the visits. Lastly, due to the cross-sectional design of the study, only associations and no cause-effect relationships can be shown (Döring & Bortz, 2016). Further studies with longitudinal data could be helpful to detect changes over time.

8. Conclusions

In line with the previously presented results and limitations of this study, this section highlights possible implications for further research and practice in the healthcare system. For autism health services research, this is the first contribution to the connection between sociodemographic and clinical factors, the perceived barriers to care and the use of various health services in Germany. Although partial variance is explained through clinical factors, this study could not prove that perceived barriers to care and certain sociodemographic factors affect the use of certain health services significantly. This suggests that there are other predictors that affect the overall healthcare use in that population that are yet to be identified. It can be stated that there is a big need in healthcare services for autistic adults in Germany.

8.1 Implications for future research

The current thesis highlights many gaps for future research. Specifically, the need to further examine the true effect of barriers in accessing healthcare for autistic individuals and also examining other facilitators for accessing treatment for mental health or somatic problems. Autistic adults report having many barriers specific to the delivery of healthcare but still have high healthcare utilization rates compared to other groups or the normal population. More research is needed to not only further explore the barriers to accessing care, but rather the barriers to sustained engagement in therapy. This can then help explain why the group presents with higher-than-average visits to healthcare providers. Furthermore, it can ensure that once an autistic adult has managed to access therapy, they feel comfortable continuing with it and that it is as effective as possible at meeting the therapy goals set for this individual. One way the effects of the barriers can be better understood is by conducting qualitative interviews with autistic adults informing about the extent to which confronting these barriers stops them from reaching out to important medical care.

Another interesting research direction would be to assess the use patterns among certain cities in Germany, to find out whether use patterns differ among urban vs rural areas, and whether the travel distance to these providers has an effect on accessing/using the services. It would also be beneficial to research the associations between the impact of access barriers and healthcare utilization for specific services and to use the evidence to support relevant stakeholders in creating individualized treatment plans/considerations for autistic adults.

As has been noted in a 2019 systematic review of selection bias on intellectual ability in autism research (Russell et al., 2019) there is a lack of studies from the perspectives of adults themselves, and also from the perspectives of autistic individuals with ID. Therefore, it would be beneficial to also include this population in future research among the German population of autistic adults.

It is imperative to also look beyond the autistic individual. For example, examining how the providers behavior (e.g. it would be interesting to find out if autistic patients have ever been denied services and referred to other specialists with more autism knowledge/experience, how often has this happened, and what was their reaction upon being denied appointments/treatments) affects healthcare use or perception of perceived barriers and how healthcare organizations/system must change in the future.

8.2 Implications for practice and stakeholders

An important aspect for minimizing the existing disparities in healthcare for the autistic population in Germany and worldwide would be in effectively informing healthcare funders and providers about the features of developmentally appropriate transitional care likely to be associated with improved outcomes for young people (King et al., 2020). By exploring various aspects of transitional care, including its components, delivery methods, and implementation strategies, stakeholders can gain a comprehensive understanding of how to optimize transitional care programs (Colver et al., 2019).

Publications in the field have consistently emphasized the critical importance of several key factors in facilitating successful transitions in healthcare for young autistic adults and improving the quality of the services they are receiving (Colver et al., 2019; Mazurek et al., 2020; NICE, 2016). Among these factors are early planning, which allows for adequate preparation and support leading up to the transition; continuity of care, ensuring that there is seamless coordination and transfer of medical information between pediatric and adult healthcare providers; and a focus on addressing the developmental needs of young people, rather than rigidly adhering to arbitrary age cut-offs for transfer. In line with these principles, the UK National Institute for Health and Care Excellence (NICE) guidelines provide clear recommendations to support effective transitional care practices. These guidelines stress the importance of transition support that is not only developmentally appropriate but also person-centered, recognizing the unique needs and preferences of each autistic individual. Furthermore, they advocate for young people to have a designated healthcare worker who can provide personalized support and guidance throughout the transition process. Additionally, the guidelines emphasize the importance of facilitating early introductions between young people and the adult healthcare team prior to transfer, fostering a smooth transition and helping to alleviate anxiety (NICE, 2016). Similarly, is the need-oriented healthcare concept being proposed by the BASS study. Which through a test implementation in the Germany population, of both clinical effectiveness and sustainability of the developed concept of services and recommendations, could allow for further concept refinement and specifics to foster German wide implementation. One way this test implementation could be done is through a randomized controlled trial. Since the study is funded by the Innovation Fund of the German Federal Joint Committee, (which is the highest decision-making body of the joint self-government of practitioners, hospitals and health insurance funds in Germany), it is foreseeable that the BASS project will likely drive positive change among the German autism healthcare scene. Furthermore, it possibly will have a direct and immediate impact on healthcare policies and contribute to improving outcomes in people and families with autism and alleviate the burdens on individuals, families, and socioeconomic conditions caused by inadequate services for adults with autism (David et al., 2022).

Moreover, developing programs for medical and healthcare professional training are needed to enhance physicians' understanding of the standard of care for autistic individuals. By doing so, there exists a chance to equip physicians with the necessary knowledge and skills to effectively address the needs of autistic individuals. This includes the utilization of suitable tools, technologies, and approaches to care such as healthcare transition and management of sensory sensitivities. Faculties of medicine and accrediting organizations responsible for medical school curricula development, should prioritize integrating training that aligns with the latest evidence-based practices in caring for individuals with autism across all stages of life and for all healthcare study majors (Malik-Soni et al., 2022).

In conclusion, policymakers and relevant stakeholders must prioritize increasing the availability of formal healthcare services and autism case management services to mitigate healthcare inequalities and provide essential resources and support. This may involve expanding diagnostic and psychotherapeutic services to both urban and rural areas and optimizing the transitional phase for autistic adolescents into adulthood (Dückert et al., 2023). Additionally, efforts should focus on enhancing community understanding of autism to reduce stigma and training healthcare providers to deliver respectful and appropriate care for autistic adults.

Sustainable improvement in autism research and treatment requires collaboration among all stakeholders. Despite some limitations, this thesis represents a contribution to the literature by examining the interplay between sociodemographic factors, clinical aspects, perceived barriers to healthcare, and overall health service utilization among autistic individuals in Germany. This research also highlights the need for further investigation and development in this critical area. Finally, future studies should delve deeper into the subject under more favorable methodological conditions to enhance long-term healthcare access for this demographic.

Declaration of Academic Honesty

Hereby, I declare that I have composed the presented master thesis independently on my own and without any other resources than the ones indicated. All thoughts taken directly or indirectly from external sources are properly denoted as such.

Hamburg, 07.03.2024

Shaden Suleiman

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Appendix

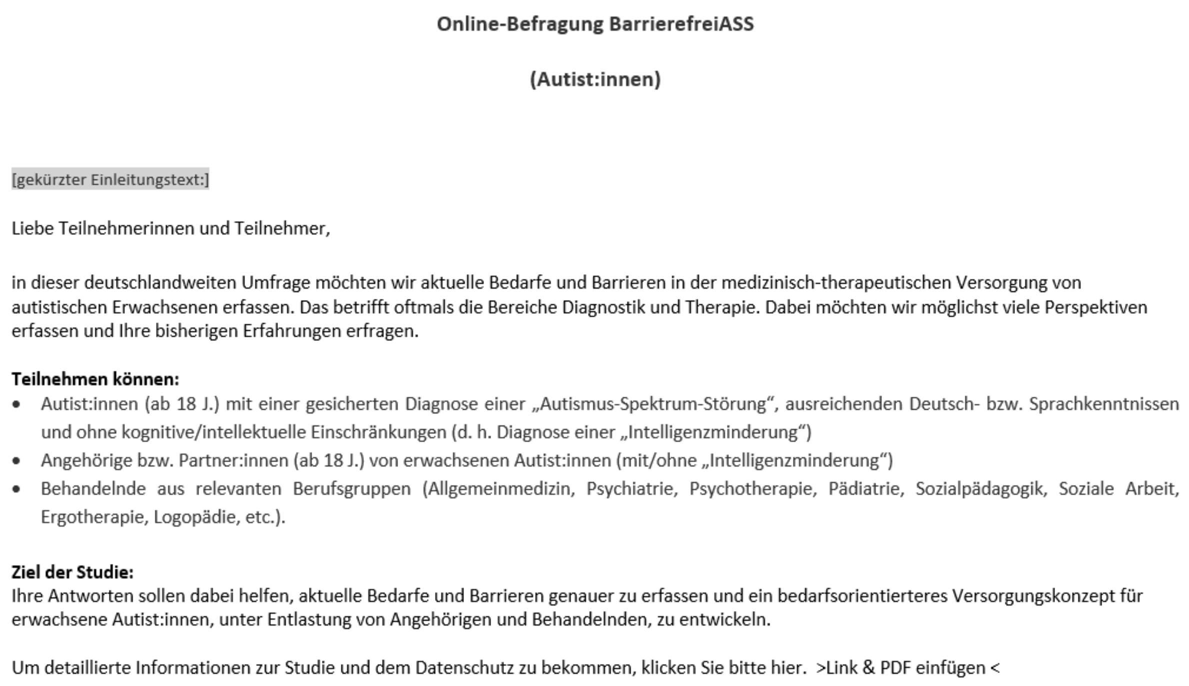
Appendix I: Excerpts from the BASS & general population study questionnaires

Appendix II: SPSS syntax for all analyses

Appendix III: Supplementary output from SPSS

Appendix IV: BASS sample gender differences

Appendix I: Excerpts from the BASS & general population study questionnaires



Online-Befragung BarrierefreiASS

(Autist:innen)

[gekürzter Einleitungstext:]

Liebe Teilnehmerinnen und Teilnehmer,

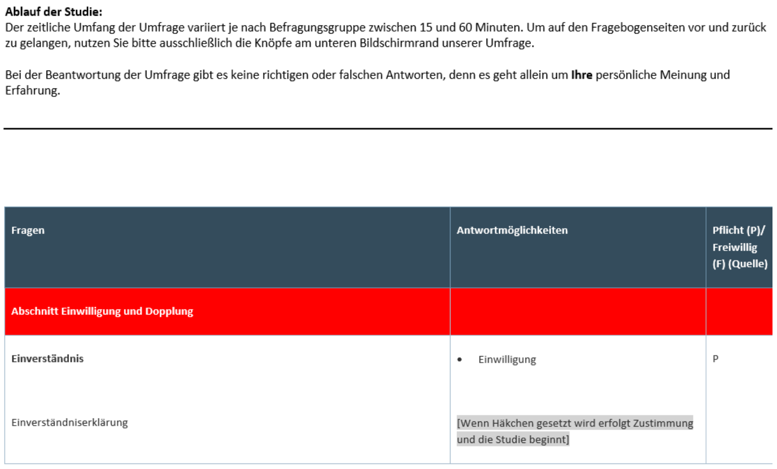
in dieser deutschlandweiten Umfrage möchten wir aktuelle Bedarfe und Barrieren in der medizinisch-therapeutischen Versorgung von autistischen Erwachsenen erfassen. Das betrifft oftmals die Bereiche Diagnostik und Therapie. Dabei möchten wir möglichst viele Perspektiven erfassen und Ihre bisherigen Erfahrungen erfragen.

Teilnehmen können:

- Autist:innen (ab 18 J.) mit einer gesicherten Diagnose einer „Autismus-Spektrum-Störung“, ausreichenden Deutsch- bzw. Sprachkenntnissen und ohne kognitive/intellektuelle Einschränkungen (d. h. Diagnose einer „Intelligenzminderung“)
- Angehörige bzw. Partner:innen (ab 18 J.) von erwachsenen Autist:innen (mit/ohne „Intelligenzminderung“)
- Behandelnde aus relevanten Berufsgruppen (Allgemeinmedizin, Psychiatrie, Psychotherapie, Pädiatrie, Sozialpädagogik, Soziale Arbeit, Ergotherapie, Logopädie, etc.).

Ziel der Studie:
Ihre Antworten sollen dabei helfen, aktuelle Bedarfe und Barrieren genauer zu erfassen und ein bedarfsorientierteres Versorgungskonzept für erwachsene Autist:innen, unter Entlastung von Angehörigen und Behandelnden, zu entwickeln.

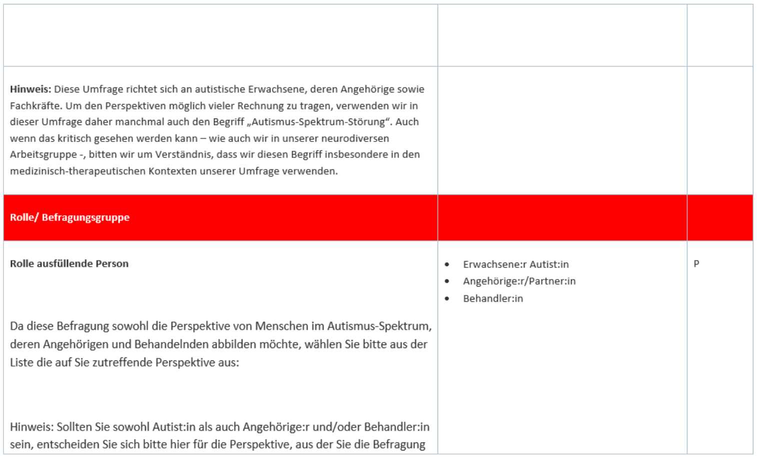
Um detaillierte Informationen zur Studie und dem Datenschutz zu bekommen, klicken Sie bitte hier. >Link & PDF einfügen <



Ablauf der Studie:
Der zeitliche Umfang der Umfrage variiert je nach Befragungsgruppe zwischen 15 und 60 Minuten. Um auf den Fragebogenseiten vor und zurück zu gelangen, nutzen Sie bitte ausschließlich die Knöpfe am unteren Bildschirmrand unserer Umfrage.

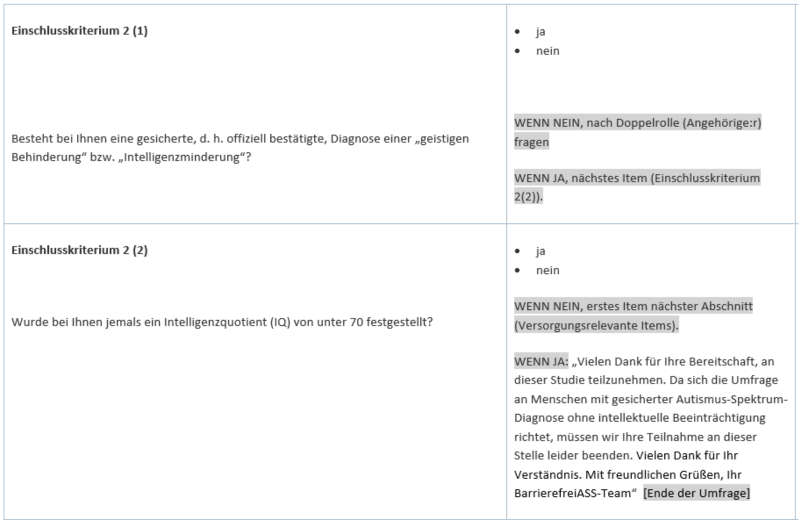
Bei der Beantwortung der Umfrage gibt es keine richtigen oder falschen Antworten, denn es geht allein um **Ihre** persönliche Meinung und Erfahrung.

Fragen	Antwortmöglichkeiten	Pflicht (P)/ Freiwillig (F) (Quelle)
Abschnitt Einwilligung und Dopplung		
Einverständnis	- Einwilligung	P
Einverständniserklärung	[Wenn Häkchen gesetzt wird erfolgt Zustimmung und die Studie beginnt]	



Hinweis: Diese Umfrage richtet sich an autistische Erwachsene, deren Angehörige sowie Fachkräfte. Um den Perspektiven möglich vieler Rechnung zu tragen, verwenden wir in dieser Umfrage daher manchmal auch den Begriff „Autismus-Spektrum-Störung“. Auch wenn das kritisch gesehen werden kann – wie auch wir in unserer neurodiversen Arbeitsgruppe -, bitten wir um Verständnis, dass wir diesen Begriff insbesondere in den medizinisch-therapeutischen Kontexten unserer Umfrage verwenden.		
Rolle/ Befragungsgruppe		
Rolle ausfüllende Person Da diese Befragung sowohl die Perspektive von Menschen im Autismus-Spektrum, deren Angehörigen und Behandelnden abbilden möchte, wählen Sie bitte aus der Liste die auf Sie zutreffende Perspektive aus: Hinweis: Sollten Sie sowohl Autist:in als auch Angehörige:r und/oder Behandler:in sein, entscheiden Sie sich bitte hier für die Perspektive, aus der Sie die Befragung	• Erwachsene:r Autist:in • Angehörige:r/Partner:in • Behandler:in	P

Ein/ Ausschlusskriterien	
Doppelte Beantwortung Wir möchten verhindern, dass die Umfrage mehrmals für dieselbe Person ausgefüllt wird. Daher unsere Frage: Haben Sie diese Umfrage bereits einmal ausgefüllt?	• ja • nein Wenn JA: „Bitte teilen Sie uns kurz mit, warum Sie die Umfrage noch einmal ausfüllen möchten:“ [Freitext] • WENN NEIN, nächstes Item
Einschlusskriterium 1 **Besteht bei Ihnen eine gesicherte, d. h. offiziell bestätigte Diagnose einer „Autismus-Spektrum-Störung“, wie sie von Ärzt:innen und Psycholog:innen gestellt wird?**	• ja • nein WENN JA, nächstes Item. WENN NEIN: „Vielen Dank für Ihre Bereitschaft, an dieser Studie teilzunehmen. Da sich die Umfrage



Einschlusskriterium 2 (1) Besteht bei Ihnen eine gesicherte, d. h. offiziell bestätigte, Diagnose einer „geistigen Behinderung“ bzw. „Intelligenzminderung“?	• ja • nein WENN NEIN, nach Doppelrolle (Angehörige:r) fragen WENN JA, nächstes Item (Einschlusskriterium 2(2)).
Einschlusskriterium 2 (2) Wurde bei Ihnen jemals ein Intelligenzquotient (IQ) von unter 70 festgestellt?	• ja • nein WENN NEIN, erstes Item nächster Abschnitt (Versorgungsrelevante Items). WENN JA: „Vielen Dank für Ihre Bereitschaft, an dieser Studie teilzunehmen. Da sich die Umfrage an Menschen mit gesicherter Autismus-Spektrum-Diagnose ohne intellektuelle Beeinträchtigung richtet, müssen wir Ihre Teilnahme an dieser Stelle leider beenden. Vielen Dank für Ihr Verständnis. Mit freundlichen Grüßen, Ihr BarrierefreiASS-Team“ [Ende der Umfrage]

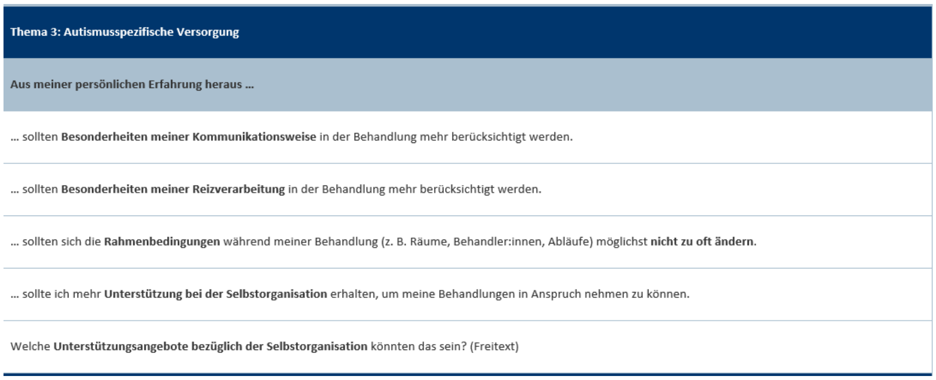
Sind Sie auch ein:e Angehörige:r von einer/einem erwachsenen Autisten:in?	• ja • nein WENN JA: „Versuchen Sie bitte bei der Beantwortung der Fragen diese Perspektive nicht einzunehmen, sondern ganz bei Ihrer Sicht als erwachsene:r Autist:in zu bleiben.“
Sind Sie auch ein:e Behandler:in von erwachsenen Autist:innen?	• ja • nein WENN JA: „Versuchen Sie bitte bei der Beantwortung dieser Umfrage diese Perspektive nicht einzunehmen, sondern ganz bei Ihrer Sicht als erwachsene:r Autist:in zu bleiben.“

Fragen	**Antwortmöglichkeiten**	**Pflicht (P)/ Freiwillig (F) (Quelle)**	**Prio**
Abschnitt Versorgungs- und Bedarfsanalyse (Basierend auf Quali)			
Teil 1 von 3: Wir möchten nun von Ihnen wissen, wie **Ihre bisherigen Erfahrungen** in der medizinisch-therapeutischen **Versorgung von erwachsenen Autist:innen** sind. Wir haben mögliche Barrieren für die Nutzung von Versorgungsangeboten gesammelt und bitten Sie, für jede Aussage **aus Ihrer persönlichen Erfahrung** anzugeben, wie sehr Sie der Aussage zustimmen bzw. nicht zustimmen.			1

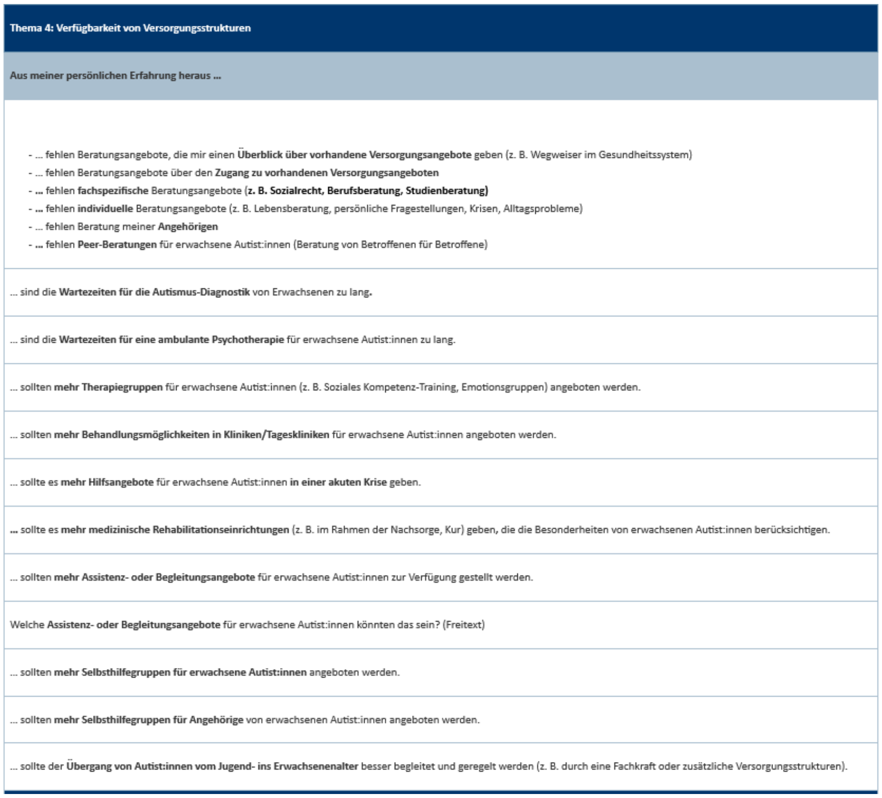
	1	2	3	4	5
	Stimmt nicht	Stimmt wenig	Stimmt mittelmäßig	Stimmt ziemlich	Stimmt sehr

Thema 1: Aufklärung/Wissensvermittlung					
Aus meiner persönlichen Erfahrung heraus …					
… sollten **Angehörige** mehr über Autismus-Spektrum-Störungen **aufgeklärt** werden.					
… sollten **Behandelnde** mehr **Wissen über Autismus-Spektrum-Störungen im Erwachsenenalter** haben.					
… sollten **erwachsene Autist:innen** mehr bei der **Vermittlung von Wissen** über Autismus-Spektrum-Störungen (z. B. an Behandelnde und Angehörige) beteiligt werden.					
… wurde **meine Behandlung** als erwachsene:r Autist:in **abgelehnt,** weil der/die Behandelnde **kein autismusspezifisches Fachwissen** hatte**.**					
… sollte es mehr **fachspezifische Fortbildungen zu erwachsenen Patient:innen mit Autismus-Spektrum-Störungen geben** (z. B. für Psychiater:innen, Hausärzt:innen, Zahnärzt:innen)**.**					

Thema 2: Teilhabe/Mitbestimmung					
Aus meiner persönlichen Erfahrung heraus …					
… sollte das **private Umfeld** in meine Behandlung **einbezogen** werden.					
… sollten mir (als erwachsene:r Autist:in) **Behandlungsschritte transparent mitgeteilt werden.**					
… sollte ich (als erwachsene:r Autist:in) aktiv an **Behandlungsentscheidungen beteiligt** werden.					

