technische universität dortmund

Fakultät Rehabilitations-wissenschaften

Connecting the dots between stress, demands, and coping resources of parents to children with autism spectrum disorder

vorgelegt von

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als Dissertation zur Erlangung des Grades einer

Doktorin der Philosophie (Dr. phil.)

in der

Fakultät Rehabilitationswissenschaften

der Technischen Universität Dortmund

Dortmund

2024

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Die vorliegende Arbeit wurde von der Fakultät Rehabilitationswissenschaften
der Technischen Universität Dortmund als Dissertation angenommen.
Gutachter: Prof. Dr. Heinrich Tröster
Gutachter: Prof. Dr. Jörg-Tobias Kuhn
Tag der Disputation: 28.05.2024
Dortmund

Acknowledgements

First and foremost, I would like to thank my two supervisors, Prof. Dr. Heinrich Tröster and Prof. Dr. Jörg-Tobias Kuhn, for sharing their professional expertise, valuable and constructive feedback, and continuously reliable support throughout the entire doctoral period.

Thanks to Dr. Sarah Sons who inspired me as a student and always gave me good advice as a colleague. I would also like to thank Prof. Dr. Olga Kunina-Habenicht for her support during the second data collection phase and the freedom she gave me in my work.

I would like to thank the members of my writing group who helped me to stay focused. I would especially like to thank Sarah Lamb for her always uplifting and supportive words and actions.

Thanks also to the members of the departments of Methods in Empirical Educational Research, Psychological and Diagnostics, and Rehabilitation Sociology of the Department of Rehabilitation Sciences at TU Dortmund University who supported me during my doctoral phase with an appreciative working atmosphere.

A great thanks is owed to my family and especially to my husband who was not only emotionally supportive but also an excellent proofreader during the entire time.

Finally, I would like to thank all the parents who took the time to participate in our studies and share their experiences with us despite their numerous daily demands. I would also like to thank all the facilities and therapists for their commitment to the data collection.

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Abstract

According to numerous studies, parents to children with an autism spectrum disorder (ASD) are more affected by stress than other parents. From a transactional perspective, parental stress is caused by the demands placed on parents and the assessment of their available resources for coping with these demands. The three studies in this doctoral dissertation therefore deal with the connections between parental stress, everyday demands, and the coping resources of parents to children with ASD. The first study aimed to find out which coping resources mediate between the demands and parental stress. This was examined by means of mediation analyses using data from $N = 266$ parents to children with ASD. Parental self-efficacy beliefs and dysfunctional coping were found to be significant mediators. In study II, a random intercept cross-lagged panel model was used to examine how stress and perceived partnership quality of parents to children with ASD predict each other longitudinally. Data from $N = 160$ parents collected at three measurement points were used. The results showed a decrease in stress levels over the course of therapy, which resulted in a lower perceived partnership quality at the last measurement point. In order to find out which demands explain parental stress before and during times of crisis, data from $N = 168$ before and $N = 105$ parents to children with ASD during the COVID-19 pandemic were used in study III and simple and multiple linear regression analyses were calculated. At both time points, dealing with the child's problem behavior, cooperation with the partner and restrictions in one's personal way of life were significant predictors of stress. Prior to the time of crisis, the stigmatizing reactions of others were also found to be informative for parental stress. The results provide evidence of the connections between the three constructs and show that parental stress should not be seen in isolation from the demands and coping resources, which suggests a more holistic view in research as well as in practical work with parents to children with ASD.

Studies relevant to the doctoral dissertation

The three studies relevant to this cumulative dissertation *Connecting the dots between stress, demands, and coping resources of parents to children with autism spectrum disorder* have been published in peer-reviewed international journals:

Study I (Appendix A): **Sartor, T.**, Sons, S., Kuhn, J.-T., & Tröster, H. (2023a). Coping resources and stress due to demands in parents to children with autism spectrum disorders. *Frontiers in Rehabilitation Sciences, 4*(1240977), 1–10. https://doi.org/10.3389/fresc.2023.1240977

Study II (Appendix B): **Sartor, T.**, Lange, S., Kuhn, J.-T., & Tröster, H. (2024). Stress and perceived partnership quality of parents to children with autism spectrum disorder: A random intercept cross-lagged panel approach. *The Family Journal, 32*(1), 139–148. https://doi.org/10.1177/10664807231198093

Study III (Appendix C): **Sartor, T.**, Sons, S., Kunina-Habenicht, O., Tröster, H., & Kuhn, J.-T. (2023b). Demands and stress before and during the COVID-19 pandemic of parents to children with autism spectrum disorder. *Frontiers in Psychology, 14*(1212556), 1–11. https://doi.org/10.3389/fpsyg.2023.1212556

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1 Introduction

Raising a child is one of the most demanding tasks in life and holds an enormous potential for stress (Kaluza, 2012). If the child has an autism spectrum disorder (ASD), additional stress-inducing demands are added due to the symptoms (e.g. Davis & Carter, 2008; Estes et al., 2013; Jungbauer & Meye, 2008; Sarimski, 2016; Tomanik, 2004; Tröster & Lange, 2019). According to the 11th revision of the *International Statistical Classification of Diseases and Related Health Problems* (ICD), ASD is a neuronal developmental disorder and manifests itself in deficits in social interaction and communication as well as in repetitive, restricted behaviors (World Health Organization (WHO), 2023). In children with ASD, these symptoms can cause stress, especially for their parents, who are usually their closest caregivers (e.g. Hoffman et al., 2009). Stress is associated with many health problems, for example with mental illnesses such as depressive disorder (Kupferschmid & Koch, 2014). For example, parents to children with ASD show a higher probability of depression than other parents (Cohrs & Leslie, 2017). Parental stress can have an additional negative impact on child development (Wiedebusch & Seelhorst, 2014), as parents find it more difficult to adequately fulfill their parental responsibilities such as care, supervision, and education (Tröster, 2011). As stress has been shown to be higher in parents to children with ASD than in other parents (e.g. Corbett et al., 2021; Hastings & Johnston, 2001; Kalb et al., 2021; Sarimski, 2016; Weiss, 2002), the relevance of empirically investigating further aspects of this topic is particularly high and is considered necessary (e.g. Zawacki, 2019). In order to understand how the parental stress of parents to children with ASD develops, it is necessary to look at the demands and coping resources from a transactional perspective. Stress arises when the available coping resources are assessed as insufficient for dealing with the demands (see Lazarus' *Transactional Stress Model*: Lazarus, 1999; Lazarus & Folkman, 1984; Lazarus & Launier, 1978). To address the need to examine the three constructs (stress, demands and coping resources) holistically for the highly stressed group of parents to children with ASD, three empirical studies were conducted focusing on the connections

between demands, coping resources and stress from a transactional perspective. For this purpose, the *Parenting Stress Model* (Abidin 1990, 1992, 1995) was used as a basis, which specifies the transactional approach applicable to the target group of parents (Abidin, 1992). Study I used a cross-sectional mediation model to examine the connections between demands, coping resources and stress of parents to children with ASD (Sartor et al., 2023a, see Appendix A). Study II looked at the correlation between the stress of these parents and their perceived partnership quality in a longitudinal path model (Sartor et al., 2024, see Appendix B). Study III investigated the stress of parents to children with ASD before and during a time of crisis, using the COVID-19 pandemic as an example (Sartor et al., 2023b, see Appendix C). As a connecting element, the present synopsis is intended to address the overarching research question of how the stress of parents to children with ASD is linked to their everyday demands and their available coping resources. The overarching research question is answered, categorized and discussed with the help of the three studies.