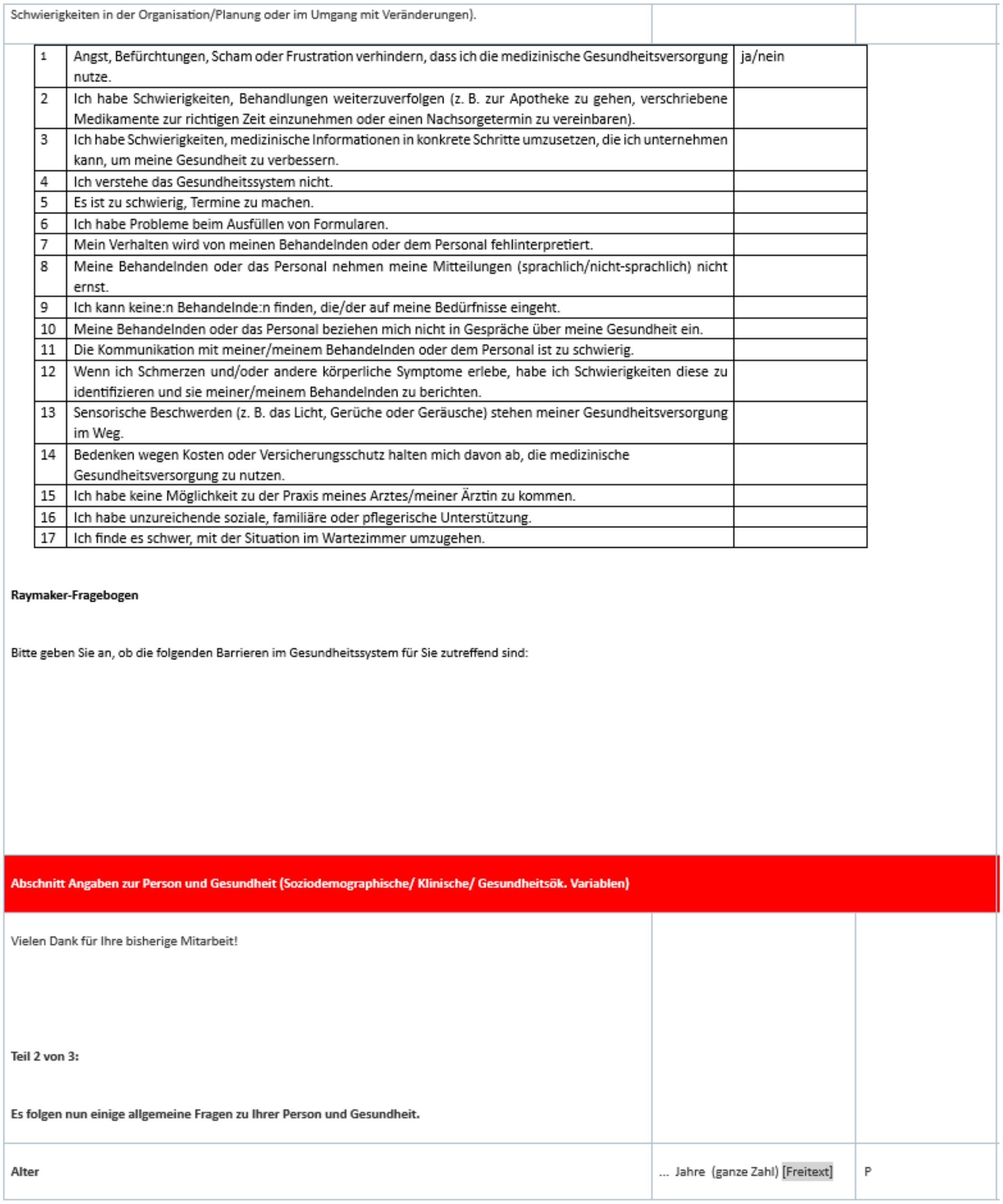


Thema 3: Autismusspezifische Versorgung
Aus meiner persönlichen Erfahrung heraus …
… sollten **Besonderheiten meiner Kommunikationsweise** in der Behandlung mehr berücksichtigt werden.
… sollten **Besonderheiten meiner Reizverarbeitung** in der Behandlung mehr berücksichtigt werden.
… sollten sich die **Rahmenbedingungen** während meiner Behandlung (z. B. Räume, Behandler:innen, Abläufe) möglichst **nicht zu oft ändern**.
… sollte ich mehr **Unterstützung bei der Selbstorganisation** erhalten, um meine Behandlungen in Anspruch nehmen zu können.
Welche **Unterstützungsangebote bezüglich der Selbstorganisation** könnten das sein? (Freitext)



Thema 4: Verfügbarkeit von Versorgungsstrukturen
Aus meiner persönlichen Erfahrung heraus …
- … fehlen Beratungsangebote, die mir einen **Überblick über vorhandene Versorgungsangebote** geben (z. B. Wegweiser im Gesundheitssystem) - … fehlen Beratungsangebote über den **Zugang zu vorhandenen Versorgungsangeboten** - **…** fehlen **fachspezifische** Beratungsangebote (**z. B. Sozialrecht, Berufsberatung, Studienberatung)** - **…** fehlen **individuelle** Beratungsangebote (z. B. Lebensberatung, persönliche Fragestellungen, Krisen, Alltagsprobleme) - … fehlen Beratung meiner **Angehörigen** - **…** fehlen **Peer-Beratungen** für erwachsene Autist:innen (Beratung von Betroffenen für Betroffene)
… sind die **Wartezeiten für die Autismus-Diagnostik** von Erwachsenen zu lang**.**
… sind die **Wartezeiten für eine ambulante Psychotherapie** für erwachsene Autist:innen zu lang.
… sollten **mehr Therapiegruppen** für erwachsene Autist:innen (z. B. Soziales Kompetenz-Training, Emotionsgruppen) angeboten werden.
… sollten **mehr Behandlungsmöglichkeiten in Kliniken/Tageskliniken** für erwachsene Autist:innen angeboten werden.
… sollte es **mehr Hilfsangebote** für erwachsene Autist:innen **in einer akuten Krise** geben.
… sollte es **mehr medizinische Rehabilitationseinrichtungen** (z. B. im Rahmen der Nachsorge, Kur) geben, die die Besonderheiten von erwachsenen Autist:innen berücksichtigen.
… sollten **mehr Assistenz- oder Begleitungsangebote** für erwachsene Autist:innen zur Verfügung gestellt werden.
Welche **Assistenz- oder Begleitungsangebote** für erwachsene Autist:innen könnten das sein? (Freitext)
… sollten **mehr Selbsthilfegruppen für erwachsene Autist:innen** angeboten werden.
… sollten **mehr Selbsthilfegruppen für Angehörige** von erwachsenen Autist:innen angeboten werden.
… sollte der **Übergang von Autist:innen vom Jugend- ins Erwachsenenalter** besser begleitet und geregelt werden (z. B. durch eine Fachkraft oder zusätzliche Versorgungsstrukturen).

Abschnitt Versorgungsindikatoren		
Vielen Dank für Ihre bisherigen Angaben. **Es folgen nun einige Fragen zu Diagnostik und Behandlung.**		
Autismusdiagnose Welche Autismus-Diagnose wurde bei Ihnen gestellt?	• frühkindlicher Autismus (nach ICD-10: F84.0) • atypischer Autismus (nach ICD-10: F84.1) • Asperger-Syndrom (nach ICD-10: F84.5) • andere Autismus-Diagnose: [Freitext]	P
Alter bei Diagnose Wie alt waren Sie ungefähr, als die Diagnose gestellt wurde?	• ... (in Jahren)	P
Wartezeit Diagnostik Wie lange haben Sie **ungefähr** auf Ihren ersten Termin zur Abklärung der Autismus-Diagnose gewartet?	• ... Tage/ Wochen/ Monate (Ganze Zahl) • weiß ich nicht	P
Distanz Diagnostik Wie weit war der Ort/die Einrichtung, wo die Autismus-Diagnose gestellt wurde, **ungefähr** von Ihrem (damaligen) Wohnort entfernt?	• ... (km) (ganze Zahl) • weiß ich nicht	P
Ort Diagnostik Wo wurde die Autismus-Diagnose bei Ihnen sicher festgestellt?	• Spezialambulanz bzw. spezialisierte Sprechstunde für Autismus-Spektrum-Störung z. B. einer Klinik/eines Krankenhauses oder eines Medizinischen Versorgungszentrums (MVZ)	P
DSM-5 Wie sehr benötigen Sie Unterstützung aufgrund von Schwierigkeiten ...	• keine • wenig • mittelmäßig • ziemlich • sehr	



Schwierigkeiten in der Organisation/Planung oder im Umgang mit Veränderungen).

1	Angst, Befürchtungen, Scham oder Frustration verhindern, dass ich die medizinische Gesundheitsversorgung nutze.	ja/nein
2	Ich habe Schwierigkeiten, Behandlungen weiterzuverfolgen (z. B. zur Apotheke zu gehen, verschriebene Medikamente zur richtigen Zeit einzunehmen oder einen Nachsorgetermin zu vereinbaren).	
3	Ich habe Schwierigkeiten, medizinische Informationen in konkrete Schritte umzusetzen, die ich unternehmen kann, um meine Gesundheit zu verbessern.	
4	Ich verstehe das Gesundheitssystem nicht.	
5	Es ist zu schwierig, Termine zu machen.	
6	Ich habe Probleme beim Ausfüllen von Formularen.	
7	Mein Verhalten wird von meinen Behandelnden oder dem Personal fehlinterpretiert.	
8	Meine Behandelnden oder das Personal nehmen meine Mitteilungen (sprachlich/nicht-sprachlich) nicht ernst.	
9	Ich kann keine:n Behandelnde:n finden, die/der auf meine Bedürfnisse eingeht.	
10	Meine Behandelnden oder das Personal beziehen mich nicht in Gespräche über meine Gesundheit ein.	
11	Die Kommunikation mit meiner/meinem Behandelnden oder dem Personal ist zu schwierig.	
12	Wenn ich Schmerzen und/oder andere körperliche Symptome erlebe, habe ich Schwierigkeiten diese zu identifizieren und sie meiner/meinem Behandelnden zu berichten.	
13	Sensorische Beschwerden (z. B. das Licht, Gerüche oder Geräusche) stehen meiner Gesundheitsversorgung im Weg.	
14	Bedenken wegen Kosten oder Versicherungsschutz halten mich davon ab, die medizinische Gesundheitsversorgung zu nutzen.	
15	Ich habe keine Möglichkeit zu der Praxis meines Arztes/meiner Ärztin zu kommen.	
16	Ich habe unzureichende soziale, familiäre oder pflegerische Unterstützung.	
17	Ich finde es schwer, mit der Situation im Wartezimmer umzugehen.	

Raymaker-Fragebogen

Bitte geben Sie an, ob die folgenden Barrieren im Gesundheitssystem für Sie zutreffend sind:

Abschnitt Angaben zur Person und Gesundheit (Soziodemographische/ Klinische/ Gesundheitsök. Variablen)

Vielen Dank für Ihre bisherige Mitarbeit!

Teil 2 von 3:

Es folgen nun einige allgemeine Fragen zu Ihrer Person und Gesundheit.

Alter	… Jahre (ganze Zahl) [Freitext]	P

Wie alt sind Sie?		
Geschlecht **Welches Geschlecht haben Sie?**	• weiblich • männlich • divers	P
Krankenversicherung **Sind Sie gesetzlich krankenversichert?**	• ja, ich bin gesetzlich krankenversichert (ggf. inkl. privater Zusatzversicherungen) • nein (z. B. privat versichert) • Ich habe keine Krankenversicherung.	P
Familienstand **Welchen Familienstand haben Sie?**	• ledig • verheiratet (Ehepartner:in, eingetragene:r Lebenspartner:in) oder feste Partnerschaft • verheiratet (in Trennung lebend) • geschieden • verwitwet	P/ Normwerte
Haushalt (1/2) Wie viele Personen leben insgesamt ständig in Ihrem Haushalt, Sie selbst eingeschlossen?	• Zahl der Personen	P/ GesuÖk

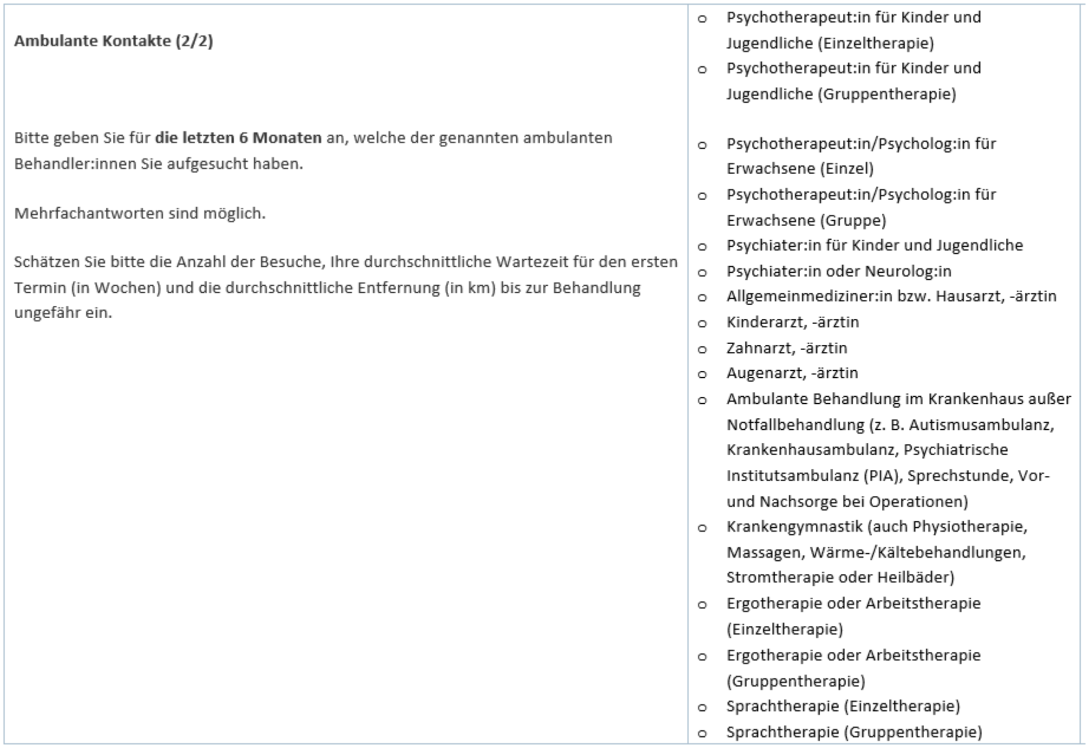
Komorbiditäten (1/2) Haben Sie aufgrund einer der folgenden körperlichen Erkrankungen **in den letzten 6 Monaten** irgendwelche Gesundheitsleistungen in Anspruch genommen oder eine Arztpraxis besucht? Bitte wählen Sie zutreffendes aus. Mehrfachnennungen sind möglich.	• Lungenerkrankung, z. B. Asthma, chron. Bronchitis • Gelenkerkrankung, z. B. Rheuma, Arthrose, Arthritis • Stoffwechselstörungen, z. B. hohes Cholesterin, Schilddrüsenerkrankung • Diabetes • Chron. Schmerzen, z. B. Kopfschmerzen, Rückenschmerzen • Erkrankungen des Verdauungstraktes, z. B. Magen-/Darmgeschwür, Blinddarm-, Lebererkrankung, Gallenblasenerkrankung • Krebserkrankung • Herz- und Kreislauferkrankungen, z. B. Herzinfarkt, Herzschwäche, Schlaganfall, Bluthochdruck, Arterienverkalkung • Hauterkrankung, z. B. Neurodermitis oder Psoriasis • Osteoporose • Epilepsie • keine der genannten somatischen Erkrankungen • nicht zutreffend

Komorbiditäten (2/2) Haben Sie aufgrund einer der folgenden psychischen Erkrankungen **in den letzten 6 Monaten** irgendwelche Gesundheitsleistungen in Anspruch genommen oder eine Arztpraxis besucht? Bitte wählen Sie Zutreffendes aus. Mehrfachnennungen sind möglich.	• Abhängigkeitserkrankung, z. B. aufgrund von Alkohol, Drogen oder Medikamenten • Psychose, z. B. Schizophrenie, Schizoaffektive Störung, „Drogenpsychose" • Affektive Störung, z. B. Depression oder Bipolare Störung • Angststörung, z. B. Panikstörung, Soziale Phobie, generalisierte Angsterkrankung • Zwangsstörung • Posttraumatische Belastungsstörung • Somatoforme Störung (z. B. auch Schmerzstörung) oder psychosomatische Körperbeschwerden • Essstörung • ADHS (Aufmerksamkeits-Defizit-Hyperaktivitätssyndrom) • Persönlichkeitsstörung • anderes: (Freitexteingabe) • nicht zutreffend

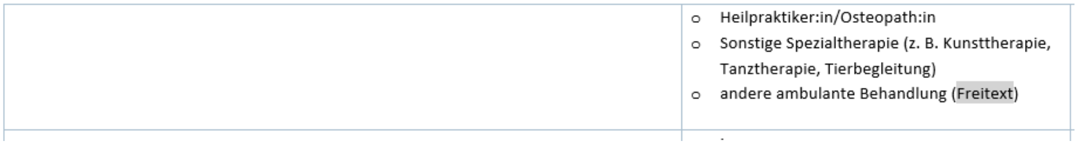
Höchster Schulabschluss Bitte geben Sie Ihren höchsten Schulabschluss an.	• bin noch Schüler:in • ohne Abschluss von der Schule abgegangen • Förder-/Sonderschulabschluss • Hauptschul-/Volksschulabschluss • Realschulabschluss/Mittlere Reife/Abschluss der polytechnischen Oberschule (POS) • Abitur/Fachabitur/Fachhochschulreife/Abschluss der erweiterten Oberschule (EOS) • sonstiger Abschluss [Freitext]

Erwerbstätigkeit (1.3) Welchen Erwerbsstatus haben Sie **zurzeit**? Unter Erwerbstätigkeit wird jede bezahlte bzw. mit Einkommen verbundene Tätigkeit verstanden, egal welchen zeitlichen Umfang sie hat. Mehrfachnennungen sind erlaubt.	• Vollzeit erwerbstätig • Teilzeit erwerbstätig • geringfügig erwerbstätig (450 €-; Mini-; Ein-Euro-Job) • in einer beruflichen Ausbildung/Lehre oder Umschulung • nicht erwerbstätig (Schüler:in; Student:in, die nicht gegen Bezahlung arbeiten; Arbeitslose:r; Rentner:in ohne Nebenverdienst; Vorruheständler:in) • Genanntes nicht zutreffend

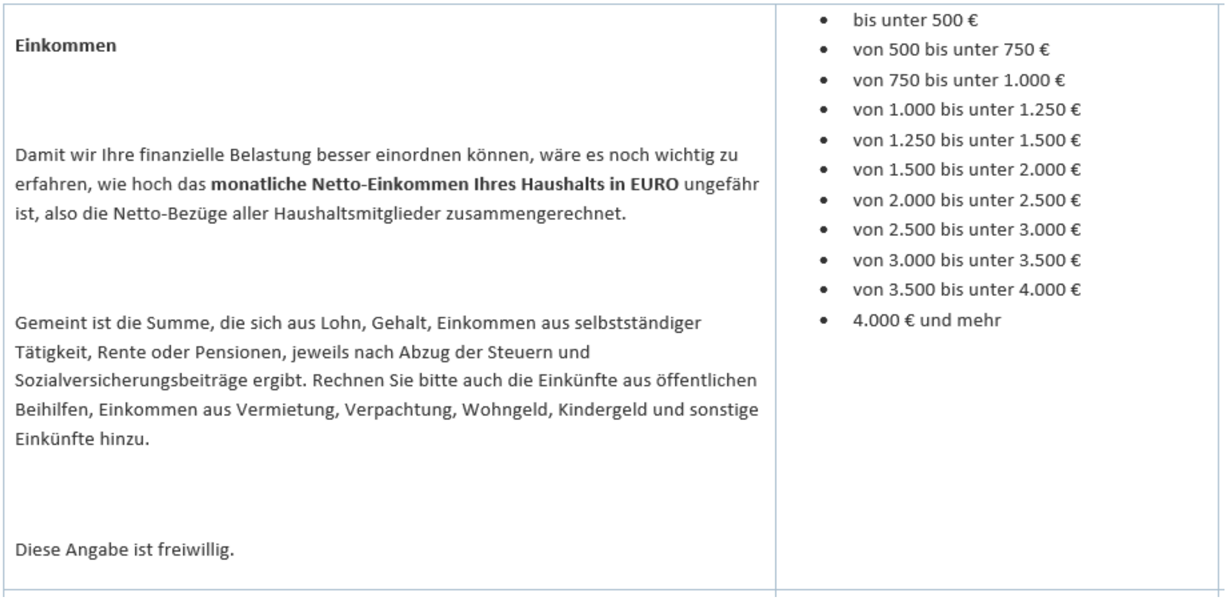
[Inanspruchnahme] Vielen Dank für Ihre bisherigen Angaben. Wir möchten Ihnen nun weitere Fragen zu Ihrer Nutzung von gesundheitlichen Angeboten im Allgemeinen (d. h. nicht nur aufgrund Ihrer Autismus-Diagnose) in der letzten Zeit stellen. Dabei sind ungefähre Angaben ausreichend.	
Ambulante Kontakte (1/2) Haben Sie in den **letzten 6 Monaten** ambulante Behandler:innen aufgesucht? Gemeint ist jeder Besuch in einer Praxis, auch wenn der/die Behandler:in selbst nicht gesprochen wurde (zum Beispiel Rezept abholen, Blutabnahme). Hausbesuche zählen auch dazu.	ja nein



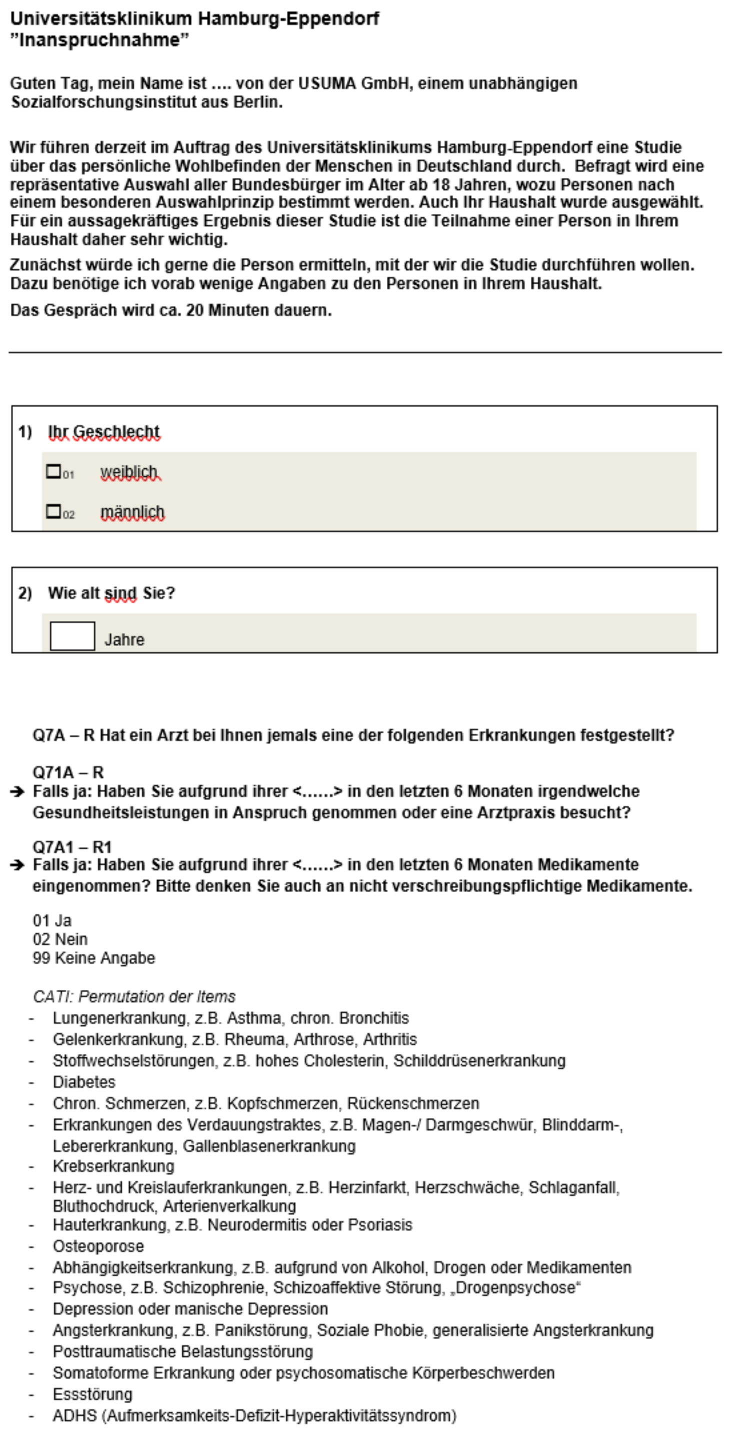
Ambulante Kontakte (2/2) Bitte geben Sie für **die letzten 6 Monaten** an, welche der genannten ambulanten Behandler:innen Sie aufgesucht haben. Mehrfachantworten sind möglich. Schätzen Sie bitte die Anzahl der Besuche, Ihre durchschnittliche Wartezeit für den ersten Termin (in Wochen) und die durchschnittliche Entfernung (in km) bis zur Behandlung ungefähr ein.	○ Psychotherapeut:in für Kinder und Jugendliche (Einzeltherapie) ○ Psychotherapeut:in für Kinder und Jugendliche (Gruppentherapie) ○ Psychotherapeut:in/Psycholog:in für Erwachsene (Einzel) ○ Psychotherapeut:in/Psycholog:in für Erwachsene (Gruppe) ○ Psychiater:in für Kinder und Jugendliche ○ Psychiater:in oder Neurolog:in ○ Allgemeinmediziner:in bzw. Hausarzt, -ärztin ○ Kinderarzt, -ärztin ○ Zahnarzt, -ärztin ○ Augenarzt, -ärztin ○ Ambulante Behandlung im Krankenhaus außer Notfallbehandlung (z. B. Autismusambulanz, Krankenhausambulanz, Psychiatrische Institutsambulanz (PIA), Sprechstunde, Vor- und Nachsorge bei Operationen) ○ Krankengymnastik (auch Physiotherapie, Massagen, Wärme-/Kältebehandlungen, Stromtherapie oder Heilbäder) ○ Ergotherapie oder Arbeitstherapie (Einzeltherapie) ○ Ergotherapie oder Arbeitstherapie (Gruppentherapie) ○ Sprachtherapie (Einzeltherapie) ○ Sprachtherapie (Gruppentherapie)



	○ Heilpraktiker:in/Osteopath:in ○ Sonstige Spezialtherapie (z. B. Kunsttherapie, Tanztherapie, Tierbegleitung) ○ andere ambulante Behandlung (Freitext)



Einkommen Damit wir Ihre finanzielle Belastung besser einordnen können, wäre es noch wichtig zu erfahren, wie hoch das **monatliche Netto-Einkommen Ihres Haushalts in EURO** ungefähr ist, also die Netto-Bezüge aller Haushaltsmitglieder zusammengerechnet. Gemeint ist die Summe, die sich aus Lohn, Gehalt, Einkommen aus selbstständiger Tätigkeit, Rente oder Pensionen, jeweils nach Abzug der Steuern und Sozialversicherungsbeiträge ergibt. Rechnen Sie bitte auch die Einkünfte aus öffentlichen Beihilfen, Einkommen aus Vermietung, Verpachtung, Wohngeld, Kindergeld und sonstige Einkünfte hinzu. Diese Angabe ist freiwillig.	• bis unter 500 € • von 500 bis unter 750 € • von 750 bis unter 1.000 € • von 1.000 bis unter 1.250 € • von 1.250 bis unter 1.500 € • von 1.500 bis unter 2.000 € • von 2.000 bis unter 2.500 € • von 2.500 bis unter 3.000 € • von 3.000 bis unter 3.500 € • von 3.500 bis unter 4.000 € • 4.000 € und mehr



Universitätsklinikum Hamburg-Eppendorf
"Inanspruchnahme"

Guten Tag, mein Name ist …. von der USUMA GmbH, einem unabhängigen Sozialforschungsinstitut aus Berlin.

Wir führen derzeit im Auftrag des Universitätsklinikums Hamburg-Eppendorf eine Studie über das persönliche Wohlbefinden der Menschen in Deutschland durch. Befragt wird eine repräsentative Auswahl aller Bundesbürger im Alter ab 18 Jahren, wozu Personen nach einem besonderen Auswahlprinzip bestimmt werden. Auch Ihr Haushalt wurde ausgewählt. Für ein aussagekräftiges Ergebnis dieser Studie ist die Teilnahme einer Person in Ihrem Haushalt daher sehr wichtig.

Zunächst würde ich gerne die Person ermitteln, mit der wir die Studie durchführen wollen. Dazu benötige ich vorab wenige Angaben zu den Personen in Ihrem Haushalt.

Das Gespräch wird ca. 20 Minuten dauern.

---

1) Ihr Geschlecht

☐01 weiblich
☐02 männlich

2) Wie alt sind Sie?

☐ Jahre

Q7A – R Hat ein Arzt bei Ihnen jemals eine der folgenden Erkrankungen festgestellt?

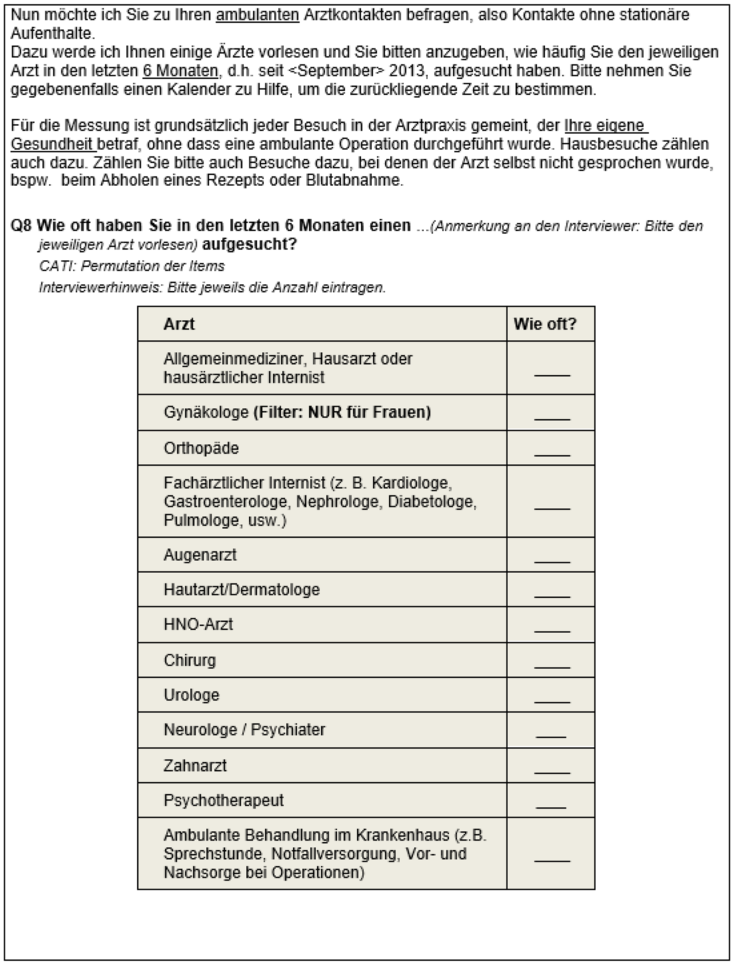
Q71A – R
➔ Falls ja: Haben Sie aufgrund ihrer <……> in den letzten 6 Monaten irgendwelche Gesundheitsleistungen in Anspruch genommen oder eine Arztpraxis besucht?

Q7A1 – R1
➔ Falls ja: Haben Sie aufgrund ihrer <……> in den letzten 6 Monaten Medikamente eingenommen? Bitte denken Sie auch an nicht verschreibungspflichtige Medikamente.

01 Ja
02 Nein
99 Keine Angabe

CATI: Permutation der Items

- Lungenerkrankung, z.B. Asthma, chron. Bronchitis
- Gelenkerkrankung, z.B. Rheuma, Arthrose, Arthritis
- Stoffwechselstörungen, z.B. hohes Cholesterin, Schilddrüsenerkrankung
- Diabetes
- Chron. Schmerzen, z.B. Kopfschmerzen, Rückenschmerzen
- Erkrankungen des Verdauungstraktes, z.B. Magen-/ Darmgeschwür, Blinddarm-, Lebererkrankung, Gallenblasenerkrankung
- Krebserkrankung
- Herz- und Kreislauferkrankungen, z.B. Herzinfarkt, Herzschwäche, Schlaganfall, Bluthochdruck, Arterienverkalkung
- Hauterkrankung, z.B. Neurodermitis oder Psoriasis
- Osteoporose
- Abhängigkeitserkrankung, z.B. aufgrund von Alkohol, Drogen oder Medikamenten
- Psychose, z.B. Schizophrenie, Schizoaffektive Störung, „Drogenpsychose"
- Depression oder manische Depression
- Angsterkrankung, z.B. Panikstörung, Soziale Phobie, generalisierte Angsterkrankung
- Posttraumatische Belastungsstörung
- Somatoforme Erkrankung oder psychosomatische Körperbeschwerden
- Essstörung
- ADHS (Aufmerksamkeits-Defizit-Hyperaktivitätssyndrom)

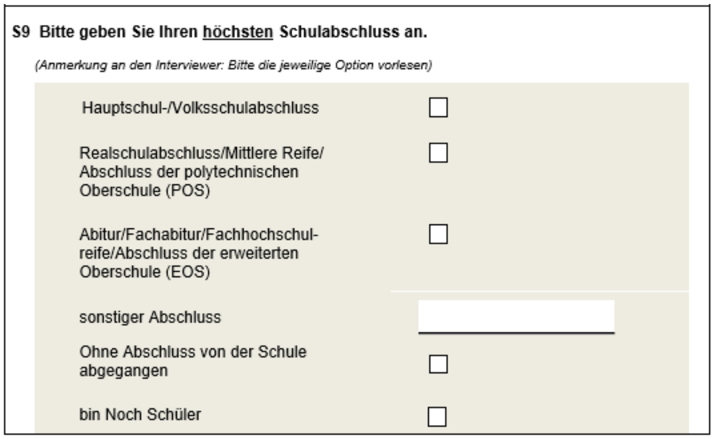


Nun möchte ich Sie zu Ihren ambulanten Arztkontakten befragen, also Kontakte ohne stationäre Aufenthalte.
Dazu werde ich Ihnen einige Ärzte vorlesen und Sie bitten anzugeben, wie häufig Sie den jeweiligen Arzt in den letzten 6 Monaten, d.h. seit <September> 2013, aufgesucht haben. Bitte nehmen Sie gegebenenfalls einen Kalender zu Hilfe, um die zurückliegende Zeit zu bestimmen.

Für die Messung ist grundsätzlich jeder Besuch in der Arztpraxis gemeint, der Ihre eigene Gesundheit betraf, ohne dass eine ambulante Operation durchgeführt wurde. Hausbesuche zählen auch dazu. Zählen Sie bitte auch Besuche dazu, bei denen der Arzt selbst nicht gesprochen wurde, bspw. beim Abholen eines Rezepts oder Blutabnahme.

Q8 Wie oft haben Sie in den letzten 6 Monaten einen *...(Anmerkung an den Interviewer: Bitte den jeweiligen Arzt vorlesen)* **aufgesucht?**
CATI: Permutation der Items
Interviewerhinweis: Bitte jeweils die Anzahl eintragen.

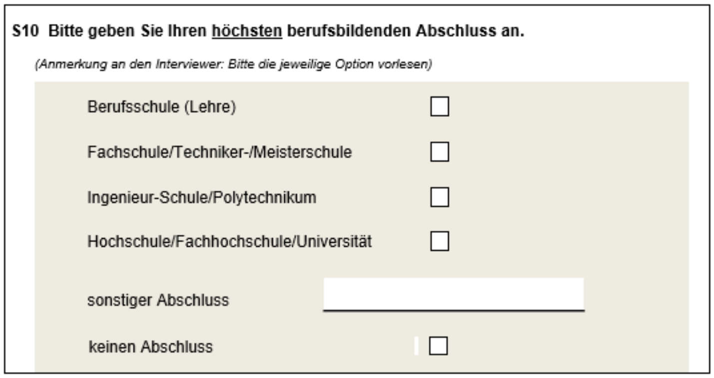
Arzt	**Wie oft?**
Allgemeinmediziner, Hausarzt oder hausärztlicher Internist	____
Gynäkologe **(Filter: NUR für Frauen)**	____
Orthopäde	____
Fachärztlicher Internist (z. B. Kardiologe, Gastroenterologe, Nephrologe, Diabetologe, Pulmologe, usw.)	____
Augenarzt	____
Hautarzt/Dermatologe	____
HNO-Arzt	____
Chirurg	____
Urologe	____
Neurologe / Psychiater	____
Zahnarzt	____
Psychotherapeut	____
Ambulante Behandlung im Krankenhaus (z.B. Sprechstunde, Notfallversorgung, Vor- und Nachsorge bei Operationen)	____



S9 Bitte geben Sie Ihren höchsten Schulabschluss an.

(Anmerkung an den Interviewer: Bitte die jeweilige Option vorlesen)

Hauptschul-/Volksschulabschluss	☐
Realschulabschluss/Mittlere Reife/ Abschluss der polytechnischen Oberschule (POS)	☐
Abitur/Fachabitur/Fachhochschulreife/Abschluss der erweiterten Oberschule (EOS)	☐
sonstiger Abschluss	______________
Ohne Abschluss von der Schule abgegangen	☐
bin Noch Schüler	☐



S10 Bitte geben Sie Ihren höchsten berufsbildenden Abschluss an.

(Anmerkung an den Interviewer: Bitte die jeweilige Option vorlesen)

Berufsschule (Lehre) ☐

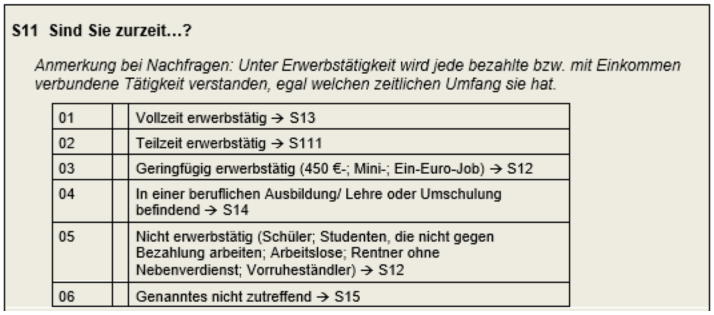
Fachschule/Techniker-/Meisterschule ☐

Ingenieur-Schule/Polytechnikum ☐

Hochschule/Fachhochschule/Universität ☐

sonstiger Abschluss ____________

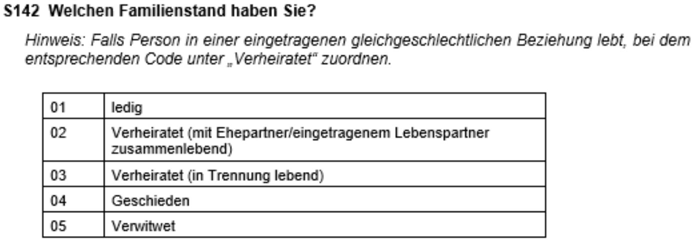
keinen Abschluss ☐



S11 Sind Sie zurzeit…?

Anmerkung bei Nachfragen: Unter Erwerbstätigkeit wird jede bezahlte bzw. mit Einkommen verbundene Tätigkeit verstanden, egal welchen zeitlichen Umfang sie hat.

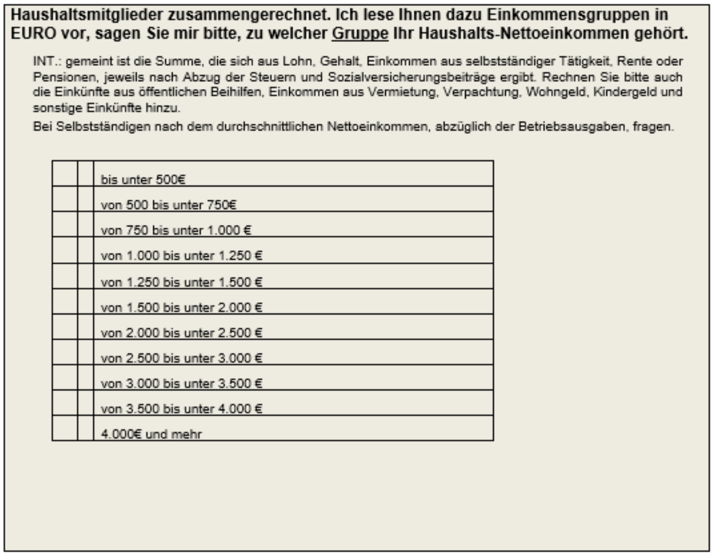
01		Vollzeit erwerbstätig → S13
02		Teilzeit erwerbstätig → S111
03		Geringfügig erwerbstätig (450 €-; Mini-; Ein-Euro-Job) → S12
04		In einer beruflichen Ausbildung/ Lehre oder Umschulung befindend → S14
05		Nicht erwerbstätig (Schüler; Studenten, die nicht gegen Bezahlung arbeiten; Arbeitslose; Rentner ohne Nebenverdienst; Vorruheständler) → S12
06		Genanntes nicht zutreffend → S15



S142 Welchen Familienstand haben Sie?

Hinweis: Falls Person in einer eingetragenen gleichgeschlechtlichen Beziehung lebt, bei dem entsprechenden Code unter „Verheiratet" zuordnen.

01	ledig
02	Verheiratet (mit Ehepartner/eingetragenem Lebenspartner zusammenlebend)
03	Verheiratet (in Trennung lebend)
04	Geschieden
05	Verwitwet



Haushaltsmitglieder zusammengerechnet. Ich lese Ihnen dazu Einkommensgruppen in EURO vor, sagen Sie mir bitte, zu welcher Gruppe Ihr Haushalts-Nettoeinkommen gehört.

INT.: gemeint ist die Summe, die sich aus Lohn, Gehalt, Einkommen aus selbstständiger Tätigkeit, Rente oder Pensionen, jeweils nach Abzug der Steuern und Sozialversicherungsbeiträge ergibt. Rechnen Sie bitte auch die Einkünfte aus öffentlichen Beihilfen, Einkommen aus Vermietung, Verpachtung, Wohngeld, Kindergeld und sonstige Einkünfte hinzu.