The theory section of the synopsis first provides an overview of the ASD disorder by systematically presenting the core symptoms using various classification systems (Chapter 2). In order to shed light on the construct of parental stress, Lazarus' Transactional Stress Model (Lazarus & Folkman, 1984) and its specific application to parents (Parenting Stress Model; Abidin, 1992) are presented schematically (Chapter 3). This is followed by an overview of the demands and stress experienced by parents to children with ASD based on a summary of previous study results (Chapter 3.2). Chapter 4 describes selected coping resources of parents to children with ASD that have emerged as significant in the research and were examined in studies I and II. The overarching research question described above is derived from the theoretical foundations and the state of research described and the three studies are briefly presented (Chapter 5). This is followed by an overall discussion of the results of studies I, II, and III, in which the dots between stress, demands and coping resources of parents to children with ASD are connected. The findings are then placed in an overarching context in order to answer the

research question (Chapter 6). In the overall discussion, implications for research and practice are also identified, before limitations of this doctoral dissertation are addressed. The dissertation is rounded off with a conclusion (Chapter 7).

2 Autism spectrum disorder (ASD)

ASD is a genetically determined, neurobiological developmental disorder (Kamp-Becker & Bölte, 2021). It is characterized by developmental deficits that are so severe that they lead to impairments in almost all important areas of functioning (e.g. personal, social, familial) (WHO, 2023). The manifestations of the deficits are highly heterogeneous (Bernard-Opitz, 2015), begin in early childhood and persist throughout life (AWMF, 2016). The disorder cannot be cured (Sappok et al., 2010) and those affected generally require long-term and extensive support (Jungbauer & Meye, 2008). The disorder consists of three core symptoms (Freitag & Petermann, 2014; Remschmidt & Kamp-Becker, 2007), which vary greatly in their severity (Herpertz-Dahlmann et al., 2010) and influence each other (Teufel & Soll, 2021): (1) a qualitative deficit in social communication, (2) a deficit in social interaction and (3) age-atypical, repetitive, and stereotypical behaviors and interests. The deficits in social communication are evident on both a verbal and non-verbal level. The verbal language of people with ASD is characterized, among other things, by the creation of new words, echolalia (non-functional repetition of what has already been said) and the incorrect use of personal pronouns (Kamp-Becker & Bölte, 2021; Remschmidt & Kamp-Becker, 2007; Teufel & Soll, 2021). Non-verbal communication also shows peculiarities such as a limited understanding of the use of gestures and facial expressions (Theunissen, 2021), as well as deviating eye contact (Heilmann, 2015), resulting in deficits in social-emotional reciprocity in interpersonal interaction (Teufel & Soll, 2021). People with ASD have difficulties establishing and maintaining contact with peers (Dodd, 2007). The low responsiveness in social interaction (Noterdaeme et al., 2017) can be explained by the realization that the thought patterns of people with ASD tend to be rigid and logical-rational rather than holistic-intuitive (Girsberger, 2020), as is often necessary in social contexts. In addition to restricted behavior in social situations, the core symptoms include age-atypical, repetitive behaviors, including motor behaviors for stimulation and calming ("stimming", Kapp et al., 2019), such as bobbing, swinging the head or waving the hands (Schirmer

& Alexander, 2015). Hypo- or hypersensitivity to sensory stimuli is also not uncommon (Teufel & Soll, 2021; Theunissen, 2021), such as hypersensitivity to certain smells or sounds or hypo-sensitivity to extreme temperatures (Girsberger, 2020). Another typical behavior is inflexibility to change (Tebartz van Elst et al., 2014) and excessive adherence to structures, routines, rituals and rules (Kamp-Becker & Bölte, 2021). Minimal changes can trigger an exaggerated reaction (Theunissen, 2021), as the new stimuli are difficult to process and reach the person with ASD unfiltered (Preißmann, 2017). In summary, ASD symptoms encompass all important areas of functioning (WHO, 2023) that impair the participation of people with ASD.

All symptoms can manifest themselves in different ways, which is why the disorder is difficult to summarize and differentiate from others (Kamp-Becker & Bölte, 2021). The various classification systems for diagnosing ASD make efforts in this regard. The ICD developed by the WHO forms the basis for medical diagnoses in Germany (Bundesinstitut für Arzneimittel und Medizinprodukte (BfArM), 2023). Statutory health insurance physicians are therefore obliged to make their diagnoses according to the ICD (Kassenärztliche Bundesvereinigung, 2023). Since 1999, ICD-10 has been the official classification system (with regular updates by the WHO), which will be replaced by ICD-11, which was adopted in 2019 and has been in force in Germany since 2022. As of 2023, Germany is in a transition phase in this respect. The draft version of the German translation of ICD-11 is largely, but still incompletely, available (BfArM, 2023). The classification of autistic disorders has been fundamentally revised. There are three subtypes of autism in the ICD-10: *Childhood autism* (F84.0), *Asperger syndrome* (F84.5), and *Atypical autism* (F84.1). In contrast, the ICD-11 presents the disorder in a spectrum (*autism spectrum disorder*), which was already implemented in 2013 in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), the American Psychiatric Association's classification system. The rationale for presenting the disorder as a spectrum is based on many years of research, which argues that two types (childhood autism and Asperger syndrome) and a residual category (atypical autism) represent the disorder too simplistically

(e.g. Lord et al., 2012). In the clinical context, it is also evident that a valid distinction between types is not possible (Kamp-Becker & Bölte, 2021). As soon as not all criteria for the diagnosis of childhood autism or Asperger syndrome are met, the person is assigned to atypical autism as a collective category (Habermann & Kißler, 2022). The word "spectrum" aims to reflect the great heterogeneity that this disorder entails (Teufel & Soll, 2021). However, the variability of symptom manifestations makes it difficult to define the disorder universally (Kamp-Becker & Bölte, 2021). In the DSM-5, the disorder was therefore only divided into degrees of severity instead of various symptoms (American Psychiatric Association, 2013). The ICD-11 solves the problem of mapping variability by specifying two characteristics: (1) differences in intelligence (Is there a disorder in the development of intelligence?) and (2) differences in functional language (Is there an impairment in functional language? Is it (slightly) limited or completely absent?). Deficits in social skills, i.e. the initiation and maintenance of reciprocal social interaction and communication as well as age-atypical, inflexible, repetitive, restricted behaviors, activities or interests are always considered a prerequisite (ICD-11). The spectrum ranges from severe to moderate autistic symptoms and extends from a complete absence of functional language with intellectual impairment (6A02.5, ICD-11) to well-developed functional language and average or above-average intelligence (6A02.0, ICD-11). The exclusion diagnosis for the diagnosis of an autism spectrum disorder is *Rett syndrome* (LD90.4, ICD-11). The three classification systems (ICD-10, DSM-5, ICD-11) are compared schematically in Figure 1.

The prevalence rates of autistic disorders have risen significantly in recent decades (Fombonne et al., 2011). This is explained by the ongoing development of diagnostic instruments and the concept of ASD itself, as well as an increase in media attention regarding the disorder (Kamp-Becker & Bölte, 2021). However, the rates reported in various studies are difficult to compare because "there is no standardization of autism survey methodology" (e.g. regarding various diagnostic and screening instruments; Fombonne, 2018, p. 717). Studies currently assume a prevalence of around 1% of the population (Vllasaliu et al., 2019), conservative

estimates conclude between 0.62 - 0.70% (Kamp-Becker & Bölte, 2021). People with ASD are often diagnosed late (Freitag et al., 2017) because the symptoms worsen in the absence of support or because differences between the developmental stages become more pronounced over time (e.g. high dependence on parental support and care even in late stages of development; Habermann & Kißler, 2022). In ICD-10, some criteria were related to childhood (e.g. the use of functional play), which has been opened up in ICD-11 so that not only children but also adults can be diagnosed in a more targeted manner. Despite the opening, some researchers (Freitag, 2021; Kamp-Becker & Bölte, 2021) assume that the number of cases will fall again when ICD-11 comes into force, as the imprecise residual category of atypical autism (F84.1, ICD-10) will no longer apply. Under ICD-11, not all people who would have received a diagnosis of atypical Autism under ICD-10 are diagnosed as ASD, as they do not meet all the diagnostic criteria in ICD-11 (Habermann & Kißler, 2022). This in turn means that these individuals and their families cannot benefit from specific services for people with ASD. To ensure that these individuals and their impairments are also recognized and can benefit from support services, the diagnosis *Developmental Language Disorder with impairment of mainly pragmatic language* (6A01.22, ICD-11) was created, which is already used in the DSM-5 (315.39) (Freitag, 2021).

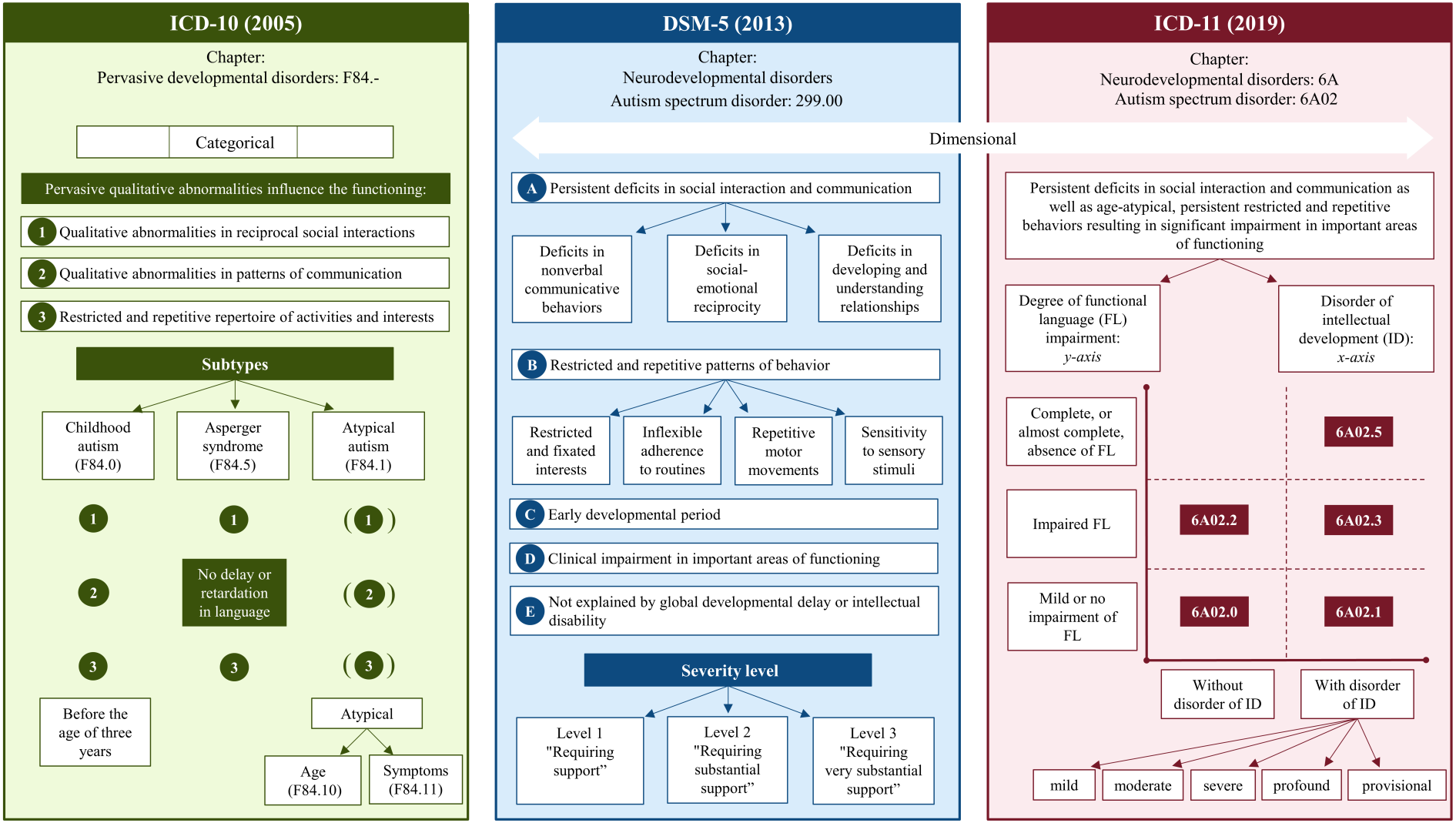
In addition to the symptoms of ASD, additional symptoms of comorbid disorders are not uncommon in ASD, but are actually the rule according to the findings of Posserud et al. (2018). In their study, only two percent of children with ASD showed no other symptoms that were indicative of other disorders. The meta-analysis by Falter-Wagner (2020) also shows that people with ASD have a significantly higher prevalence of comorbid mental disorders (e.g. depressive disorders, bipolar disorders or obsessive-compulsive disorders). The most common comorbid disorders were found to be attention deficit/hyperactivity disorder (20%) and anxiety disorders (13%). In general, it should be noted that ASD and *Attention Deficit Hyperactivity Disorder* (ADHD) in particular are often confused when making a diagnosis due to some