Bei Selbstständigen nach dem durchschnittlichen Nettoeinkommen, abzüglich der Betriebsausgaben, fragen.

		bis unter 500€
		von 500 bis unter 750€
		von 750 bis unter 1.000 €
		von 1.000 bis unter 1.250 €
		von 1.250 bis unter 1.500 €
		von 1.500 bis unter 2.000 €
		von 2.000 bis unter 2.500 €
		von 2.500 bis unter 3.000 €
		von 3.000 bis unter 3.500 €
		von 3.500 bis unter 4.000 €
		4.000€ und mehr

Appendix II: SPSS syntax for all analyses

********** Data preparation.

```
***Binary variable for sex.

IF (Geschlecht = 1) sex_binary = 1.
IF (Geschlecht = 2) OR (Geschlecht = 3) sex_binary = 0.
VALUE LABELS sex_binary
   1 'female'
   0 'not female'.
EXECUTE.

***Binary variable for famstand.

IF (familienstand = 1) famstatus_binary = 1.
IF (Familienstand = 2) OR (Familienstand = 3) OR (Familienstand = 4) OR (Familienstand = 5)
famstatus_binary = 0.
VALUE LABELS famstatus_binary
   1 'single'
   0 'in a relationship'.
EXECUTE.

***Binary variable for education level.

IF (Schule_rec = 6) school_binary = 1.
IF (Schule_rec= 1) OR (Schule_rec = 2) OR (Schule_rec = 3) OR (Schule_rec = 4) OR
(Schule_rec = 5)  school_binary = 0.
VALUE LABELS school_binary_binary
   1 'with abitur'
   0 'no abitur'.
RECODE school_binary (SYSMIS=999).
MISSING VALUES school_binary (999).
VALUE LABELS school_binary 999 'k.A.'.
EXECUTE.

***Binary variable for employment status.

IF (Erwe1_SQ005= 1) OR (Erwe1_SQ006= 1) job_binary = 0.
IF (Erwe1_SQ004= 1) OR (Erwe1_SQ003 = 1) OR (Erwe1_SQ002= 1) OR (Erwe1_SQ001 = 1)
job_binary = 1.
VALUE LABELS job_binary
   1 'employed'
   0 'not employed'.
execute.
RECODE job_binary (SYSMIS=999).
MISSING VALUES job_binary (999).
VALUE LABELS job_binary 999 'k.A.'.
EXECUTE.
```

```
***Binary variable for income.

*First income variable recoding into nominal form.
RECODE Einkom ('A1'=1) ('A2'=2) ('A3'=3) ('A4'=4) ('A5'=5) ('A6'=6) ('A7'=7) ('A8'=8) ('A9'=9)
('A10'=10) ('A11'=11) (MISSING=SYSMIS) INTO Einkom_new.
EXECUTE.
*Set the Median.
COMPUTE Median = 6.
*Create new variable for median split.
DO IF (Einkom_new <= Median).
   COMPUTE Income_Median = 1.
ELSE.
   COMPUTE Income_Median = 2.
END IF.
VALUE LABELS Income_Median 1 'lower than 2,000 euros per month' 2 'higher than 2,000
euros per month'.
RECODE Income_Median (SYSMIS = -99).
MISSING VALUES Income_Median (-99).
EXECUTE.

***New variable for the AUT region they live in Germany.

NUMERIC Germany_Region.
DO IF (BundeslandAut = 7) OR (BundeslandAut = 11) OR (BundeslandAut = 3) OR
(BundeslandAut = 15).
  COMPUTE Germany_Region = 1. /* North */
ELSE IF (BundeslandAut = 14) OR (BundeslandAut = 13) OR (BundeslandAut = 5) OR
(BundeslandAut = 6) OR (BundeslandAut = 8) OR (bundeslandAut =10).
  COMPUTE Germany_Region = 3. /* East */
ELSE IF (BundeslandAut = 9) OR (BundeslandAut = 1).
  COMPUTE Germany_Region = 2. /* South */
ELSE IF (BundeslandAut = 2) OR (BundeslandAut = 4) OR (BundeslandAut = 12) OR
(BundeslandAut = 16).
  COMPUTE Germany_Region = 4. /* West */
END IF.
EXECUTE.

***Number of physical comorbidities.

COMPUTE numberofkom1=Kom1_SQ001 + Kom1_SQ002 + Kom1_SQ003 + Kom1_SQ004 +
Kom1_SQ005 + Kom1_SQ006 + Kom1_SQ007 + Kom1_SQ008 + Kom1_SQ009 +
Kom1_SQ010.
EXECUTE.
RECODE numberofkom1 (SYSMIS=999).
MISSING VALUES numberofkom1 (999).
VALUE LABELS numberofkom1 999 'k.A.'.
EXECUTE.

***Number of mental comorbidities.
```

```
COMPUTE numberofkom2=Kom2_SQ001 + Kom2_SQ002 + Kom2_SQ003 + Kom2_SQ004 +
Kom2_SQ005 + Kom2_SQ006 + Kom2_SQ007 + Kom2_SQ008 + Kom2_SQ009 +
Kom2_SQ010.
EXECUTE.
RECODE numberofkom2 (SYSMIS=999).
MISSING VALUES numberofkom2 (999).
VALUE LABELS numberofkom2 999 'k.A.'.
EXECUTE.

***DSM 5 mean calculation.

COMPUTE DSM5_mean=(DSM5_Aut1_neu + DSM5_Aut2_neu) / 2.
VARIABLE LABELS  DSM5_mean 'DSM5 item 1 and 2 mean'.
EXECUTE.

****Coding of the outcome overall use of healthcare.

***1-General practitioner services: Ambul_SQ005 and Ambul_SQ006.

COMPUTE generalmed = Ambul_SQ005 + Ambul_SQ006.
RECODE generalmed (SYSMIS=999).
MISSING VALUES generalmed (999).
VALUE LABELS generalmed 999 'k.A.'.
EXECUTE.

*Binary variable for GP.
IF (generalmed= 0) GP_binary = 0.
IF (generalmed = 1) OR (generalmed = 2) GP_binary = 1.
VALUE LABELS GP_binary
   1 'Yes GP visit'
   0 'no GP visit'.
EXECUTE.
RECODE GP_binary (SYSMIS=999).
MISSING VALUES GP_binary (999).
VALUE LABELS GP_binary 999 'k.A.'.
EXECUTE.

***2-Dental services recoding: Ambul_SQ007.

*Binary variable for dental.
IF (Ambul_SQ007= 0) dental_binary = 0.
IF (Ambul_SQ007 = 1) dental_binary = 1.
VALUE LABELS dental_binary
   1 'Yes dental visit'
   0 'no dental visit'.
EXECUTE.
RECODE dental_binary (SYSMIS=999).
MISSING VALUES dental_binary (999).
VALUE LABELS dental_binary 999 'k.A.'.
EXECUTE.
```

```
***3-ER services recoding: Ambul_SQ009.

*Binary variable for ER.
IF (Ambul_SQ009= 0) ER_binary = 0.
IF (Ambul_SQ009 = 1) ER_binary = 1.
VALUE LABELS ER_binary
   1 'Yes ER visit'
   0 'no ER visit'.
EXECUTE.
RECODE ER_binary (SYSMIS=999).
MISSING VALUES ER_binary (999).
VALUE LABELS ER_binary 999 'k.A.'.
EXECUTE.

***4-Opthalmologist services recoding: Ambul_SQ008.

*Binary variable for augen.
IF (Ambul_SQ008= 0) augen_binary = 0.
IF (Ambul_SQ008 = 1) augen_binary = 1.
VALUE LABELS augen_binary
   1 'Yes augen visit'
   0 'no augen visit'.
EXECUTE.

RECODE augen_binary (SYSMIS=999).
MISSING VALUES augen_binary (999).
VALUE LABELS augen_binary 999 'k.A.'.
EXECUTE.

***5-mental services recoding: Ambul_SQ001, Ambul_SQ015, Ambul_SQ002,Ambul_SQ016,
Ambul_SQ003, Ambul_SQ004.

COMPUTE mentalhelp =SUM.1( Ambul_SQ001, Ambul_SQ002, Ambul_SQ003,Ambul_SQ004,
Ambul_SQ015, Ambul_SQ016).

IF (mentalhelp= 1) OR (mentalhelp= 2)  OR (mentalhelp= 3) OR (mentalhelp= 4) OR
(mentalhelp= 5)  mental_binary = 1.
IF (mentalhelp= 0)  mental_binary = 0.
VALUE LABELS mental_binary
   1 'Yes mental visit'
   0 'no mental visit'.
EXECUTE.
RECODE mental_binary (SYSMIS=999).
MISSING VALUES mental_binary (999).
VALUE LABELS mental_binary 999 'k.A.'.
EXECUTE.

***Outcome variable calculation: “overall use of healthcare”.

COMPUTE total_use_HC=GP_binary+dental_binary+ER_binary+augen_binary+mental_binary.
EXECUTE.
```

```
RECODE total_use_HC(SYSMIS=999).
MISSING VALUES total_use_HC (999).
VALUE LABELS total_use_HC 999 'k.A.'.
EXECUTE.

***Binary coding for use of outpatient care services general.
AUTORECODE VARIABLES=ambul_allgemein
  /INTO ambul_allgemein_bi
  /PRINT.


*Outcome variable calculation with people who didn’t take any outpatient services included.
IF (total_use_HC= 0) OR  (ambul_allgemein_bi=2) total_use_HC_new = 0.
IF (total_use_HC= 1) total_use_HC_new = 1.
IF (total_use_HC= 2) total_use_HC_new = 2.
IF (total_use_HC= 3) total_use_HC_new = 3.
IF (total_use_HC= 4) total_use_HC_new = 4.
IF (total_use_HC= 5) total_use_HC_new = 5.
EXECUTE.

*overall use of healthcare new calc.
RECODE total_use_HC_new (0=0) (1=1) (2=2) (3=3) (4=4) (5=5) (999=SYSMIS)
(MISSING=SYSMIS).
EXECUTE.
RECODE total_use_HC_new (SYSMIS=999).
MISSING VALUES total_use_HC_new (999).
VALUE LABELS total_use_HC_new 999 'k.A.'.
EXECUTE.

***Raymaker experienced barriers sum score calc.

COMPUTE Ray_summe=Ray1 + Ray2 + Ray3 + Ray4 + Ray5 + Ray6 + Ray7 + Ray8 + Ray9 +
Ray10 + Ray11 + Ray12 + Ray13 + Ray14 + Ray15 + Ray16 + Ray17.
EXECUTE.
```

************Case control matching between BASS sample and General population sample and new matched sample data preparation.**

```
*Recoding sex variable into binary form so maximum number of matches is taken into
consideration.

RECODE sex (0=0) (2=0) (1=1) INTO sex_binary.
VARIABLE LABELS sex_binary 'sex binary female vs not female'.
EXECUTE.

*Case control process, end result is 288 people from BASS and 288 people from the general
population.

FUZZY BY=Alter sex_binary SUPPLIERID=ID NEWDEMANDERIDVARS=matchID
GROUP=group FUZZ=0 0
```

```
MATCHGROUPVAR=matchgroup DS3=MATCH_ID BEST=PROPOR

/OPTIONS SAMPLEWITHREPLACEMENT=NO SHUFFLE=FALSE.

DATASET COPY Selecteddata_matching.
DATASET ACTIVATE Selecteddata_matching.
FILTER OFF.
USE ALL.
SELECT IF (matchdiff_ = 0).
EXECUTE.

DATASET ACTIVATE Selecteddata_matching.
ADD FILES /FILE=*
  /FILE='MATCH_ID'.
EXECUTE.

*t-test on age and chi2 for sex binary to make sure there is no sig difference between my
matched population.

CROSSTABS
  /TABLES=group BY sex_binary
  /FORMAT=AVALUE TABLES
  /STATISTICS=CHISQ
  /CELLS=COUNT
  /COUNT ROUND CELL.

T-TEST GROUPS=group(0 1)
  /MISSING=ANALYSIS
  /VARIABLES=Alter
  /ES DISPLAY(TRUE)
  /CRITERIA=CI(.95).

***recoding of sociodemographic and clinical factors for comparison of matched data.

*Binary variable for famstand.

IF (familienstandAut = 1) famstatus_binary = 1.
IF (familienstandAut = 2) OR (familienstandAut = 3) OR (FamilienstandAut = 4) OR
(FamilienstandAut = 5) famstatus_binary = 0.

VALUE LABELS famstatus_binary
    1 'single'
    0 'in a relationship'.
EXECUTE.

*Binary variable for education level.
IF (Schule = 6) school_binary = 1.
IF (Schule= 1) OR (Schule = 2) OR (Schule = 3) OR (Schule = 4) OR (Schule = 5)
school_binary = 0.

VALUE LABELS school_binary_binary
```

```
   1 'with abitur'
   0 'no abitur'.

RECODE school_binary (SYSMIS=999).
MISSING VALUES school_binary (999).
VALUE LABELS school_binary 999 'k.A.'.
EXECUTE.

***Binary variable for employment status.

IF (Erwerb= 5) OR (Erwerb= 6) job_binary = 0.
IF (Erwerb= 1) OR (Erwerb= 2) OR (Erwerb= 3) OR (Erwerb = 4) job_binary = 1.

VALUE LABELS job_binary
   1 'employed'
   0 'not employed'.
execute.
RECODE job_binary (SYSMIS=999).
MISSING VALUES job_binary (999).
VALUE LABELS job_binary 999 'k.A.'.
EXECUTE.

***New calculation of the number of somatic comorbidities for the comparison with only the
variables included that are present in both data sets (as some coms were not asked from the
people in the general population study).

COMPUTE numberofkom1_CG=Kom1_SQ001 + Kom1_SQ002 + Kom1_SQ003 +
Kom1_SQ004 +Kom1_SQ005+ Kom1_SQ006 +Kom1_SQ007 + Kom1_SQ008+Kom1_SQ009.
EXECUTE.

***New calculation of the number of mental comorbidities for the comparison with only the
variables included that are present in both data sets (as some coms were not asked from the
people in the general population study).

COMPUTE numberofkom2_CG=Kom2_SQ001 + Kom2_SQ002 + Kom2_SQ003 +
Kom2_SQ004 + Kom2_SQ006 + Kom2_SQ007 + Kom2_SQ008.
EXECUTE.

***Binary variable for GP.

RECODE amb_allgarzt (0=0) (SYSMIS=SYSMIS) (1 thru 50=1) INTO amb_allg_new.
VARIABLE LABELS  amb_allg_new 'new coding of ambulante allgemein arzt into yes or no '.
EXECUTE.

DATASET ACTIVATE dataset2.
RECODE amb_kindarzt (0=0) (SYSMIS=SYSMIS) (1 thru 11=1) INTO amb_kinderarzt_new.
VARIABLE LABELS  amb_kinderarzt_new 'new coding of ambulante allgemein arzt into yes or
no '.
EXECUTE.
RECODE amb_kinderarzt_new (SYSMIS=999).
MISSING VALUES amb_kinderarzt_new  (999).
```

```
VALUE LABELS amb_kinderarzt_new  'k.A.'.
EXECUTE.


COMPUTE generalmed = amb_allg_new + amb_kinderarzt_new.

RECODE generalmed (SYSMIS=999).
MISSING VALUES generalmed (999).
VALUE LABELS generalmed 999 'k.A.'.
EXECUTE.

IF (generalmed= 0) GP_binary = 0.
IF (generalmed = 1)  OR ( generalmed =2) GP_binary = 1.

VALUE LABELS GP_binary
   1 'Yes GP visit'
   0 'no GP visit'.

EXECUTE.

RECODE GP_binary (SYSMIS=999).
MISSING VALUES GP_binary (999).
VALUE LABELS GP_binary 999 'k.A.'.
EXECUTE.

***2-dental services recoding: Ambul_SQ007.

RECODE amb_zahnarzt (0=0) (SYSMIS=SYSMIS) (1 thru 30=1) INTO amb_zahnarzt_new.
VARIABLE LABELS  amb_zahnarzt_new 'new coding of ambulante zahn arzt into yes or no '.
EXECUTE.

*Binary variable for dental.
IF (amb_zahnarzt_new= 0) dental_binary = 0.
IF (amb_zahnarzt_new = 1)  dental_binary = 1.

VALUE LABELS dental_binary
   1 'Yes dental visit'
   0 'no dental visit'.

EXECUTE.

RECODE dental_binary (SYSMIS=999).
MISSING VALUES dental_binary (999).
VALUE LABELS dental_binary 999 'k.A.'.
EXECUTE.

***3-ER services recoding:
RECODE amb_KH (0=0) (SYSMIS=SYSMIS) (1 thru 52=1) INTO amb_KH_new.
VARIABLE LABELS  amb_KH_new 'new coding of ambulante KH arzt into yes or no '.
EXECUTE.
```

```
*binary variable for ER.
IF (amb_KH_new= 0) ER_binary = 0.
IF (amb_KH_new = 1)  ER_binary = 1.

VALUE LABELS ER_binary
   1 'Yes ER visit'
   0 'no ER visit'.
EXECUTE.

RECODE ER_binary (SYSMIS=999).
MISSING VALUES ER_binary (999).
VALUE LABELS ER_binary 999 'k.A.'.
EXECUTE.

***4-opthalmologist services recoding.

RECODE amb_augarzt (0=0) (SYSMIS=SYSMIS) (1 thru 11=1) INTO amb_augarzt_new.
VARIABLE LABELS  amb_augarzt_new 'new coding of ambulante augen arzt into yes or no '.
EXECUTE.

*binary variable for augen.
IF (amb_augarzt_new= 0) augen_binary = 0.
IF (amb_augarzt_new= 1)  augen_binary = 1.

VALUE LABELS augen_binary
   1 'Yes augen visit'
   0 'no augen visit'.
   EXECUTE.

RECODE augen_binary (SYSMIS=999).
MISSING VALUES augen_binary (999).
VALUE LABELS augen_binary 999 'k.A.'.
EXECUTE.

***mental health services binary recoding.

RECODE amb_pt_kj_einz (0=0) (SYSMIS=SYSMIS) (1 thru 190=1) INTO amb_pt_kj_einz_new.
VARIABLE LABELS amb_pt_kj_einz_new 'new coding of ambulante amb pt jk einz arzt into yes
or no '.
EXECUTE.

RECODE amb_pt_kj_gr (0=0) (SYSMIS=SYSMIS) (1 thru 190=1) INTO amb_pt_kj_gr_new.
VARIABLE LABELS amb_pt_kj_gr_new 'new coding of ambulante amb pt kj gr einz arzt into yes
or no '.
EXECUTE.

RECODE amb_pt_erw_gr (0=0) (SYSMIS=SYSMIS) (1 thru 190=1) INTO amb_pt_erw_gr_new.
VARIABLE LABELS amb_pt_erw_gr_new 'new coding of ambulante amb pt erw einz arzt into
yes or no '.
EXECUTE.
```

```
RECODE amb_pt_erw_einz (0=0) (SYSMIS=SYSMIS) (1 thru 190=1) INTO
amb_pt_erw_einz_new.
VARIABLE LABELS amb_pt_erw_einz_new 'new coding of ambulante amb pt erw  einz arzt into
yes or no '.
EXECUTE.

RECODE amb_psy_erw (0=0) (SYSMIS=SYSMIS) (1 thru 190=1) INTO amb_psy_erw_new.
VARIABLE LABELS amb_psy_erw_new 'new coding of ambulante amb psy erw  arzt into yes or
no '.
EXECUTE.

RECODE amb_psy_kj (0=0) (SYSMIS=SYSMIS) (1 thru 190=1) INTO amb_psy_kj_new.
VARIABLE LABELS amb_psy_kj_new 'new coding of ambulante amb psy kj  arzt into yes or no'.
EXECUTE.


IF (amb_pt_kj_einz_new= 0) OR (amb_pt_kj_gr_new= 0)  OR (amb_pt_erw_einz_new= 0) OR
(amb_pt_erw_gr_new= 0) OR  (amb_psy_kj_new= 0) OR  (amb_psy_erw_new= 0)
mental_binary = 0.
IF (amb_pt_kj_einz_new= 1) OR (amb_pt_kj_gr_new= 1)  OR (amb_pt_erw_einz_new= 1) OR
(amb_pt_erw_gr_new= 1) OR  (amb_psy_kj_new= 1) OR  (amb_psy_erw_new= 1)
mental_binary = 1.

VALUE LABELS mental_binary
   1 'Yes mental visit'
   0 'no mental visit'.
   EXECUTE.

RECODE mental_binary (SYSMIS=999).
MISSING VALUES mental_binary (999).
VALUE LABELS mental_binary 999 'k.A.'.
EXECUTE.


***overall use of healthcare variable calculation.

COMPUTE total_use_HC=GP_binary+dental_binary+ER_binary+augen_binary+mental_binary.
EXECUTE.
RECODE total_use_HC(SYSMIS=999).
MISSING VALUES total_use_HC (999).
VALUE LABELS total_use_HC 999 'k.A.'.
EXECUTE.
```

************Descriptive analysis of BASS sample.**

```
DESCRIPTIVES VARIABLES=Einkom_new Alter AlterDiagAut Familienstand Geschlecht
AutDiagnose Schule_rec Erwe1_SQ001 Erwe1_SQ002 Erwe1_SQ003 Erwe1_SQ004
Erwe1_SQ005
  /STATISTICS=MEAN STDDEV MIN MAX.
```

```
FREQUENCIES Einkom_new Familienstand Geschlecht AutDiagnose
    Schule_rec Erwe1_SQ001 Erwe1_SQ002 Erwe1_SQ003 Erwe1_SQ004 Erwe1_SQ005.

FREQUENCIES Ray1 Ray2 Ray3 Ray4 Ray5 Ray6 Ray7 Ray8 Ray9 Ray10 Ray11 Ray12
Ray13 Ray14 Ray15 Ray16 Ray17 DSM5_Aut1_neu DSM5_Aut2_neu.

FREQUENCIES Kom1_SQ001 Kom1_SQ002 Kom1_SQ003 Kom1_SQ004
    Kom1_SQ005 Kom1_SQ006 Kom1_SQ007 Kom1_SQ008 Kom1_SQ009 Kom1_SQ010
Kom2_SQ001 Kom2_SQ002 Kom2_SQ003
    Kom2_SQ004 Kom2_SQ005 Kom2_SQ006 Kom2_SQ007 Kom2_SQ008 Kom2_SQ009
Kom2_SQ010 Kom2_SQ01.

***Normality distribution tests.

EXAMINE VARIABLES=Alter AlterDiagAut Ray_Summe numberofkom1 numberofkom2
DSM5_mean total_use_HC_new
  /PLOT BOXPLOT STEMLEAF HISTOGRAM NPPLOT
  /COMPARE GROUPS
  /STATISTICS DESCRIPTIVES
  /CINTERVAL 95
  /MISSING LISTWISE
  /NOTOTAL.

*** graph country distribution.
GRAPH
  /PIE=COUNT BY Germany_Region.

***Descriptive analysis outcome variable and binary predictors of BASS sample.

DESCRIPTIVES VARIABLES= Alter job_binary Income_Median sex_binary famstatus_binary
school_binary DSM5_mean total_use_HC_new Ray_Summe numberofkom1 numberofkom2
  /STATISTICS=MEAN STDDEV MIN MAX.

FREQUENCIES VARIABLES=job_binary Income_Median sex_binary
    famstatus_binary school_binary total_use_HC_new.

***Descriptive analysis of GENERAL POPULATION SAMPLE.

SORT CASES  BY group.
SPLIT FILE SEPARATE BY group.
*Group 0 = general population sample, Group 1 = BASS sample.

DESCRIPTIVES VARIABLES=Alter
  /STATISTICS=MEAN STDDEV MIN MAX.

FREQUENCIES sex_binary famstatus_binary school_binary job_binary numberofkom1
    numberofkom2 total_use_HC.

*** comparison healthcare services graphs between BASS and kontrolle.
GRAPH
```