overlapping symptoms. However, the symptoms are exhibited for different reasons in both disorders (Mayes et al., 2012). For example, individuals with both ADHD and ASD show deficits in orientation. In people with ADHD, this results from inattention or hyperactivity; in people with ASD, it results from sensory overload (Habermann & Kißler, 2022). In order to avoid misdiagnosis, the diagnosis should therefore be carried out by trained professionals (Teufel, 2023). In addition, the ICD-11 has not made diagnosis any easier for diagnosticians, as the criteria do not provide a concrete description of the symptoms that must be present, nor do they specify a number of symptoms (Freitag, 2021). Although the criteria are more clearly stated in the DSM-5, the classification into severity levels must be viewed critically. Severity levels can change over the course of a person's life, e.g. symptoms can be alleviated by therapeutic support (AWMF, 2021) or intensified by crisis situations. During the COVID-19 pandemic, for example, it was shown that many people with ASD experienced a significant increase in their symptoms (e.g. Latzer er al., 2021; Vasa et al., 2021), which can ultimately lead to a temporary or persistent increase in severity, meaning that the diagnosis would no longer be correct.

The complex ASD symptomatology not only shapes the life of the person with ASD itself, but also the life of their family (e.g. Herpertz-Dahlmann et al., 2010) and especially that of the parents as key persons (Tröster et al., 2017). In the media, little attention is paid to the topic of parental stress of parents to children with ASD (Kamp-Becker et al., 2020), which is why it is important to devote research to this target group in order to depict and make visible the reality of their lives. This doctoral dissertation therefore focuses on parents and their stress. Parental stress and the everyday challenges of coping with a child with ASD are examined in more detail in the following chapter (Chapter 3).

Figure 1

Comparison of autism spectrum disorder in ICD-10, DSM-5 and ICD-11



3 Parental stress

The phenomenon *stress* can be found in many different areas of life (Kaluza, 2012) and is described in everyday life as an unpleasant state of tension (Lyon, 2012; Zapf & Semmer, 2004). Stress research describes that every phase of tension triggered by stressors must be followed by a relaxation phase to avoid long-term health consequences (Korittko et al., 2016; McEwen & Seeman, 2003). In order to understand the effects of stress on health, a holistic view of the construct and the effects of stressors is required (Monroe & Slavich, 2016), which is why numerous different disciplines have been researching stress (Kaluza, 2012) and have been developing various theories and models on the development and effects of stress for decades (Petras et al., 2021). In family research, stress is seen as a natural component of the family system and part of family development (Korittko et al., 2016). In this system, parents are ascribed the task of raising children, which involves many demands such as educational, care, and provision tasks and brings with it the potential for stress (Kaluza, 2012; Sperlich et al., 2011). With this focus on families, the term *parental stress* is used (Petras et al., 2021), which includes not only the effects of parental stress on parents themselves, but also the effects on children. This is because parental stress not only has a potentially negative impact on parents' mental and physical health, but also on their child's development (e.g. Kupferschmid & Koch, 2014; Maat et al., 2021), e.g. due to dysfunctional parenting behavior caused by stress (Tröster, 2011).

As a theoretical foundation, reference is made below to the transactional view of (parental) stress, outlining the models of Lazarus (e.g. Lazarus & Folkman, 1984) and Abidin (1992) in Chapter 3.1. This is followed by an overview of study results on stress in parents to children with ASD.

3.1 Transactional view of (parental) stress

Depending on the discipline, numerous stress theory models depict different perspectives (e.g. psychological, biological, sociological points of view) in order to understand stress (for an overview see Rusch, 2019). The Transactional Stress Model by Lazarus and his research

group (Lazarus, 1999; Lazarus & Folkman, 1984; Lazarus & Launier, 1978) is still considered a cornerstone of psychological stress research (e.g. Faltermaier, 2017; Rusch, 2019; Schwarzer, 2000; Stemmler, 2007) and continues to be used in numerous studies to provide a theoretical foundation (e.g. Bartels et al., 2023; Bebermeier et al., 2022; Krause et al., 2021; Si et al., 2023). The basic idea of this relational model is that stress is not considered solely in terms of the stimulus or reaction, but always in relation to a reciprocal person-environment relationship (Lazarus & Launier, 1978; Semmer & Zapf, 2018). In this context, Lazarus and Folkman (1984) speak of a process consisting of cognitive appraisals and coping. The process consists of two steps, whereby they influence each other and occur simultaneously: (1) In the *primary appraisal*, a potential stressor in the context of a challenging situation is evaluated in terms of its significance for one's own well-being. If the situation is classified as positive or irrelevant, no examination of possible coping is required. If, in contrast, the situation is assessed as stressful, a simultaneous comparison is made with the (2) *secondary appraisal* as to whether sufficient and the right resources are available to effectively cope with a challenge. If there is a subjective discrepancy between the demands and the coping resources, a psychological stress reaction occurs. Coping attempts are repeatedly checked for their effectiveness within the reaction loop and a reappraisal takes place, whereby a different result may occur within the loop (Lazarus & Folkman, 1984). In simplified terms, the model is summarized and applied in studies as follows: Stress arises when a demand or a potentially stressful situation is assessed as threatening and one's own available coping resources are assessed as insufficient to deal with it (e.g. Cina & Bodenmann, 2009; Krafft, 2022; Reif & Spieß, 2018; Schuh et al., 2020; Tröster, 2011). In the model presented, it becomes clear that the emergence of stress is shaped by individual assessments of the situation and one's own coping options, so that the view on stress can be explained as a personalized phenomenon (Fink, 2016; Kaluza, 2012). The greatest criticism of Lazarus' model is the difficulty of adequately measuring stress as a transactional and processual construct with postulated evaluations (summarized by Faltermaier, 2017). For this reason, the basic

assumptions of the Transactional Stress Model in particular are used in various research areas (e.g. stress at work: Laugaa et al., 2008; social stress: Vella et al., 2012), including attempts to explain parental stress. The Parenting Stress Model according to Abidin (1992) is presented below, which has specified the basic assumptions of the Transactional Stress Model for the specific group of parents and made them measurable with its Parenting Stress Index instrument.