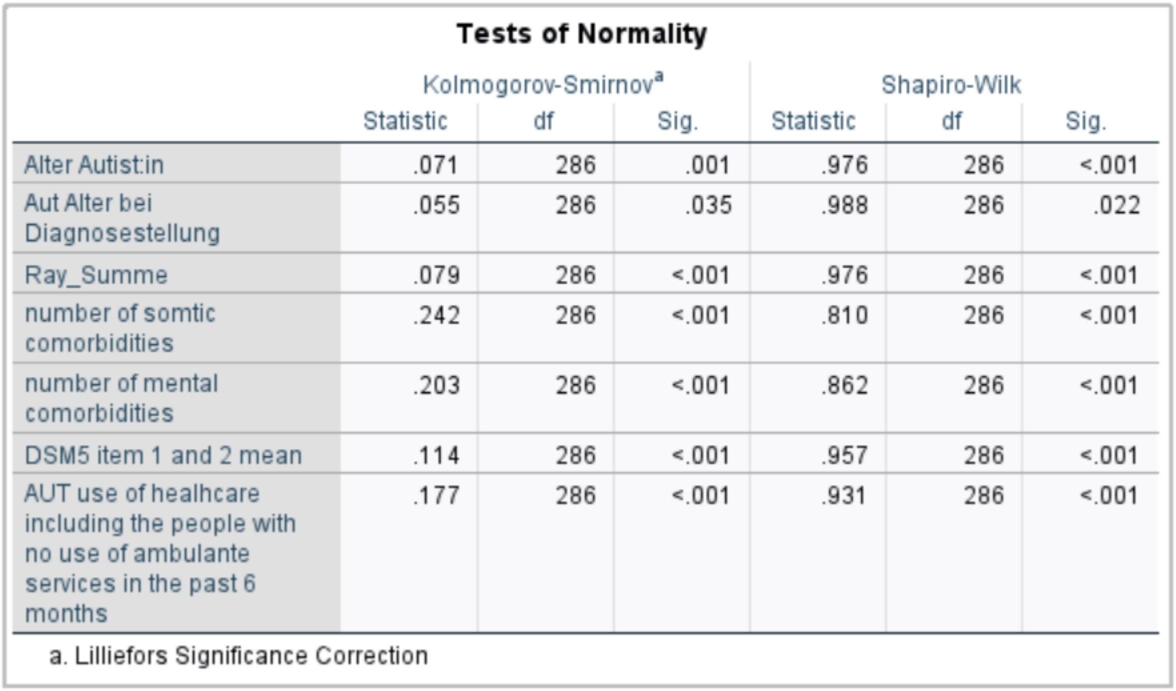
```
  /PIE=SUM(GP_binary) SUM(dental_binary) SUM(ER_binary) SUM(augen_binary)
SUM(mental_binary)
  /MISSING=LISTWISE.

***comparison between number of somatic and mental comorbidities among both pop.
GRAPH
  /BAR(GROUPED)=SUM(Kom1_SQ001) SUM(Kom1_SQ002) SUM(Kom1_SQ003)
SUM(Kom1_SQ004) SUM(Kom1_SQ005)
    SUM(Kom1_SQ006) SUM(Kom1_SQ007) SUM(Kom1_SQ008) SUM(Kom1_SQ009) BY
group
  /MISSING=LISTWISE.

GRAPH
  /BAR(GROUPED)=SUM(Kom2_SQ001) SUM(Kom2_SQ002) SUM(Kom2_SQ003)
SUM(Kom2_SQ004) SUM(Kom2_SQ006)
    SUM(Kom2_SQ007) SUM(Kom2_SQ008) BY group
  /MISSING=LISTWISE.

***Test metric variables for normal distribution.

*For matched data set in prep of comparison.

EXAMINE VARIABLES= Alter total_use_HC
  /PLOT BOXPLOT HISTOGRAM NPPLOT
  /COMPARE GROUPS
  /STATISTICS DESCRIPTIVES
  /CINTERVAL 95
  /MISSING LISTWISE
  /NOTOTAL.

EXAMINE VARIABLES=Alter total_use_HC physicalkom_rec mentalkom_rec
  /PLOT BOXPLOT HISTOGRAM NPPLOT
  /COMPARE GROUPS
  /STATISTICS DESCRIPTIVES
  /CINTERVAL 95
  /MISSING LISTWISE
  /NOTOTAL.

***Man-Whitney-U test.

* First turn split off, then run MWU.

split file off.
EXECUTE.

NPAR TESTS
  /M-W= total_use_HC BY group(1 0)
  /K-S= total_use_HC BY group(1 0)
  /STATISTICS=DESCRIPTIVES
  /MISSING ANALYSIS.
```

```
***comparison healthcare use between BASS and kontrolle.

GRAPH
  /BAR(GROUPED)=PCT BY total_use_HC BY group.

***Multiple imputation which will be used for the regression analysis later on.

*Impute Missing Data Values.

DATASET DECLARE MI_dataset_final.
MULTIPLE IMPUTATION Income_Median Alter job_binary numberofkom1 numberofkom2
school_binary
    famstatus_binary sex_binary Ray_Summe DSM5_mean total_use_HC_new
  /IMPUTE METHOD=AUTO NIMPUTATIONS=10 MAXPCTMISSING=NONE
  /CONSTRAINTS Alter( ROLE=IND)
  /CONSTRAINTS numberofkom1( ROLE=DEP)
  /CONSTRAINTS numberofkom2( ROLE=DEP)
  /CONSTRAINTS famstatus_binary( ROLE=IND)
  /CONSTRAINTS sex_binary( ROLE=IND)
  /CONSTRAINTS Ray_Summe( ROLE=IND)
  /CONSTRAINTS DSM5_mean( ROLE=IND)
  /CONSTRAINTS total_use_HC_new( ROLE=IND)
  /MISSINGSUMMARIES NONE
  /IMPUTATIONSUMMARIES MODELS
  /OUTFILE IMPUTATIONS=MI_dataset_final.

***First regression model with only sociodemographic factors.

REGRESSION
  /MISSING LISTWISE
  /STATISTICS COEFF OUTS R ANOVA
  /CRITERIA=PIN(.05) POUT(.10)
  /NOORIGIN
  /DEPENDENT total_use_HC_new
  /METHOD= Alter sex_binary famstatus_binary job_binary Income_Median school_binary.

*** Second model with only clinical factors.

REGRESSION
  /MISSING LISTWISE
  /STATISTICS COEFF OUTS R ANOVA
  /CRITERIA=PIN(.05) POUT(.10)
  /NOORIGIN
  /DEPENDENT total_use_HC_new
  /METHOD=ENTER numberofkom1 numberofkom2 DSM5_mean.

***Third model with only barriers to healthcare experienced.

REGRESSION
  /MISSING LISTWISE
  /STATISTICS COEFF OUTS R ANOVA
```

```
  /CRITERIA=PIN(.05) POUT(.10)
  /NOORIGIN
  /DEPENDENT total_use_HC_new
  /METHOD=ENTER Ray_Summe.

***Final regression model that will be used for the assumptions testing of MLR and for reporting
of the results in the thesis.

REGRESSION
  /DESCRIPTIVES MEAN STDDEV CORR SIG N
  /MISSING LISTWISE
  /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL ZPP
  /CRITERIA=PIN(.05) POUT(.10)
  /NOORIGIN
  /DEPENDENT total_use_HC_new
  /METHOD=ENTER Alter sex_binary job_binary school_binary Income_Median
famstatus_binary DSM5_mean
    numberofkom1 numberofkom2 Ray_Summe
  /PARTIALPLOT ALL
  /RESIDUALS DURBIN HISTOGRAM(ZRESID) NORMPROB(ZRESID)
  /CASEWISE PLOT(ZRESID) OUTLIERS(3)
  /SAVE PRED COOK LEVER SRESID SDRESID.


*** Bivariate Analysis calculation.
CORRELATIONS
  /VARIABLES= DSM5_mean Alter Ray_Summe
  /PRINT=TWOTAIL NOSIG FULL
  /MISSING=PAIRWISE.
NONPAR CORR
  /VARIABLES=sex_binary famstatus_binary school_binary job_binary Income_Median
numberofkom1 numberofkom2
  /PRINT=SPEARMAN TWOTAIL NOSIG FULL
  /MISSING=PAIRWISE.
```

Appendix V: Supplementary output from SPSS.

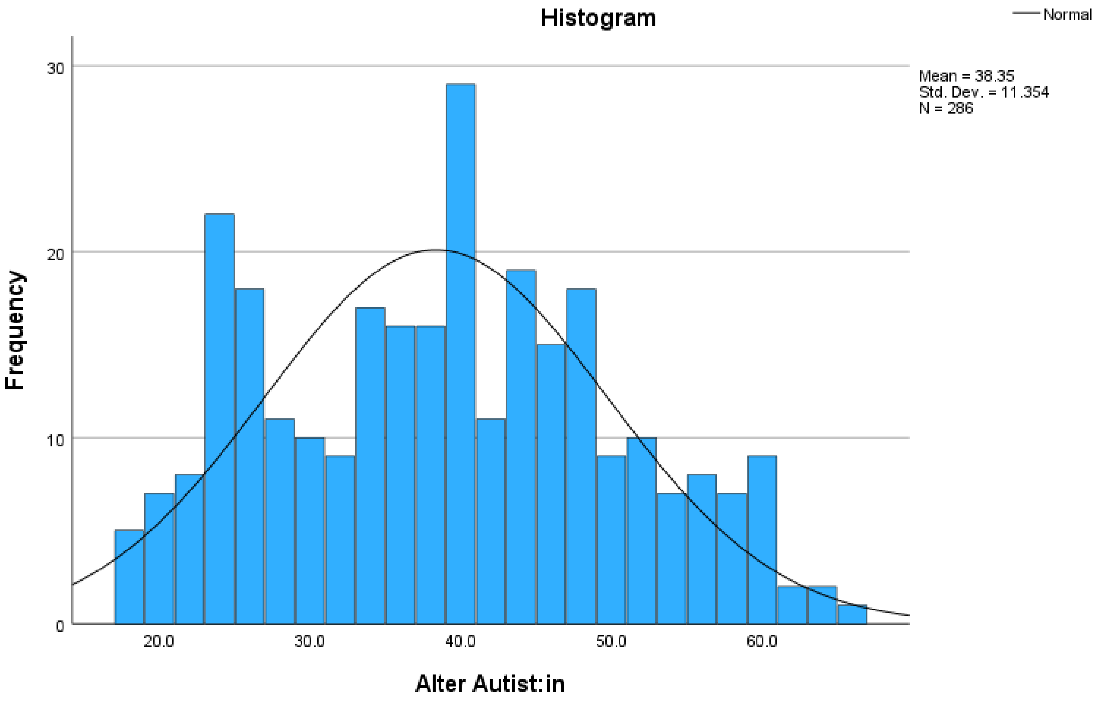
For BASS sample:

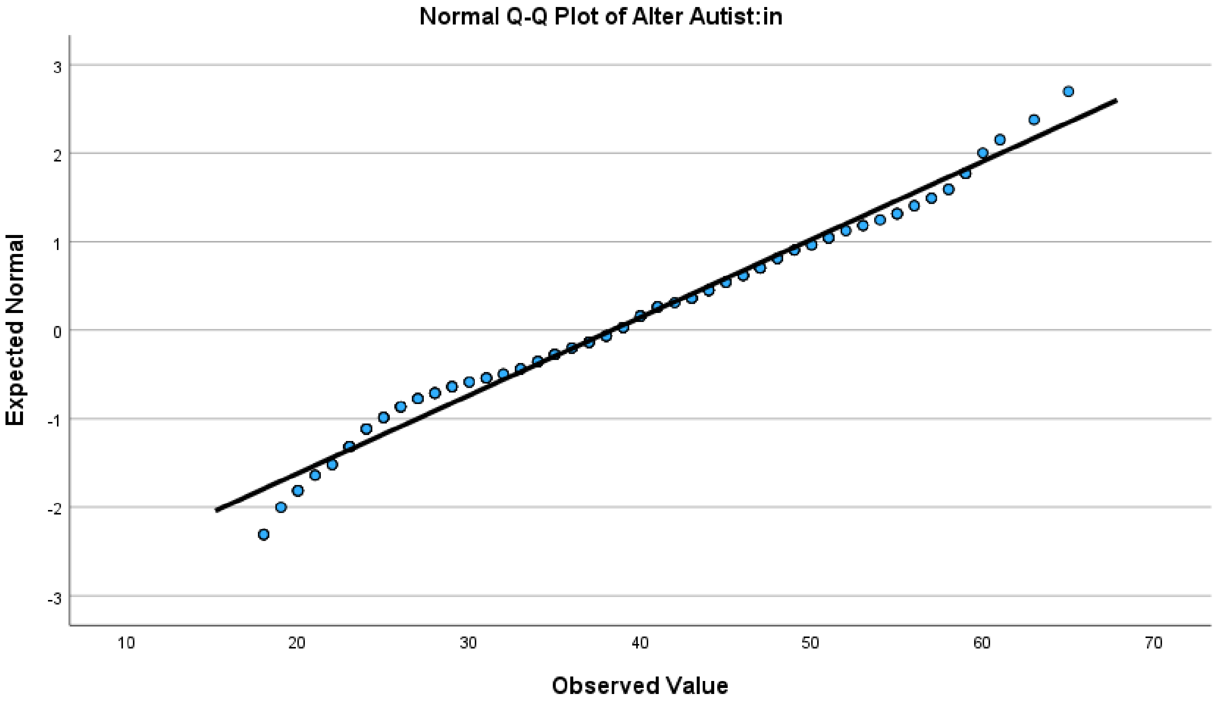


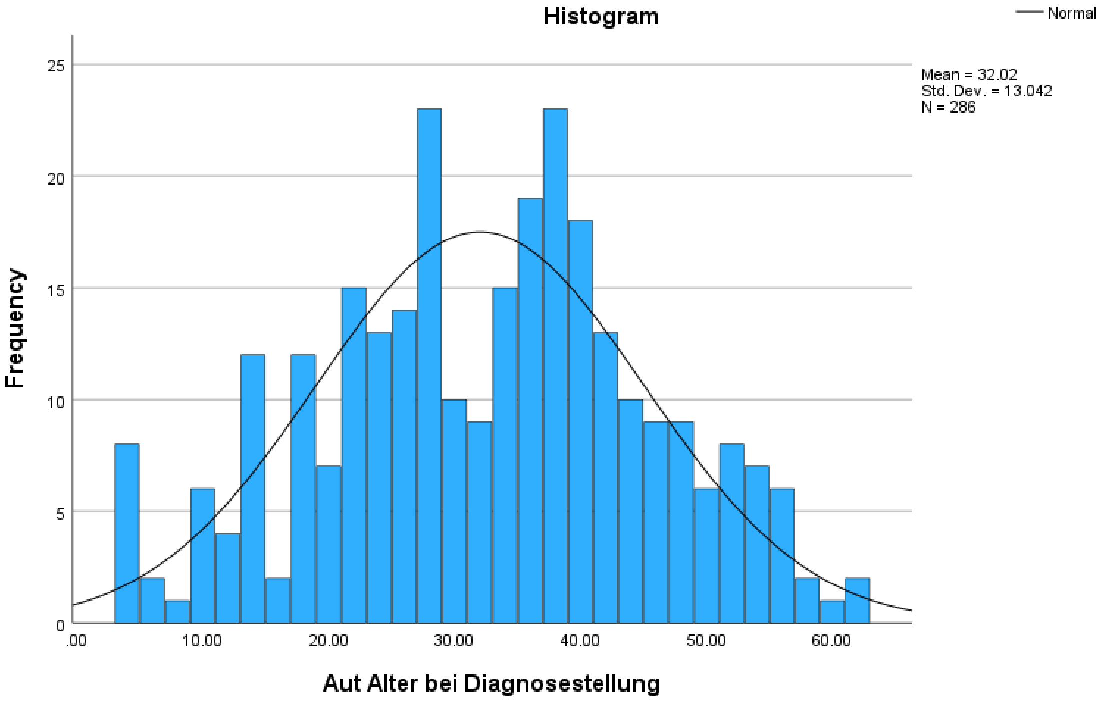
Tests of Normality

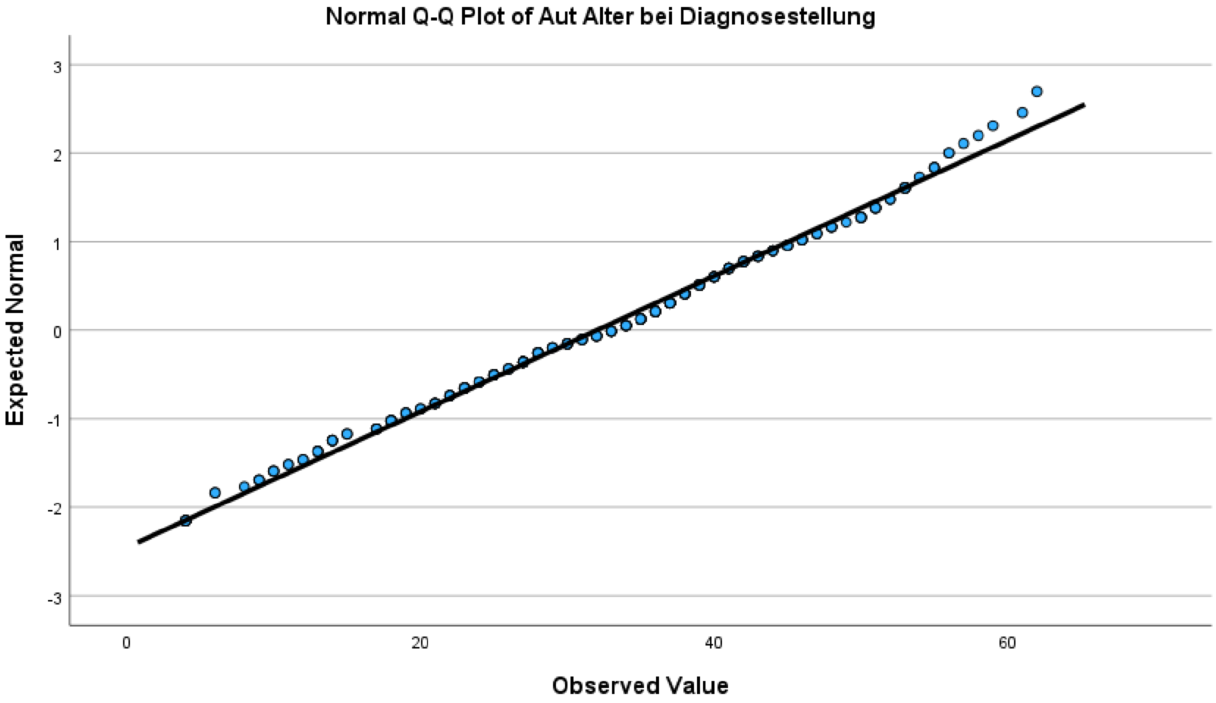
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Alter Autist:in	.071	286	.001	.976	286	<.001
Aut Alter bei Diagnosestellung	.055	286	.035	.988	286	.022
Ray_Summe	.079	286	<.001	.976	286	<.001
number of somtic comorbidities	.242	286	<.001	.810	286	<.001
number of mental comorbidities	.203	286	<.001	.862	286	<.001
DSM5 item 1 and 2 mean	.114	286	<.001	.957	286	<.001
AUT use of healhcare including the people with no use of ambulante services in the past 6 months	.177	286	<.001	.931	286	<.001

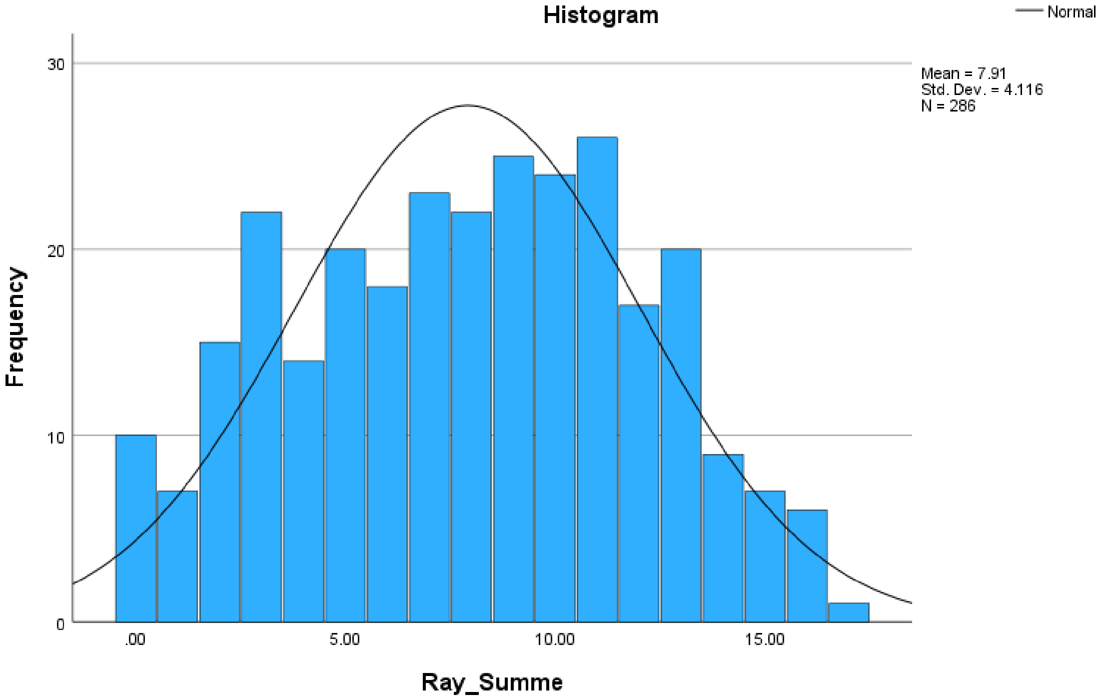
a. Lilliefors Significance Correction

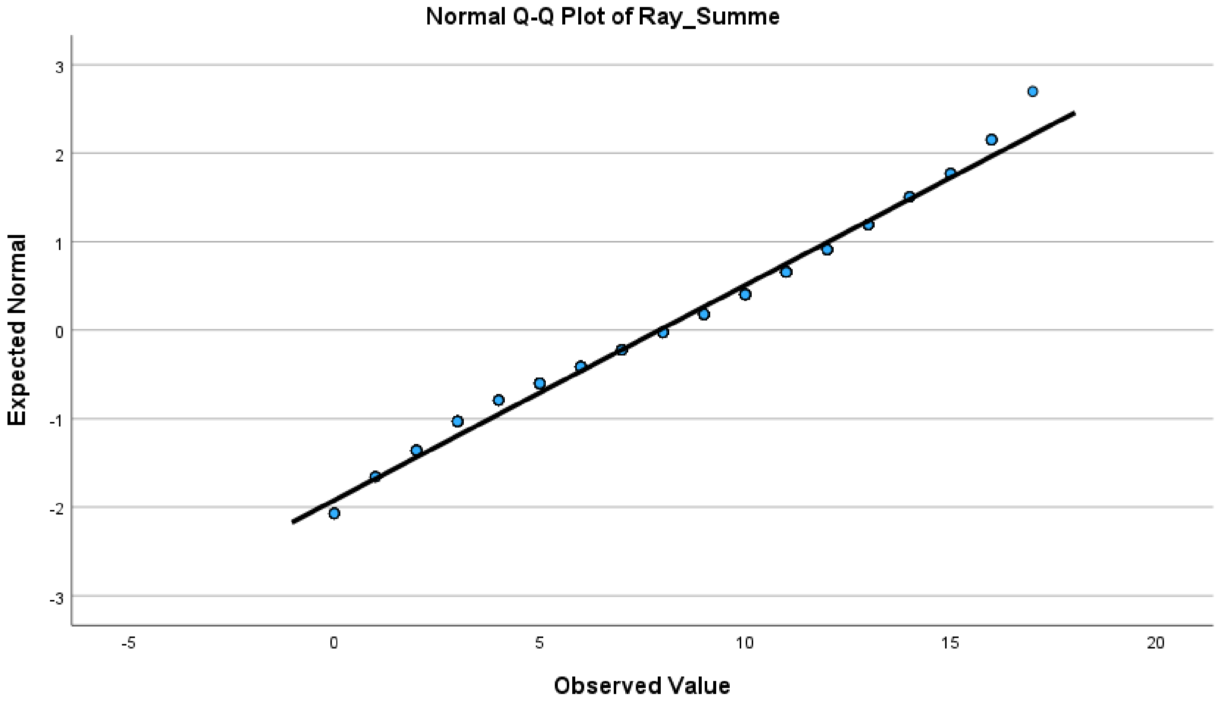


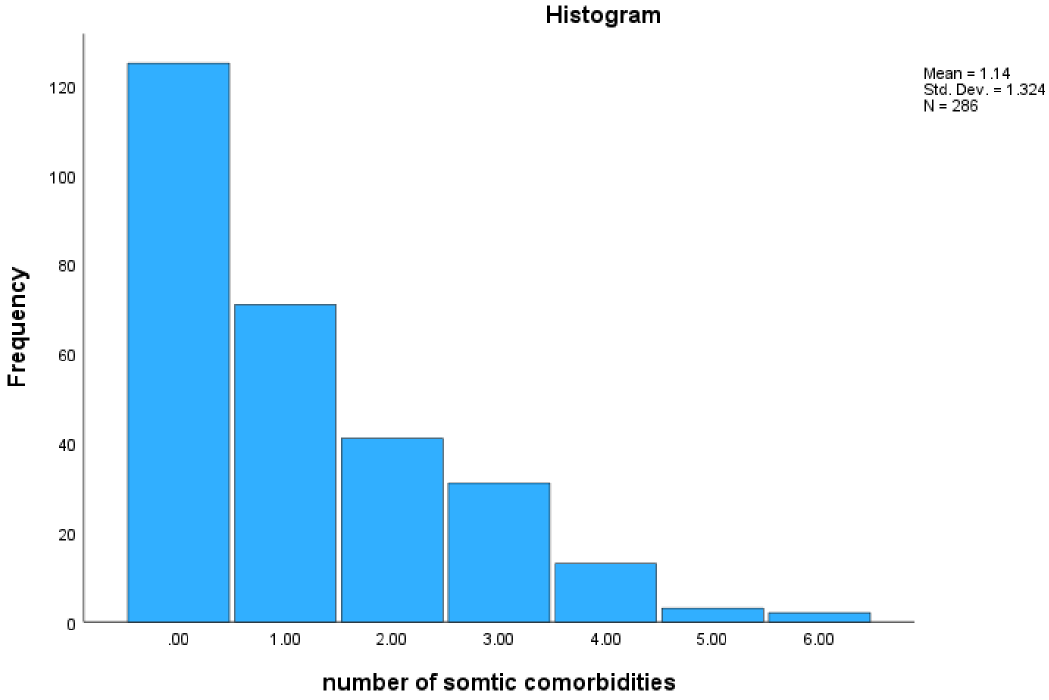

Normal Q-Q Plot of Alter Autist:in
Expected Normal
3
2
1
0
-1
-2
-3
10
20
30
40
50
60
70
Observed Value