The Parenting Stress Model by Abidin

The Parenting Stress Model by Abidin (1992) "represents an explication of a specific application of Lazarus and Folkman's general theory" (p. 410). It is similar to the Transactional Stress Model in its dynamics and basic assumptions, but focuses on the target group of parents. In this case, the appraisals relate to the parental role (Abidin, 1992). If the perceived resources in the parental role are not considered sufficient to cope with the demands of parenthood (e.g. care, education, or childcare tasks), parental stress arises (Abidin, 1992; Tröster, 2011). Abidin (1992) assessed earlier parenting models, such as the *Parenting Process Model* by Belsky (1984), as a good attempt "to define major global and sociological and personality characteristics which related to parenting behaviors" (Abidin, 1992, p. 408). However, the model was limited in "fully captur[ing] the parent as a thinking, planning, goal-oriented individual" (p. 410). In order to capture parental stress in its various facets, Abidin defines two domains in his Parenting Stress Index (PSI, 1995; German version: *Eltern-Belastungs-Inventa*r (EBI), Tröster, 2011), the parent domain and the child domain, which contain a total of 13 sources of stress (or 12 sources of stress in Tröster, 2011) (see Figure 2). By developing an instrument that measures these different sources of stress, Abidin (1995) makes the construct of parental stress and thus the basic considerations of Lazarus' Transactional Stress Model (Lazarus & Folkman, 1984) measurable. The PSI is not only used in clinical diagnostics, but also in numerous studies as a measurement instrument to validly assess parenting stress (e.g. Khalsa et al., 2021; Marie et al., 2023; Paris et al., 2022; Trumello et al., 2021). The German version of the PSI, the EBI by Tröster (2011), enables valid measurement of inter- and intra-individual parental stress in

German-speaking regions. The EBI, which was developed as an economical diagnostic screening instrument and individual diagnostic procedure for clinical practice (Tröster, 2011), is also used as a reliable measurement instrument in numerous empirical studies (e.g. Ahnert et al., 2017; Dillmann et al., 2022; Dyba et al., 2019; Knölker, 2020; Poppinga, 2021; Sarimski, 2016).

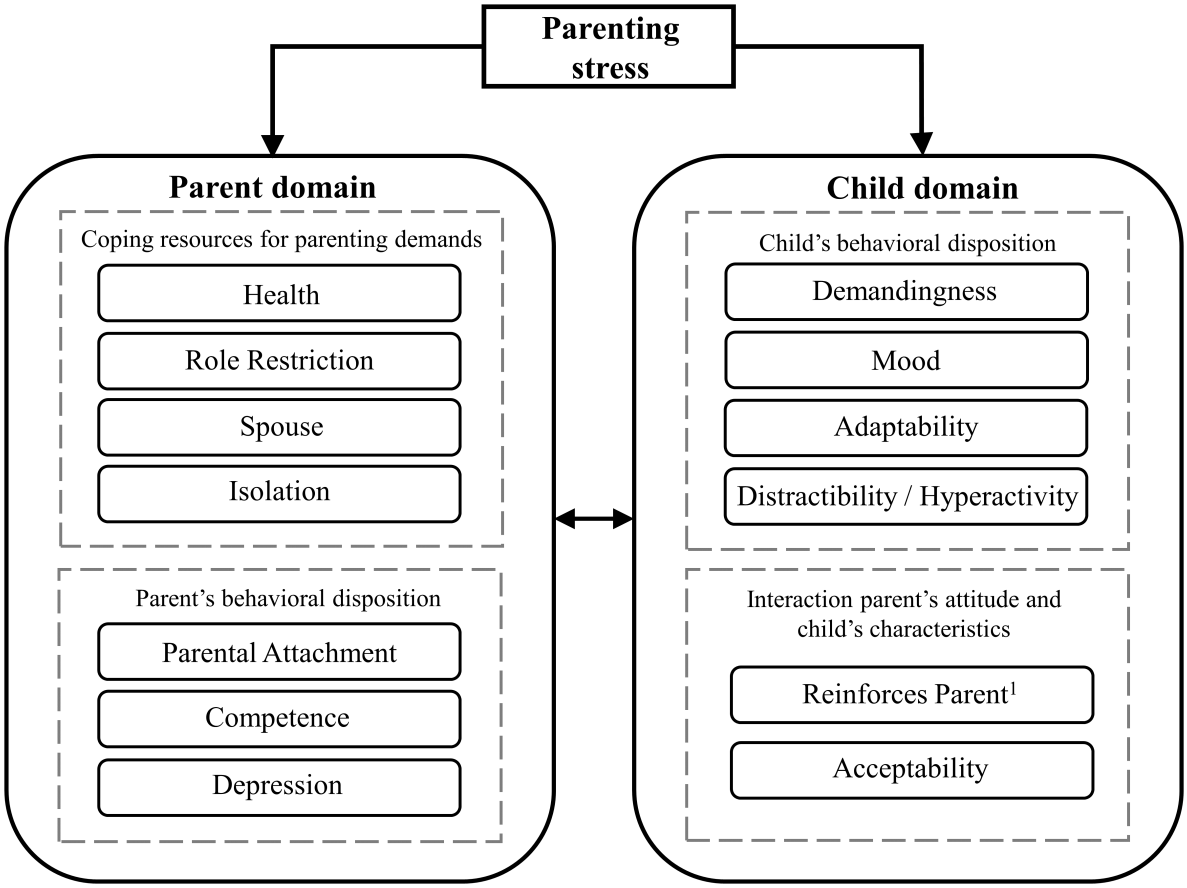
Abidin (1995) and Tröster (2011) describe the two stress domains in their instruments as follows (see Figure 2): The parent domain includes seven sources of stress that relate to limitations in the functions of their parenting role. Four of these sources relate to the strain on resources that are important for fulfilling their parental role. One of these resources is the parents' state of health in the form of limited performance (*Health* subscale), as well as a restriction in their personal way of life (*Role Restriction* subscale). Parents often have to put their own needs on hold and give up freedoms, as their existence as parents and their duties in this role take up a large part of everyday life. Fulfilling the duties of their parental role can be difficult if there is no support from a partner (*Spouse* subscale) or a social network (*Isolation* subscale). The three remaining sources of stress in the parent domain are characterized by parental behavioral dispositions. Low parental attachment (subscale *Parental Attachment*) manifests itself, among other things, in a lack of emotional parent-child interaction and in the fact that the parents have difficulty empathizing with the child. In addition, doubts about competence within the parental role can make it more difficult to cope with the demands of parenthood (*Competence* subscale). The last behavioral disposition is depressive moods on the part of the parents. These can arise from feelings of excessive demands within parenting (*Depression* subscale). The child domain comprises a total of six sources of stress arising from the child's behavior, the first four of which explicitly deal with the child's behavioral disposition, such as a strong dependency and a high need for support (*Demandingness* subscale) or a negative emotional mood, which can manifest itself in provocations and aggression towards the parents (*Mood* subscale). A lack of adaptability on the part of the child, which is particularly evident in phases of developmental transitions (*Adaptability* subscale), or particularly pronounced hyperactivity and