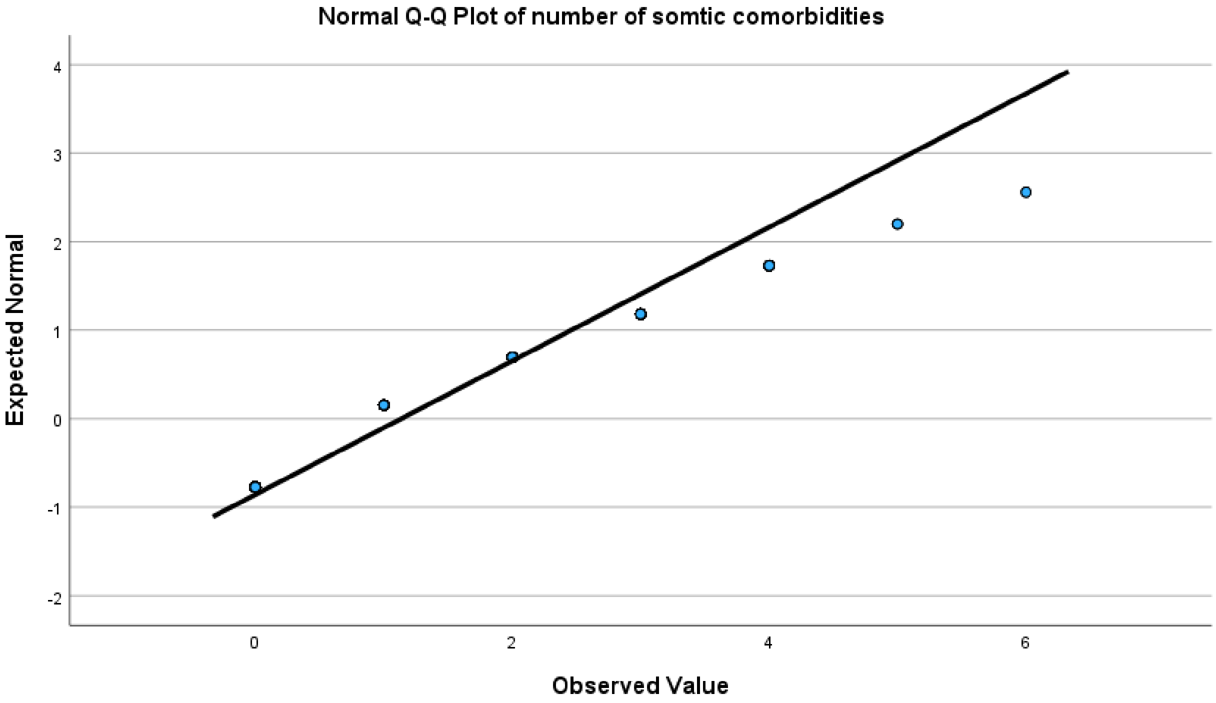

Histogram
Normal
Mean = 32.02
Std. Dev. = 13.042
N = 286
Frequency
25
20
15
10
5
0
.00
10.00
20.00
30.00
40.00
50.00
60.00
Aut Alter bei Diagnosestellung

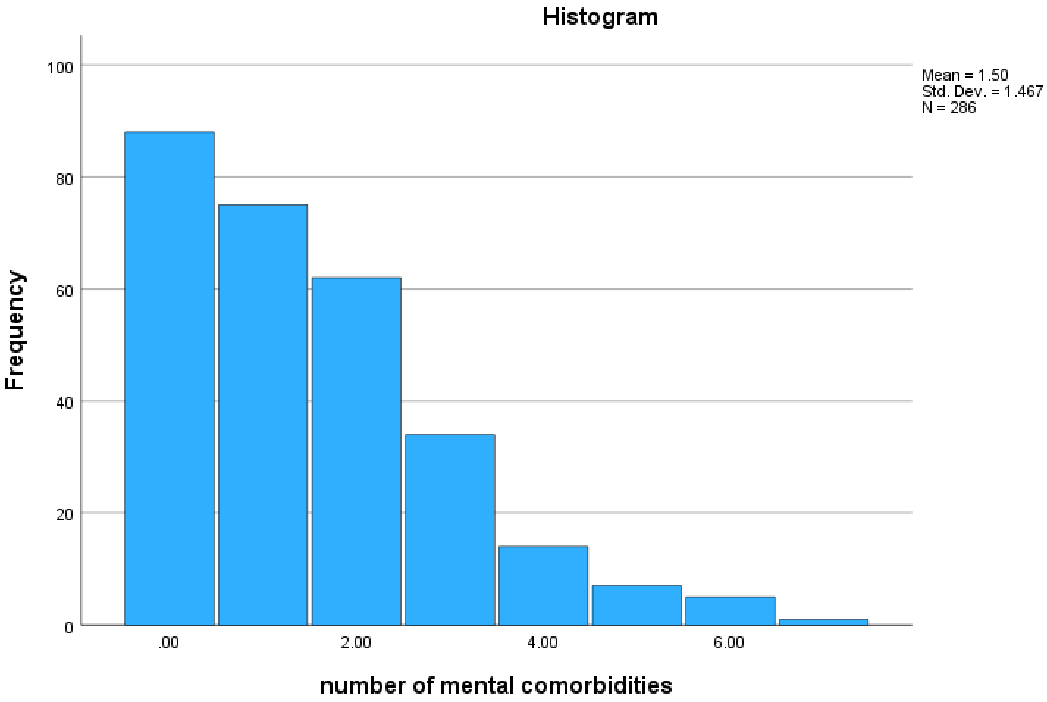

Normal Q-Q Plot of Aut Alter bei Diagnosestellung
Expected Normal
3
2
1
0
-1
-2
-3
0
20
40
60
Observed Value

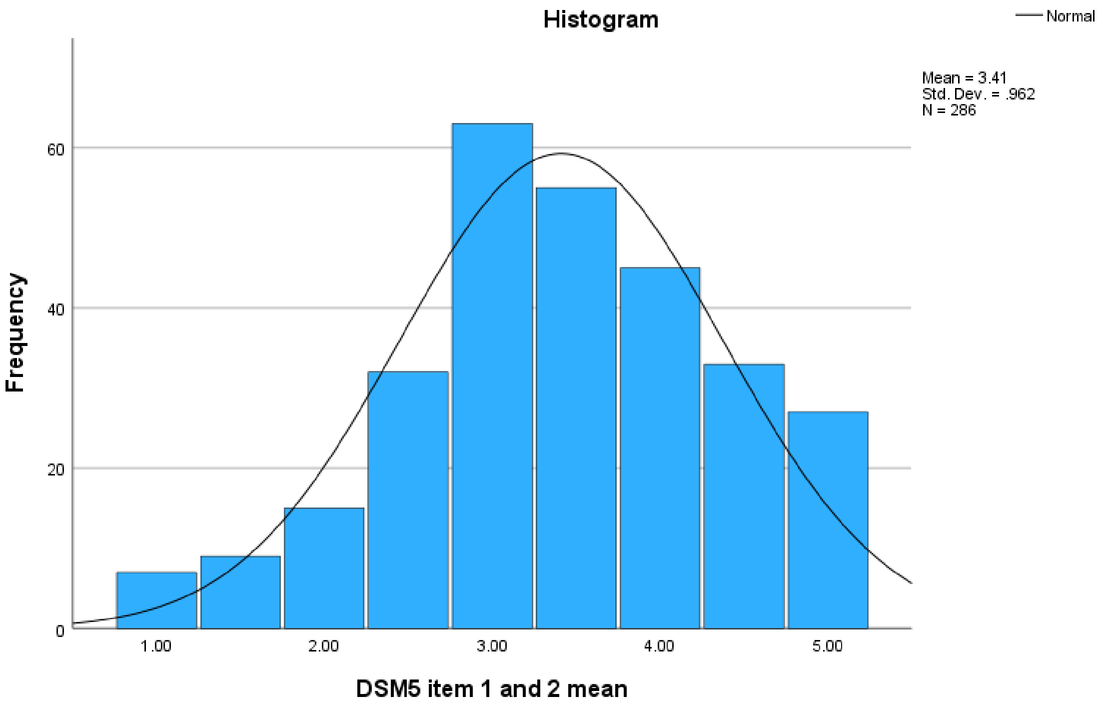

Histogram
Normal
Mean = 7.91
Std. Dev. = 4.116
N = 286
Frequency
30
20
10
0
.00
5.00
10.00
15.00
Ray_Summe

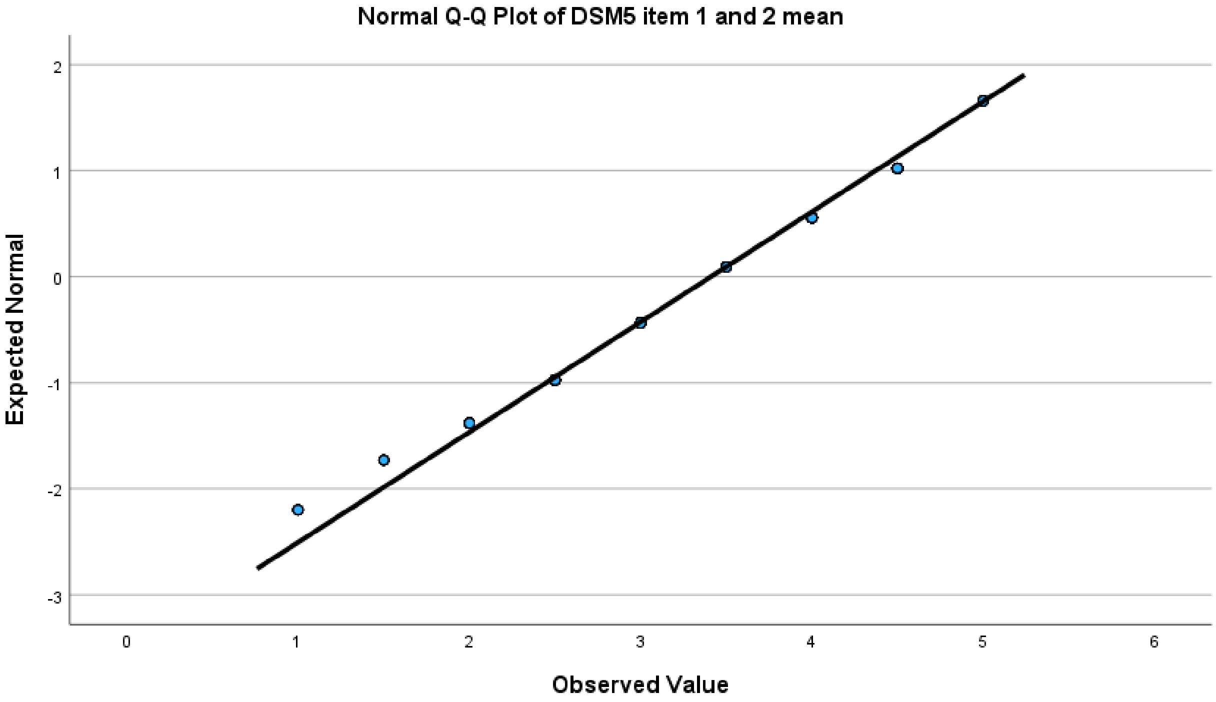

Normal Q-Q Plot of Ray_Summe
Expected Normal
3
2
1
0
-1
-2
-3
-5
0
5
10
15
20
Observed Value

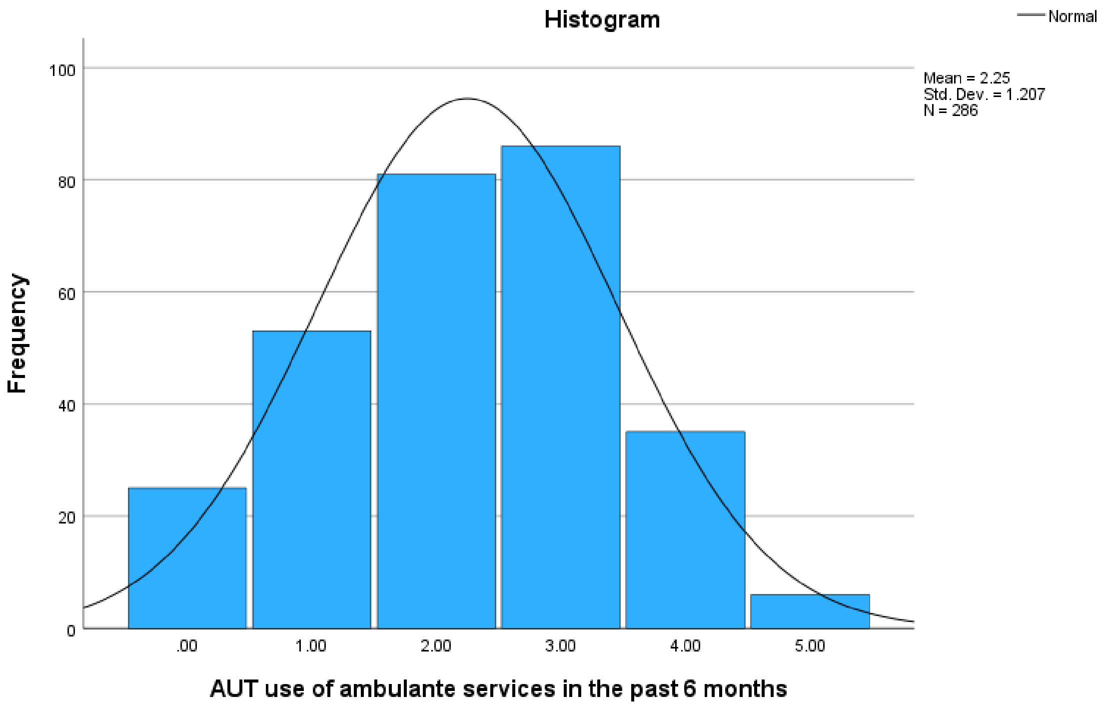

Histogram
Mean = 1.14
Std. Dev. = 1.324
N = 286
Frequency
120
100
80
60
40
20
0
.00
1.00
2.00
3.00
4.00
5.00
6.00
number of somtic comorbidities

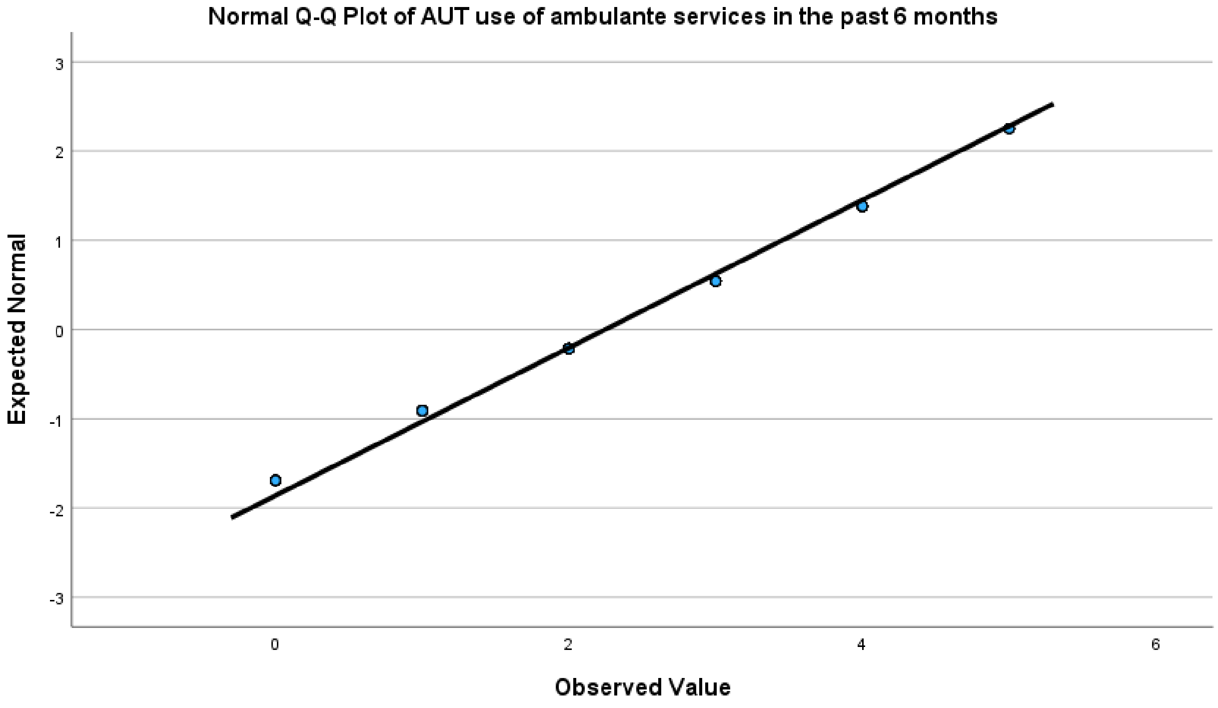

Normal Q-Q Plot of number of somtic comorbidities
Expected Normal
4
3
2
1
0
-1
-2
0
2
4
6
Observed Value


Histogram
Mean = 1.50
Std. Dev. = 1.467
N = 286
Frequency
100
80
60
40
20
0
.00
2.00
4.00
6.00
number of mental comorbidities


Histogram
Normal
Mean = 3.41
Std. Dev. = .962
N = 286
Frequency
0
20
40
60
1.00
2.00
3.00
4.00
5.00
DSM5 item 1 and 2 mean

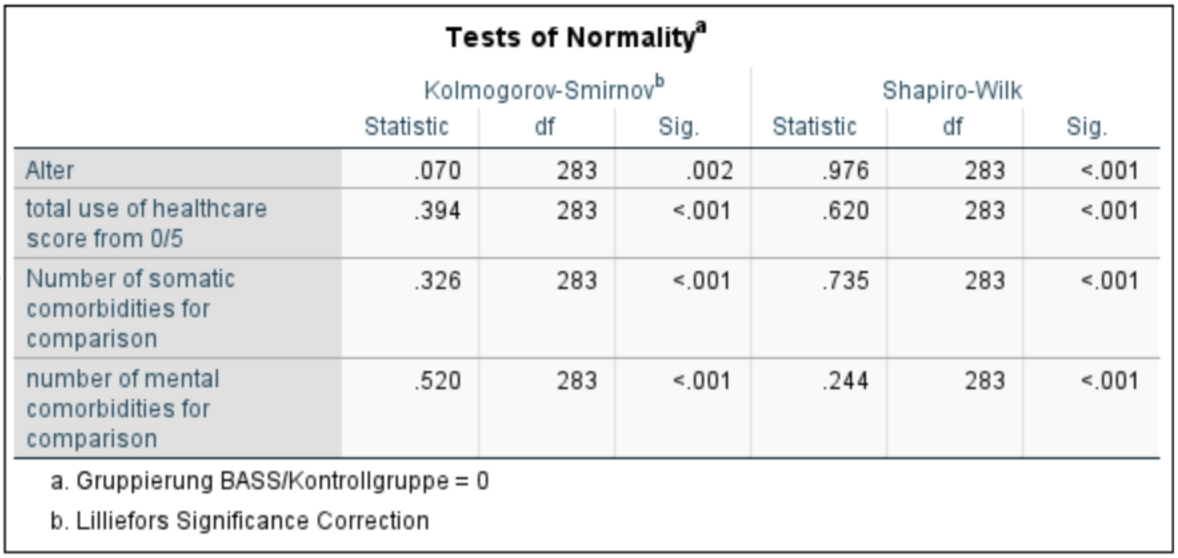

Normal Q-Q Plot of DSM5 item 1 and 2 mean
Expected Normal
2
1
0
-1
-2
-3
0
1
2
3
4
5
6
Observed Value


Histogram
Normal
Mean = 2.25
Std. Dev. = 1.207
N = 286
Frequency
100
80
60
40
20
0
.00
1.00
2.00
3.00
4.00
5.00
AUT use of ambulante services in the past 6 months


Normal Q-Q Plot of AUT use of ambulante services in the past 6 months
Expected Normal
3
2
1
0
-1
-2
-3
0
2
4
6
Observed Value

For the comparison:

***GP Group**

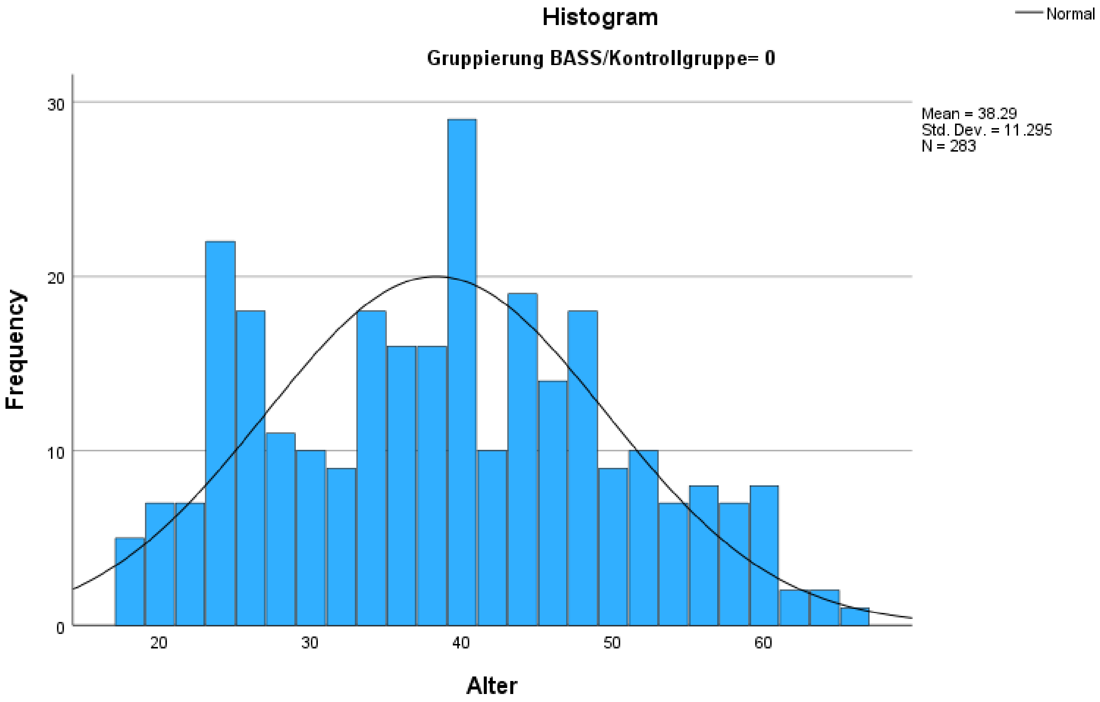


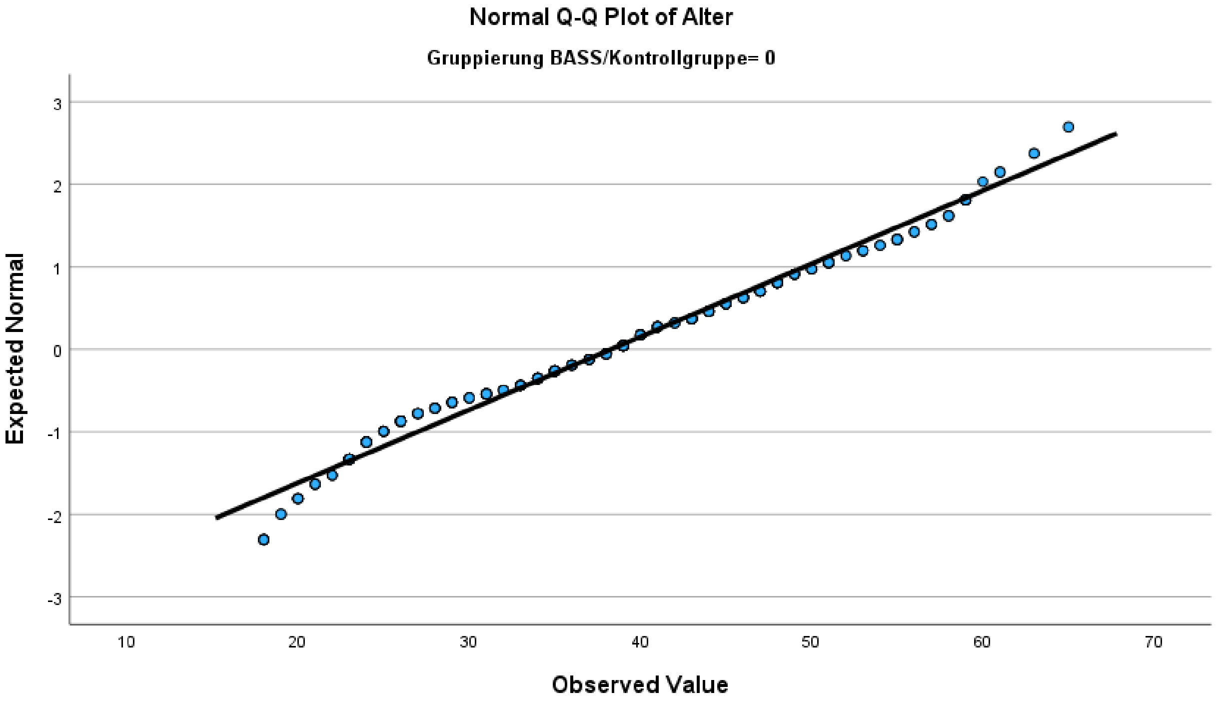
Tests of Normality[a]

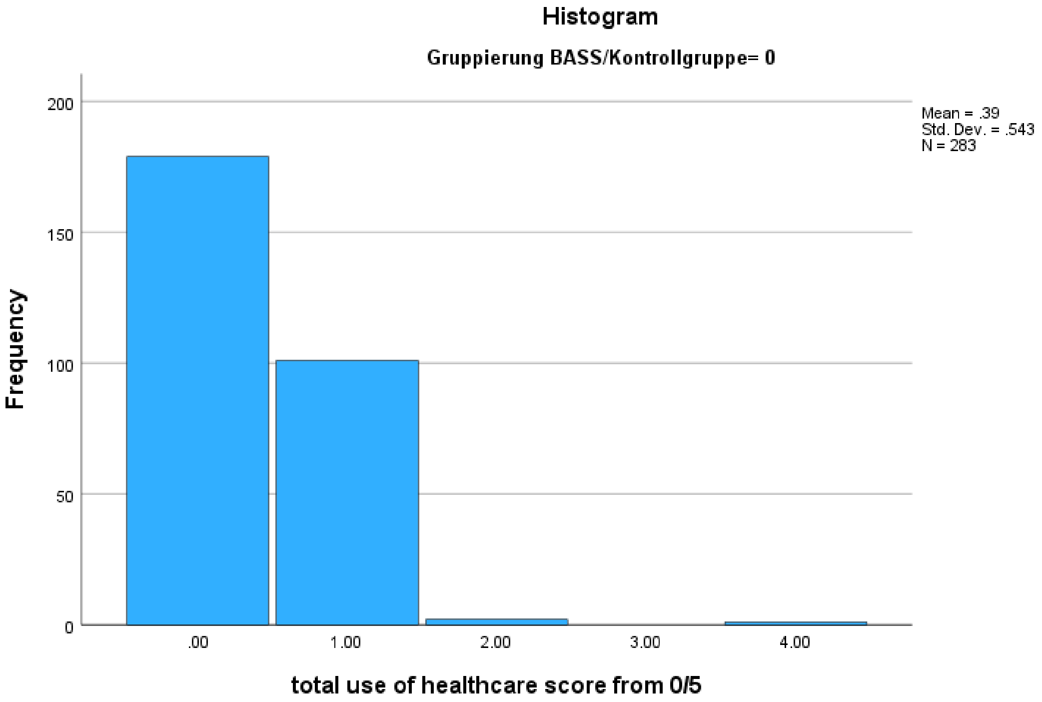
	Kolmogorov-Smirnov[b]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Alter	.070	283	.002	.976	283	<.001
total use of healthcare score from 0/5	.394	283	<.001	.620	283	<.001
Number of somatic comorbidities for comparison	.326	283	<.001	.735	283	<.001
number of mental comorbidities for comparison	.520	283	<.001	.244	283	<.001

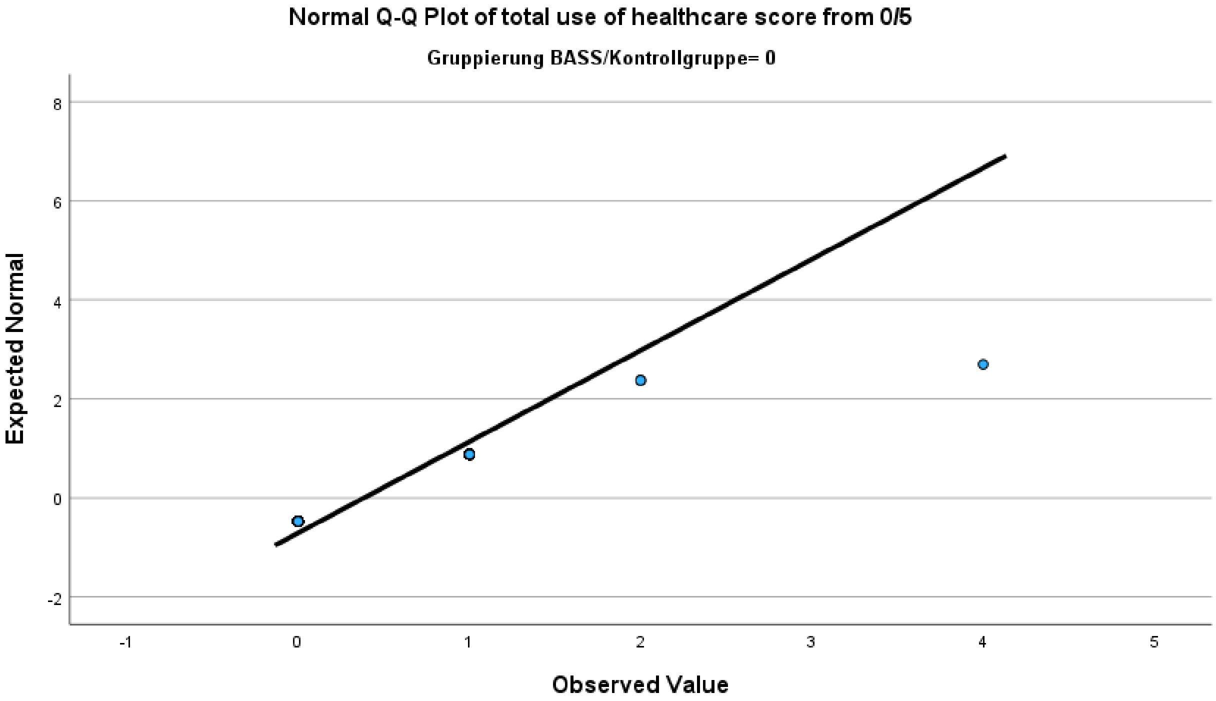
a. Gruppierung BASS/Kontrollgruppe = 0

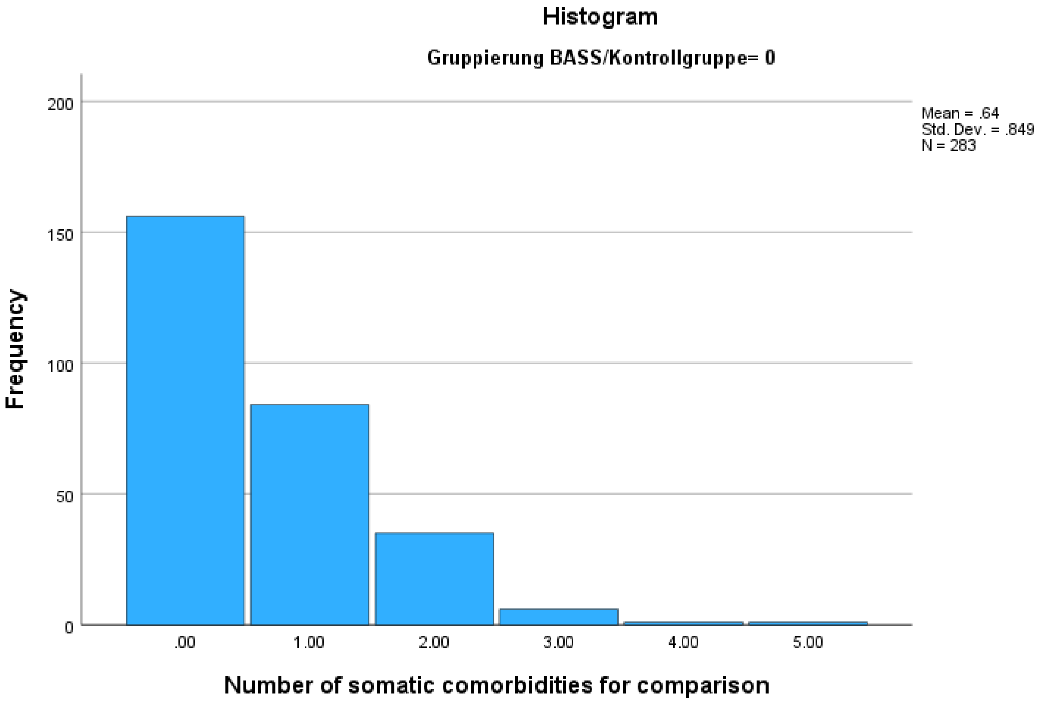
b. Lilliefors Significance Correction

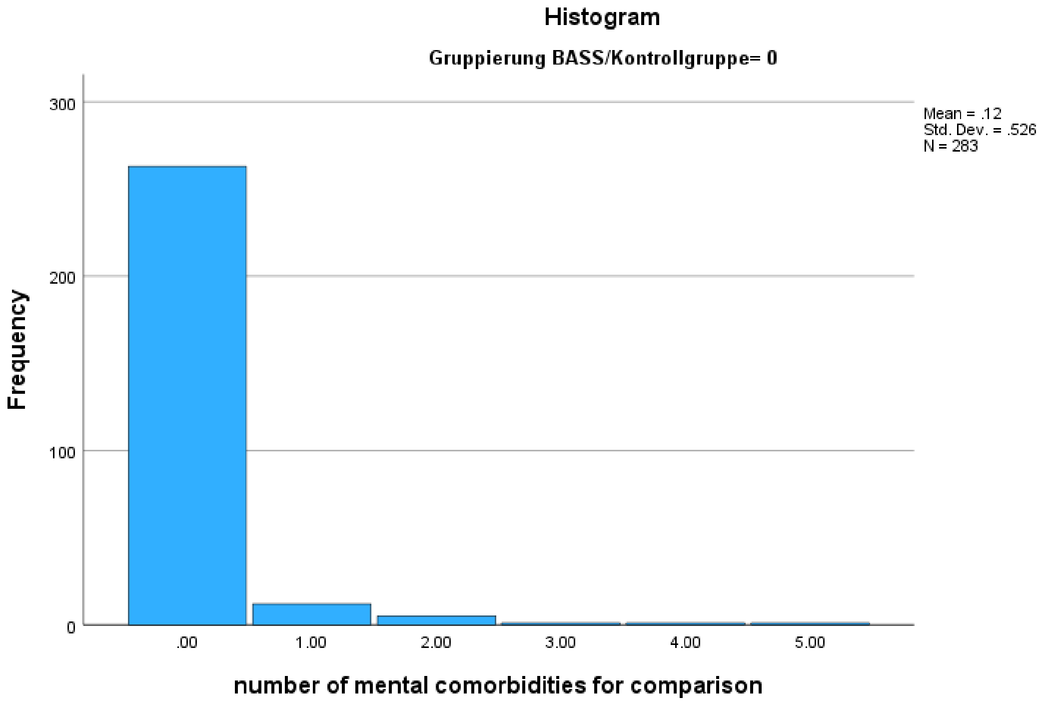


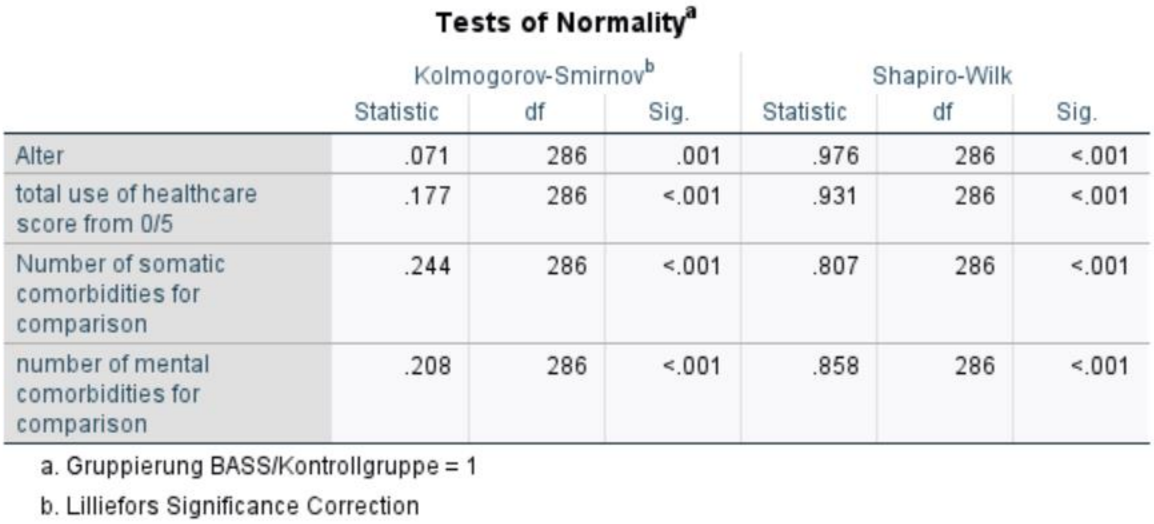

Normal Q-Q Plot of Alter
Gruppierung BASS/Kontrollgruppe= 0
Expected Normal
3
2
1
0
-1
-2
-3
10
20
30
40
50
60
70
Observed Value


Histogram
Gruppierung BASS/Kontrollgruppe= 0
Frequency
200
150
100
50
0
Mean = .39
Std. Dev. = .543
N = 283
.00
1.00
2.00
3.00
4.00
total use of healthcare score from 0/5


Normal Q-Q Plot of total use of healthcare score from 0/5
Gruppierung BASS/Kontrollgruppe= 0
Expected Normal
8
6
4
2
0
-2
-1
0
1
2
3
4
5
Observed Value


Histogram
Gruppierung BASS/Kontrollgruppe= 0
Mean = .64
Std. Dev. = .849
N = 283
Frequency
200
150
100
50
0
.00
1.00
2.00
3.00
4.00
5.00
Number of somatic comorbidities for comparison



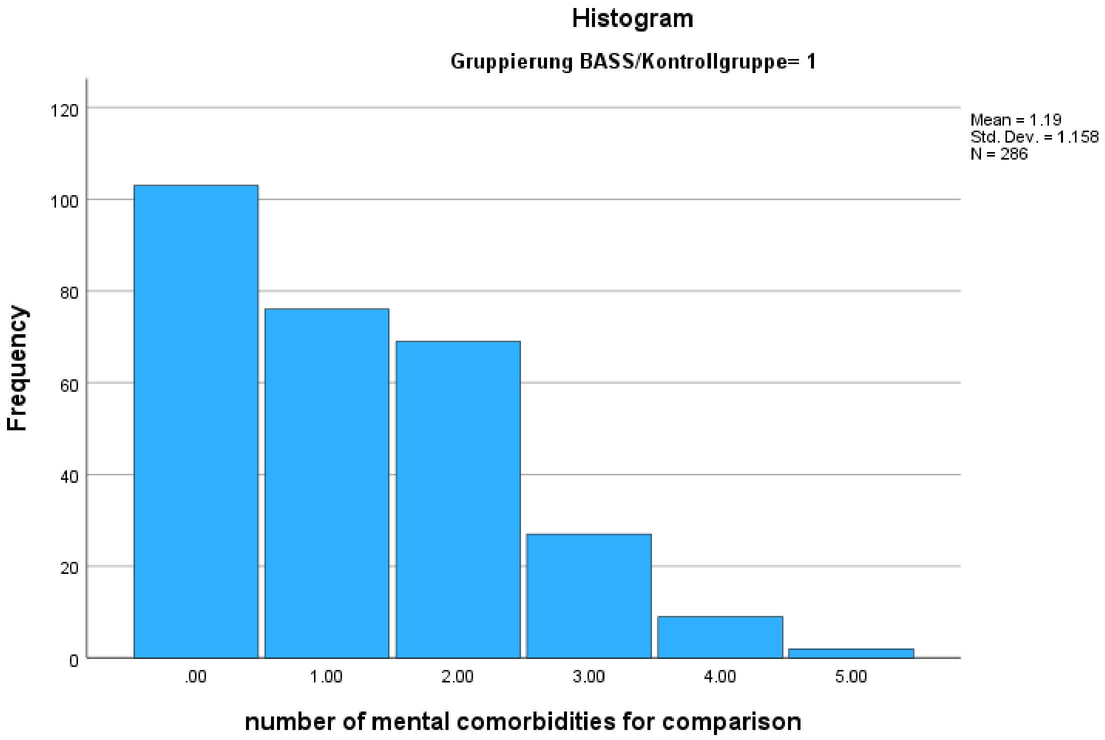


Tests of Normality[a]

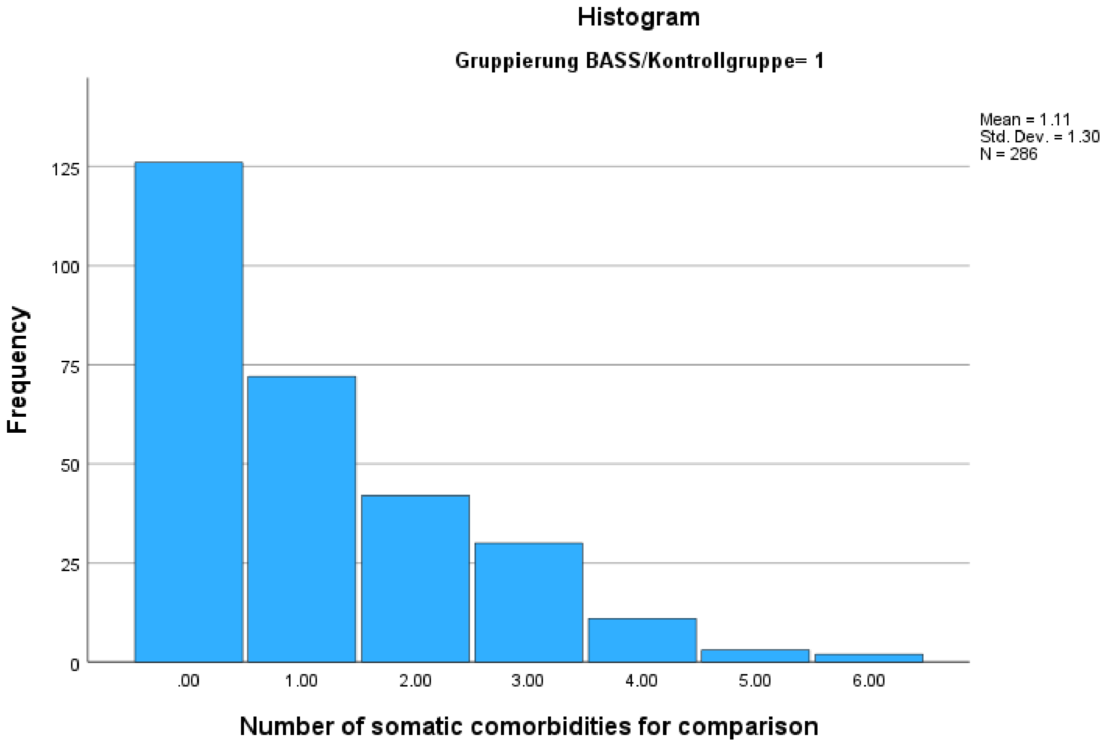
	Kolmogorov-Smirnov[b]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Alter	.071	286	.001	.976	286	<.001
total use of healthcare score from 0/5	.177	286	<.001	.931	286	<.001
Number of somatic comorbidities for comparison	.244	286	<.001	.807	286	<.001
number of mental comorbidities for comparison	.208	286	<.001	.858	286	<.001

a. Gruppierung BASS/Kontrollgruppe = 1

b. Lilliefors Significance Correction


Histogram

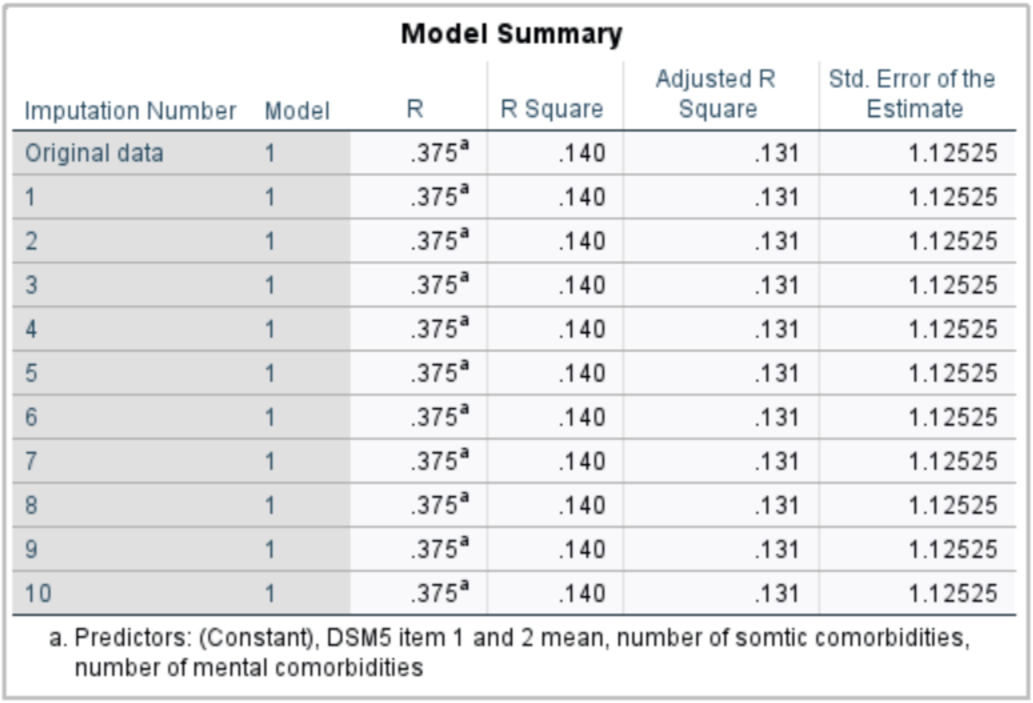
Gruppierung BASS/Kontrollgruppe= 1


Histogram

Gruppierung BASS/Kontrollgruppe= 1

*** Regression analysis.

1- Clinical factors only.