impulsivity (*Distractibility / Hyperactivity* subscale) also make everyday parenting more difficult for parents. The other two sources of stress in the child domain focus on interactions between the child's characteristics and the parents' personality traits and attitudes. Parent-child interaction can suffer from a lack of encouragement and positive affect, resulting in a lack of motivation on the part of the parents to respond adequately to the child's needs (subscale *Reinforces Parent*). The discrepancy between the child's negatively perceived behavior and the parents' expectations can be a source of stress that makes positive educational interaction more difficult (*Acceptability* subscale). For all 13 sources of stress, Abidin (1995) assumes that they interact with each other and influence parental stress, meaning that they should not be considered independently of each other.

Both the transactional idea that stress arises when the available resources are not considered adequate to cope with the demands (Lazarus & Folkman, 1984) and the Parenting Stress Model (Abidin 1992), which additionally specifies the sources of stress for parents and makes them measurable, form the basis for all three studies relevant to the doctoral dissertation. A critical examination of the transactional perspective can be found in Chapter 6, in which research limitations are discussed and implications derived.

Figure 2

Parenting Stress Model by Abidin (1995)



Note. Own representation of the Parenting Stress Model by Abidin (1995, p. 30) based on Tröster (2011, p. 6).

[1]The *Reinforces Parent* subscale was not included in the EBI due to unsatisfactory reliability (Tröster, 2011).

3.2 Stress and demands of parents to children with ASD

Numerous studies show that parents to children with ASD report higher levels of stress compared to other parents (e.g. Abbeduto et al., 2004; Hastings & Johnston, 2001; Hayes & Watson, 2013; Hoffman et al., 2009; Sarimski, 2016; Weiss, 2002). The meta-analysis by Hayes and Watson (2013) shows a higher level of stress in parents to children with ASD compared to parents to children with Down syndrome, cerebral palsy or an intellectual impairment, for

example. Parents to children with ASD also express higher levels of stress compared to parents to children with other developmental disabilities (Hastings & Johnson, 2001). Hoffman et al. (2009) used Abidin's (1995) PSI in their study of parents to children with ASD and found that parental stress manifested itself primarily in the child domain. A German study by Sarimski (2016), in which the EBI (Tröster, 2011) was used as the German version of the PSI, also showed a significantly higher experience of stress in mothers of children with ASD compared to mothers of children with an intellectual disability only in the child domain. The child's ASD symptoms are cited as an explanation for the increased parental stress. Empirical studies show associations between parental stress and the behavior of their child with ASD, such as impairment in adaptive functioning (Hoffman et al., 2009; Sarimski, 2016; Weishaupt et al., 2019) and social behavior (Estes et al., 2013; Tomanik et al., 2004), limitations in social communication (Davis & Carter, 2008), irritability and outbursts of anger (Estes et al., 2013; Hoffman et al., 2009; Sarimski, 2016; Tomanik et al., 2004) or aggressive behavior towards oneself or others (Jungbauer & Meye, 2008). Tröster et al. (2017) outline a possible process leading from ASD symptoms to parental stress in their *Four Level Model* (*Vier-Ebenen-Modell*; see illustration of the Four Level Model in Tröster & Lange, 2019, p. 71). The autistic core symptoms (level 1; see also Chapter 2) trigger the process as the first level and lead to impairments in everyday life (level 2; e.g. Habermann & Kißler, 2022; Mancil et al., 2009). An example of such an everyday impairment can be the difficulty in establishing and maintaining social relationships with peers, which can be made more difficult by the symptoms of impaired social interaction and communication. The everyday impairments in turn cause the demands that parents have to cope with (level 3), which can potentially lead to stress (level 4). Sticking with the example given, the impairment in the shape of a lack of social relationships with peers could result in the need for parents to keep the child more occupied themselves in everyday life instead of letting them play with other children, which in turn leads to further demands, such as taking care of their own relationships in addition to the time-consuming childcare. Tröster and Lange

(2019) have clustered the diverse demands placed on parents to children with ASD into eight demands. As these eight demands play a central role in this study in two of the three studies (studies I and III), they are listed in Table 1 and linked to national and international studies that have dealt with the respective demands.

Table 1

Demands of parents to children with ASD based on Tröster & Lange (2019)

Demands	Description	Example studies
Parent-child relationship	Parents are confronted with the challenge of building and maintaining a stable parent-child relationship with their child, which can be particularly challenging for a child with ASD due to their symptoms.	Woodgate et al., 2008; Schirmer & Alexander, 2015; Teague et al., 2019
Problem behavior of the child in education	Dealing with the child's problem behavior can be stressful in parenting situations due to the child's symptoms (e.g. limited communication, see Chapter 2).	Jungbauer & Meye, 2008; Ludlow et al., 2011; Ornstein Davis & Carter, 2008; Seymour et al., 2012; Zawacki, 2019
Organization of family life	Structures are particularly important for children with ASD, which is why good organization of everyday life with established routines is often helpful. Organizing family life in such a way that all the usual structures can be maintained at all times can be difficult to implement.	Boyd et al., 2014; Habermann & Kißler, 2022; Larson, 2006
Cooperation with the partner	Couples face the challenge of cooperating with the other parent as a parenting partner on the one hand and as a romantic partner on the other, with whom they have to work on maintaining the relationship. Due to the high demand for agreements on care and structuring everyday life in order to organize family life together, there is often little time to work on the relationship.	Hock et al., 2012; Jungbauer & Meye, 2008; Siman-Tov & Kaniel, 2011
Personal way of life	In addition to the care and organizational effort involved in living with a child with ASD, thinking about and fulfilling one's own needs (e.g. time for oneself and one's own hobbies or career) at the same time often gets lost in everyday life.	Jungbauer & Meye, 2008; Hackenberg, 2008; Hoogsteen & Woodgate, 2013; Sarimski, 2016; Siman-Tov & Kaniel, 2011
Social participation	Social participation and the cultivation of social contacts is not only lost due to the frequent lack of time but can also be reinforced by the fact that contacts with other parents, for example through friendships made among the children, are rarer for children with ASD.	Jungbauer & Meyer, 2008; Ludlow et al., 2011; Sarimski, 2016; Woodgate et al., 2008
Stigmatizing reactions in the social environment	Stigmatizing reactions in the social environment and in public are not uncommon with ASD. Parents are confronted with those reactions and have to find a way to deal with this challenge.	Hassan & Inam, 2013; Heckmann, 2004; Minhas et al., 2015; Schirmer & Alexander, 2015; Vollmer et al., 2020; Woodgate et al., 2008; Zawacki, 2019
Professional support	In order to be able to make use of professional support, in most cases a lot of organizational work has to be done by the parents, such as establishing contacts with cooperation partners and service providers, submitting applications, organizing and keeping appointments.	Jungbauer & Meye, 2008; Schirmer & Alexander, 2015; Stuart & McGrew, 2009; Vollmer et al., 2020