Model Summary

Imputation Number	Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
Original data	1	.375[a]	.140	.131	1.12525
1	1	.375[a]	.140	.131	1.12525
2	1	.375[a]	.140	.131	1.12525
3	1	.375[a]	.140	.131	1.12525
4	1	.375[a]	.140	.131	1.12525
5	1	.375[a]	.140	.131	1.12525
6	1	.375[a]	.140	.131	1.12525
7	1	.375[a]	.140	.131	1.12525
8	1	.375[a]	.140	.131	1.12525
9	1	.375[a]	.140	.131	1.12525
10	1	.375[a]	.140	.131	1.12525

a. Predictors: (Constant), DSM5 item 1 and 2 mean, number of somtic comorbidities, number of mental comorbidities

ANOVA[a]

Imputation Number	Model		Sum of Squares	df	Mean Square	F	Sig.
Original data	1	Regression	58.308	3	19.436	15.350	<.001[b]
		Residual	357.066	282	1.266		
		Total	415.374	285			
10	1	Regression	58.308	3	19.436	15.350	<.001[b]
		Residual	357.066	282	1.266		
		Total	415.374	285			

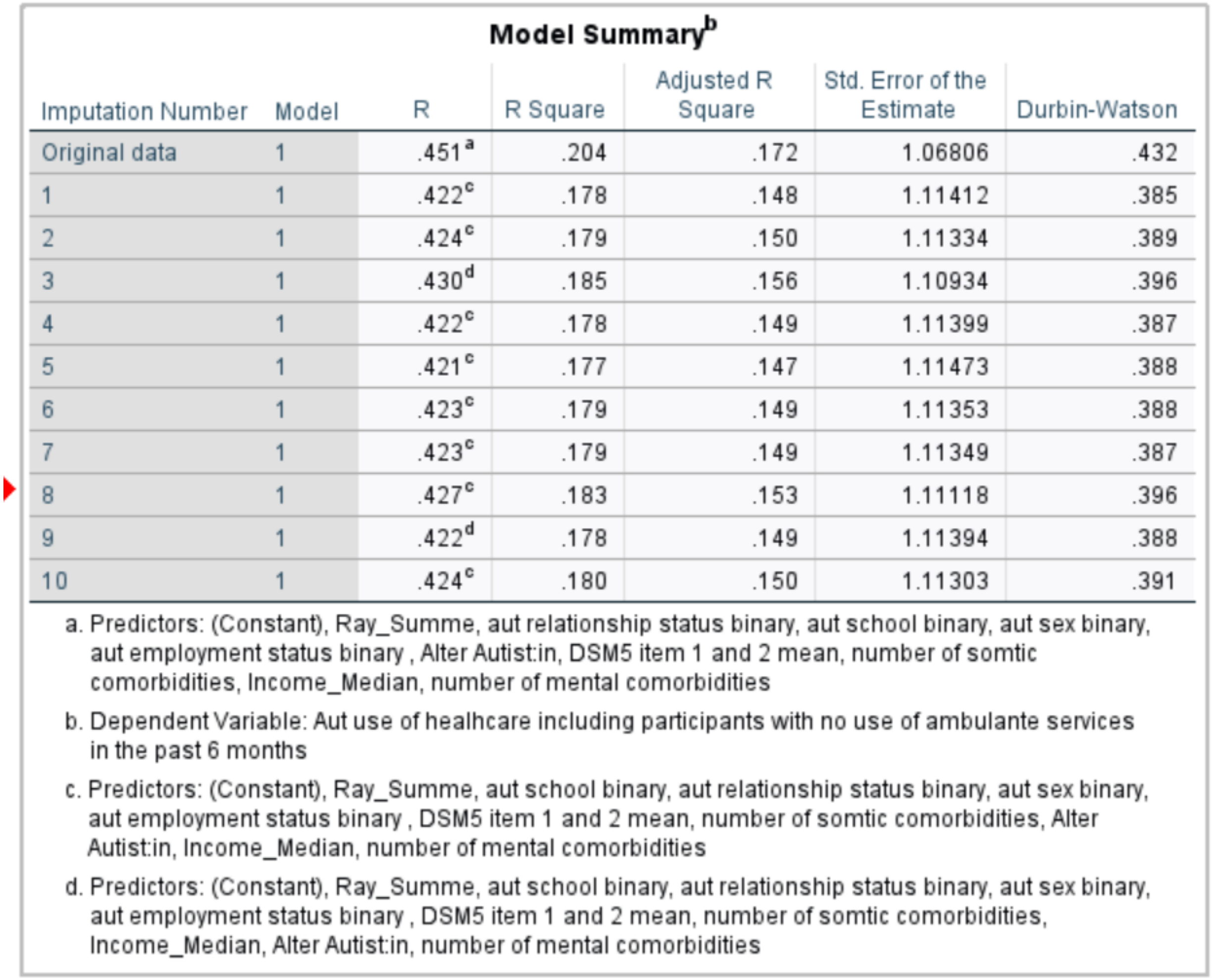
a. Dependent Variable: Aut use of healthcare including participants with no use of ambulante services in the past 6 months

b. Predictors: (Constant), DSM5 item 1 and 2 mean, number of somatic comorbidities, number of mental comorbidities

Imputation Number	Model		Unstandardized Coefficients B	Unstandardized Coefficients Std. Error	Standardized Coefficients Beta	t	Sig.
Original data	1	(Constant)	1.390	.251		5.537	<.001
		number of somatic comorbidities	.240	.053	.263	4.518	<.001

		number of mental comorbidities	.138	.049	.167	2.788	.006
		DSM5 item 1 and 2 mean	.111	.071	.089	1.555	.121
Pooled	1	(Constant)	1.390	.251		5.537	<.001
		number of somatic comorbidities	.240	.053		4.518	<.001
		number of mental comorbidities	.138	.049		2.788	.005
		DSM5 item 1 and 2 mean	.111	.071		1.555	.120

2- All predictors included.



Model Summary[b]

Imputation Number	Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
Original data	1	.451[a]	.204	.172	1.06806	.432
1	1	.422[c]	.178	.148	1.11412	.385
2	1	.424[c]	.179	.150	1.11334	.389
3	1	.430[d]	.185	.156	1.10934	.396
4	1	.422[c]	.178	.149	1.11399	.387
5	1	.421[c]	.177	.147	1.11473	.388
6	1	.423[c]	.179	.149	1.11353	.388
7	1	.423[c]	.179	.149	1.11349	.387
8	1	.427[c]	.183	.153	1.11118	.396
9	1	.422[d]	.178	.149	1.11394	.388
10	1	.424[c]	.180	.150	1.11303	.391

a. Predictors: (Constant), Ray_Summe, aut relationship status binary, aut school binary, aut sex binary, aut employment status binary , Alter Autist:in, DSM5 item 1 and 2 mean, number of somtic comorbidities, Income_Median, number of mental comorbidities

b. Dependent Variable: Aut use of healhcare including participants with no use of ambulante services in the past 6 months

c. Predictors: (Constant), Ray_Summe, aut school binary, aut relationship status binary, aut sex binary, aut employment status binary , DSM5 item 1 and 2 mean, number of somtic comorbidities, Alter Autist:in, Income_Median, number of mental comorbidities

d. Predictors: (Constant), Ray_Summe, aut school binary, aut relationship status binary, aut sex binary, aut employment status binary , DSM5 item 1 and 2 mean, number of somtic comorbidities, Income_Median, Alter Autist:in, number of mental comorbidities

ANOVA[a]

Imputation Number	Model		Sum of Squares	df	Mean Square	F	Sig.
Original data	1	Regression	72.702	10	7.270	6.373	<.001[b]
		Residual	284.048	249	1.141		
		Total	356.750	259			
1	1	Regression	74.030	10	7.403	5.964	<.001[c]
		Residual	341.345	275	1.241		
		Total	415.374	285			
2	1	Regression	74.503	10	7.450	6.011	<.001[c]
		Residual	340.871	275	1.240		
		Total	415.374	285			
3	1	Regression	76.950	10	7.695	6.253	<.001[d]
		Residual	338.424	275	1.231		
		Total	415.374	285			
4	1	Regression	74.107	10	7.411	5.972	<.001[c]
		Residual	341.267	275	1.241		
		Total	415.374	285			
5	1	Regression	73.654	10	7.365	5.927	<.001[c]
		Residual	341.720	275	1.243		
		Total	415.374	285			
6	1	Regression	74.390	10	7.439	5.999	<.001[c]
		Residual	340.984	275	1.240		
		Total	415.374	285			
7	1	Regression	74.416	10	7.442	6.002	<.001[c]
		Residual	340.958	275	1.240		
		Total	415.374	285			
8	1	Regression	75.827	10	7.583	6.141	<.001[c]
		Residual	339.547	275	1.235		
		Total	415.374	285			
9	1	Regression	74.137	10	7.414	5.975	<.001[d]
		Residual	341.237	275	1.241		
		Total	415.374	285			
10	1	Regression	74.696	10	7.470	6.030	<.001[c]
		Residual	340.679	275	1.239		
		Total	415.374	285			

a. Dependent Variable: Aut use of healthcare including participants with no use of ambulante services in the past 6 months

b. Predictors: (Constant), Ray_Summe, aut relationship status binary, aut school binary, aut sex binary, aut employment status binary , Alter Autist:in, DSM5 item 1 and 2 mean, number of somatic comorbidities, Income_Median, number of mental comorbidities

c. Predictors: (Constant), Ray_Summe, aut school binary, aut relationship status binary, aut sex binary, aut employment status binary , DSM5 item 1 and 2 mean, number of somatic comorbidities, Alter Autist:in, Income_Median, number of mental comorbidities

d. Predictors: (Constant), Ray_Summe, aut school binary, aut relationship status binary, aut sex binary, aut employment status binary , DSM5 item 1 and 2 mean, number of somatic comorbidities, Income_Median, Alter Autist:in, number of mental comorbidities

Coefficients

			Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
Imputation Number	Model		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
Original data	1	(Constant)	1.030	.471		2.187	.030	.102	1.958					
		Alter Autist:in	-.010	.006	-.093	-1.516	.131	-.022	.003	-.046	-.096	-.086	.849	1.177
		aut sex binary	.129	.138	.055	.936	.350	-.142	.400	.071	.059	.053	.934	1.070
		aut employment status binary	-.073	.143	-.031	-.512	.609	-.354	.208	-.071	-.032	-.029	.865	1.156
		aut school binary	.272	.146	.108	1.867	.063	-.015	.558	.125	.118	.106	.953	1.049
		Income_Median	.262	.151	.109	1.741	.083	-.034	.559	.037	.110	.098	.812	1.232
		aut relationship status binary	.166	.158	.067	1.050	.295	-.145	.476	.022	.066	.059	.785	1.274
		DSM5 item 1 and 2 mean	.152	.076	.123	2.005	.046	.003	.302	.148	.126	.113	.852	1.174
		number of somatic comorbidities	.243	.056	.277	4.334	<.001	.132	.353	.323	.265	.245	.784	1.275
		number of mental comorbidities	.184	.053	.230	3.486	<.001	.080	.288	.326	.216	.197	.735	1.361
		Ray_Summe	-.022	.019	-.076	-1.159	.248	-.059	.015	.108	-.073	-.066	.744	1.344
Pooled	1	(Constant)	.987	.472		2.092	.036	.062	1.911					
		Alter Autist:in	-.010	.006		-1.581	.114	-.023	.002	-.045	-.095	-.086		
		aut sex binary	.073	.138		.530	.596	-.197	.342	.041	.032	.029		

	aut employment status binary	-.044	.142		-.310	.756	-.321	.233	-.052	-.019	-.017		
	aut school binary	.273	.148		1.844	.065	-.017	.562	.109	.112	.102		
	Income_Median	.279	.153		1.819	.069	-.022	.580	.039	.112	.102		
	aut relationship status binary	.232	.158		1.463	.143	-.079	.542	.048	.088	.080		
	DSM5 item 1 and 2 mean	.148	.074		1.998	.046	.003	.293	.134	.120	.109		
	number of somatic comorbidities	.277	.056		4.938	<.001	.167	.387	.317	.285	.270		
	number of mental comorbidities	.141	.052		2.719	.007	.039	.242	.270	.162	.149		
	Ray_Summe	-.015	.018		-.825	.409	-.051	.021	.105	-.050	-.045		

Residuals Statistics[a]

Imputation Number		Minimum	Maximum	Mean	Std. Deviation	N
Original data	Predicted Value	.9421	4.2665	2.2500	.52981	260
	Std. Predicted Value	-2.469	3.806	.000	1.000	260
	Standard Error of Predicted Value	.155	.404	.217	.036	260
	Adjusted Predicted Value	1.0358	4.3110	2.2518	.53334	260
	Residual	-2.66527	2.82842	.00000	1.04724	260
	Std. Residual	-2.495	2.648	.000	.981	260
	Stud. Residual	-2.576	2.736	-.001	1.002	260
	Deleted Residual	-2.84100	3.01836	-.00180	1.09357	260
	Stud. Deleted Residual	-2.606	2.772	-.001	1.005	260
	Mahal. Distance	4.424	36.071	9.962	3.863	260
	Cook's Distance	.000	.046	.004	.005	260
	Centered Leverage Value	.017	.139	.038	.015	260
Pooled	Predicted Value			2.2483		286
	Std. Predicted Value			.000		286
	Standard Error of Predicted Value			.215		286
	Adjusted Predicted Value			2.2498		286
	Residual			.00000		286

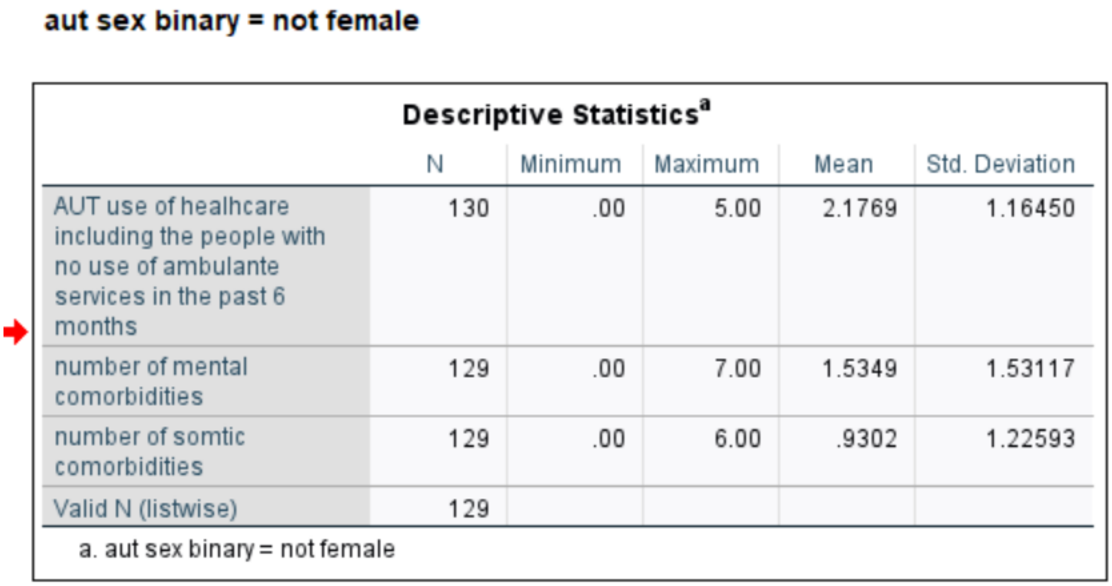
	Std. Residual			.000		286
	Stud. Residual			-.001		286
	Deleted Residual			-.00159		286
	Stud. Deleted Residual			-.001		286
	Mahal. Distance			9.965		286
	Cook's Distance			.004		286
	Centered Leverage Value			.035		286

a. Dependent Variable: Aut use of healthcare including participants with no use of ambulante services in the past 6 months

Appendix IV: BASS sample gender differences

**Syntax.

```
Sort cases by sex_binary.
split file SEPARATE by sex_binary.
 DESCRIPTIVES VARIABLES=total_use_HC_new numberofkom2 numberofkom1
  /STATISTICS=MEAN STDDEV MIN MAX.
FREQUENCIES VARIABLES=AlterDiagAut
  /ORDER=ANALYSIS.
```

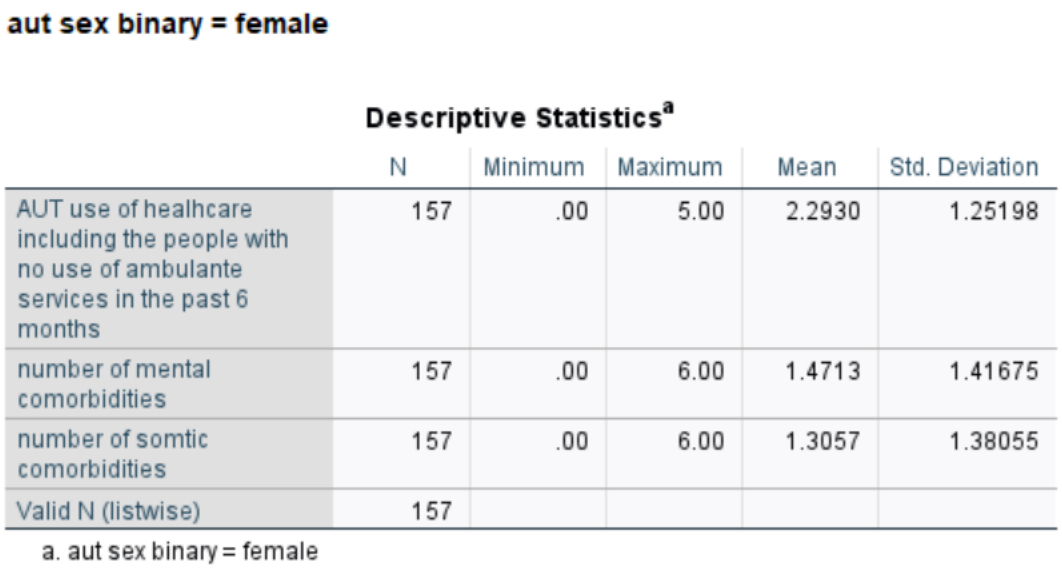


aut sex binary = not female

Descriptive Statistics[a]

	N	Minimum	Maximum	Mean	Std. Deviation
AUT use of healhcare including the people with no use of ambulante services in the past 6 months	130	.00	5.00	2.1769	1.16450
number of mental comorbidities	129	.00	7.00	1.5349	1.53117
number of somtic comorbidities	129	.00	6.00	.9302	1.22593
Valid N (listwise)	129				

a. aut sex binary = not female

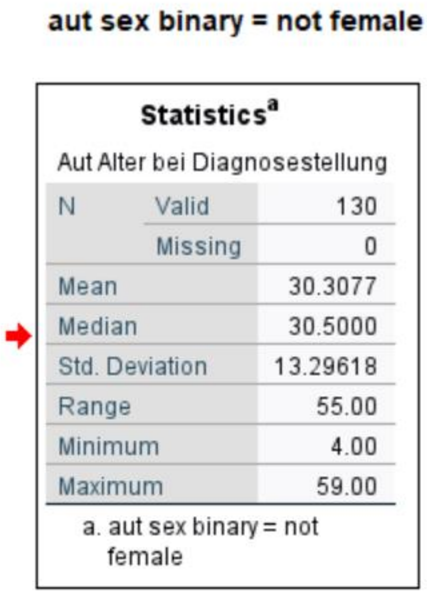


aut sex binary = female

Descriptive Statistics[a]

	N	Minimum	Maximum	Mean	Std. Deviation
AUT use of healhcare including the people with no use of ambulante services in the past 6 months	157	.00	5.00	2.2930	1.25198
number of mental comorbidities	157	.00	6.00	1.4713	1.41675
number of somtic comorbidities	157	.00	6.00	1.3057	1.38055
Valid N (listwise)	157				

a. aut sex binary = female



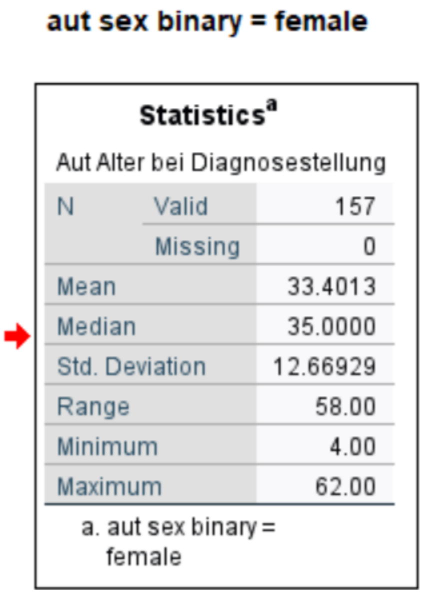
aut sex binary = not female

Statistics[a]

Aut Alter bei Diagnosestellung

N	Valid	130
	Missing	0
Mean		30.3077
Median		30.5000
Std. Deviation		13.29618
Range		55.00
Minimum		4.00
Maximum		59.00

a. aut sex binary = not female



aut sex binary = female

Statistics[a]

Aut Alter bei Diagnosestellung

N	Valid	157
	Missing	0
Mean		33.4013
Median		35.0000
Std. Deviation		12.66929
Range		58.00
Minimum		4.00
Maximum		62.00

a. aut sex binary = female