Findings on stress and demands of parents to children with ASD during the COVID-19 pandemic

As epidemics have had a negative impact on the demands and stress of the population in the past (Pan American Health Organization, 2009), this factor is highlighted below for the COVID-19 pandemic, with a focus on parents to children with ASD. During the COVID-19 pandemic, there was a general increase in stress in the population (e.g. Kuehner et al., 2020; Petras et al., 2021; Rajkumar, 2020), especially in groups with risk status and their families. Parents reported higher levels of stress compared to non-parents (e.g. American Psychological Association, 2020; Bujard et al., 2021). When parents are compared with each other in their experience of stress during the pandemic, parents to children with ASD showed higher stress than parents to neurotypical children (Corbett et al., 2021; Kalb et al., 2021). In the US study by Kalb et al. (2021), almost half (48%) of the parents to children with ASD surveyed reported suffering from substantial stress after the first few months of the pandemic, while only a quarter (25%) of the other parents reported this. It has been shown that the increased stress is associated with the worsening of the child's ASD symptoms (Manning et al., 2021). In a study from Germany and Austria (Isensee et al., 2022), almost half of the parents reported an increase in their child's ASD symptoms in the first months of the pandemic. The results of Wang et al. (2021) indicate that parents to children with ASD showed significantly more depressive and anxious symptoms than parents to neurotypical children. Bellomo et al. (2020) consider children with ASD and their families to be a vulnerable group during this time, partly due to an exacerbation of ASD symptoms. This assumption is supported by other study results. Vasa et al. (2021) showed that after the first two months of the pandemic, around 45% of children with ASD experienced a worsening of their existing psychiatric disorder and more than half had new psychiatric symptoms. In Latzer et al. (2021), the following symptoms increased:

ritualized behaviors, sleep disturbances, outbursts of anger and a decrease in motivation for social interaction, while Stadheim et al. (2022) showed increased mood symptoms and maladaptive behavior. The study by Colizzi et al. (2020) also showed a worsening of existing behavioral problems in more than a third of children with ASD. The main reasons cited for the increase and new development of symptoms are the interruption and change of routines (Latzer et al., 2021; Vasa et al., 2021), which are particularly important for children with ASD (Bagatell, 2016), as well as the lack of external support (Vasa et al., 2021), and the prolonged suspension of therapeutic measures (Latzer et al., 2021; Manning et al., 2021; White et al., 2021).

In summary, parents to children with ASD are exposed to very high levels of demand and stress. Parents are particularly stressed during a crisis, in this case during a pandemic. Research on this topic is highly relevant both for the resulting (long-term) consequences and for comparable times of crisis or possible future pandemics. The individual demands responsible for the increased stress were investigated as part of this doctoral dissertation in study III. It can also be summarized that, from a transactional perspective, the demands alone are not responsible for the stress, but are mediated via coping resources, which is why these are presented in the following chapter (Chapter 4).

4 Coping resources of parents to children with ASD

Resources are defined as everything that helps an individual to satisfy needs in a situation (Grawe, 1998). They either have the benefit of making it easier to achieve goals (e.g. through social support) or have a benefit in themselves (e.g. a sense of self-efficacy) (Hobfoll, 2002). In the family context, coping resources help parents to deal with the educational demands of everyday life (Tröster & Lange, 2019). The literature has already identified relevant resources for coping with demands and for defending against or mitigating stress for parents to children with ASD. These include internal resources, such as functional coping strategies for dealing with demands (e.g. Wang et al., 2013) or parental self-efficacy (e.g. Giallo et al., 2013; Kuhn & Carter, 2006). However, social resources such as perceived social support (e.g. Hastings & Johnston, 2001; Weiss et al., 2021) and the perceived quality of the partner relationship (e.g. Siman-Tov & Kaniel, 2011) have also been identified as parental resources. In the following part, the four coping resources mentioned are explained in general and related to parents to children with ASD and their parental stress.

4.1 Coping strategies

Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 178). Coping merely refers to the attempt to cope with stress, not to successful coping (Zapf & Semmer, 2004). Which strategy is used can vary greatly, although it is assumed that people resort to similar strategies in different situations (Aldwin, 2009). Numerous coping strategies can be found in the literature; Carver (1997) alone extracts 14 different strategies in his Brief COPE instrument. Not only the strategies vary in research, but also the classifications used to summarize the strategies (e.g. Lazarus,

1999; Schwarzer & Schwarzer, 1996; Skinner et al., 2003). According to Lazarus (1993), a strategy must always be appropriate to the situation, which makes a general classification of different strategies difficult (e.g. Stemmler, 2007). Fundamentally, however, coping strategies aim to be effective in coping with stress or demands, which is why the classification of functional (effective) and dysfunctional (ineffective) strategies is widespread (Schwarzer & Schwarzer, 1996). Empirical studies also attempt to clarify which strategies are functional or dysfunctional for parents to children with ASD. Certain strategies that are associated with higher or lower levels of stress experienced by these parents consistently emerge, especially through systematic reviews. For parents to children with ASD, active coping strategies in particular, such as reappraisal coping, have a stress-reducing or stress-preventing effect (e.g. Ni'matuzahroh et al., 2022; Wang et al., 2013). For example, avoidance behavior, such as ignoring the problem, has been shown to promote stress (e.g. Hastings et al., 2005; Vernhet et al., 2019). In the mediation analysis by Tröster and Lange (2019), only the dysfunctional coping strategies (e.g. distraction or avoidance) proved to be a significant mediator between demands and parental stress, not the functional strategies (e.g. active coping or seeking support). This could be due to the fact that parents to children with ASD mainly use avoidance strategies and have fewer functional strategies in their repertoire (Vernhet et al., 2019). When attempting to extract effective and ineffective coping strategies, the inclusion of other resources, such as strong parental self-efficacy, which is associated with more effective coping with stress (Batool & Khurshid, 2015), should not be overlooked.

4.2 Parental self-efficacy

Based on the *Social cognitive theory*, Bandura (1977, 1997) coined the concept of self-efficacy with his definition. The foundation is the assumption that emotional, cognitive,

actional and motivational processes are subject to control by subjective beliefs (action and outcome expectations). According to Bandura (1997), a person has a pronounced perceived self-efficacy if they are convinced that they are capable of carrying out actions in such a way that they can achieve their goals on the basis of their existing skills. Applying Bandura's general definition to parenting, parental self-efficacy can be seen as the parent's conviction that they are able to manage the educational tasks (e.g. developmental, educational, and care needs of the child) to the best of their ability using their existing competencies (Coleman & Karraker, 1998; Roost, 2014). Parents recognize their own competencies in order to influence the environmental conditions of their child in such a way that the best possible development is enabled (Ardelt & Eccles, 2001). Parental self-efficacy depends on various factors (Coleman et al., 1998). Montigny and Lacharité (2005) identify four basic factors that comprise parental self-efficacy. These include (1) the conviction of one's own strengths, (2) the ability to plan and carry out actions, (3) to use one's own abilities appropriately and under different conditions, and (4) to fulfill educational tasks related to the child (e.g. instrumental or affective). A clear distinction must be made from other constructs, such as optimism: Self-efficacy is not about parents believing that everything is fine, but that they are convinced that they themselves have the ability to cope with the situation (Knoll et al., 2017). Despite numerous attempts, there is no uniform definition of parental self-efficacy in research to date, which could be due to the high complexity of operationalizing this construct (Miller, 2001) and the wide range of available measurement instruments (Wittkowski et al., 2017). However, studies agree on the high clinical relevance of parental self-efficacy in relation to the well-being of parents and their children (for an overview, see Albanese et al., 2019).

A high level of self-efficacy is particularly beneficial for children with behavioral problems, as self-efficacious parents find it easier to consistently apply their skills in this role, even

in difficult situations (Teti et al., 1996). Therefore, this resource is also being addressed in autism research, with numerous studies coming to the conclusion that the more pronounced parental self-efficacy is, the less stress parents experience (e.g. Batool & Khurshid, 2015; Giallo et al., 2013; Hastings & Brown, 2002; Kuhn & Carter, 2006; Meirsschaut et al., 2010; Tröster & Lange, 2019; Weiss et al., 2013). Conversely, a low level of parental self-efficacy can explain a high level of stress. Parents to children with ASD are thus a particularly vulnerable group, as they show a lower level of self-efficacy compared to other parents, e.g. to children with emotional behavioral disorders or Down syndrome (Smart, 2016). Low parental self-efficacy is associated with the severity of social and stereotyped behavior problems in the child with ASD in the study by Daulay et al. (2018). Educational failures due to the child's emotional and social behavioral problems may be a reason for the low self-efficacy of parents to children with ASD (Fields, 2006). This may also be due to the fact that the development of children with ASD is less predictable than that of other children and this can cause uncertainty in parenting that is detrimental to self-efficacy (Kuhn & Carter, 2006). When parents know a lot about their child's development, they show higher parental self-efficacy (Hess et al., 2004) and, in turn, lower stress levels (e.g. Batool & Khurshid, 2015).

4.3 Social support

Social support can reduce stress within parenting (e.g. Tröster, 2011; Zawacki, 2019), which is why it can be seen as a parental resource. Social support is often divided into three areas in the literature: (1) emotional, (2) informative / informational and (3) practical / instrumental support (e.g. Klauer, 2009; Rinken, 2010; Schulz & Schwarzer, 2004). Emotional support is characterized by the exchange of feelings and thoughts, which can have an emotion-regulating effect. Relief through the exchange of information and educational experiences (e.g.

exchange of experiences regarding childcare facilities) can provide security and new impulses (informational support). However, social support can also be provided in practical ways, e.g. by helping out with childcare or household chores (instrumental support). Maintaining social relationships is associated with health-promoting effects depending on the strength of the relationship (Bruns, 2013). However, a strong and reliable relationship is also associated with costs in the form of relationship maintenance and expectations of the other person (Diewald, 1991; Günther, 2015). If an asymmetry between giving and receiving arises within the relationship, this can threaten well-being (Bruns, 2013) and self-worth, for example by causing feelings of inadequacy or inferiority (Laireiter & Lettner, 1993). Being indebted to the giver or returning support in order to restore balance can create negative feelings of obligation (Nestmann, 1988). However, social support can manifest itself not only in actual giving and receiving. Social support can be divided into (1) actual social support, which only retrospectively measures how much support was actually received, and (2) perceived social support, which measures the expectation of the availability of support (Kienle et al., 2006). Perceived social support is the belief that support is available and can be accessed when it is needed (Viswesvaran et al., 1999). According to Cohen and Wills (1985), this type of social support can buffer stress ("stress buffering"). This means that stress does not arise in the first place because the parents are convinced that they would receive support if it were necessary. The perceived availability of social support is negatively associated with stress in the parent domain (see Chapter 3.1) (Tröster, 2011).

Overall, the results from empirical studies show that social support represents an important resource for parents to children with ASD (e.g. Hastings & Johnston, 2001; Siman-Tov & Kaniel, 2011; Weiss et al., 2021). The study by Robinson and Weiss (2020) confirms that not only the objective, i.e. the social support received, but also the perceived support is

associated with lower stress for parents to children with ASD. Although social support appears to be important for coping with stress in parents to children with ASD, results also show that parents to children with ASD are less likely to use strategies to seek social support to cope with stress than other parents (Vernhet et al., 2019). The longitudinal results of Tröster and Lange (2019) show that parents to children with ASD feel more confident in the support potential of their social network four months after being connected to an autism therapy center (therapy for the child). This therefore appears to be a possible approach to strengthening perceived social support.

4.4 Partnership quality

The core family is seen as a person's strongest and most relevant social network, whereby intimacy and trust can be shared, especially in the relationship with the partner, in a way that does not occur in other relationships (Karrer, 2015). A stable partnership can increase general well-being within parenthood (Domsch & Lohaus, 2010), as, among other things, the cooperation of both partners has a supportive effect in coping with parental demands (e.g. Laux & Schütz, 1996). The concrete practical support from the partner in the upbringing and care of the child in everyday life has a relieving effect on the other (Domsch & Lohaus, 2010), as does the emotional support from the partner when feelings, wishes and worries are shared (Vollmer et al., 2020). In this respect, good partnership quality can be seen as a resource in parenthood that influences stress in the form of a reduction. In the study by Siman-Tov and Kaniel (2011), this was confirmed for the group of parents to children with ASD by finding negative effects between the quality of the marriage and parental stress in their path analysis.

For parents to children with ASD, inconsistent study results are reported regarding the strength of relationship quality. For example, Marciano et al. (2015) report that parents to

children with ASD feel more connected to each other as they face and manage the challenging task of parenting a child with ASD together. This connection can be derived from the concept of parenting alliance, in which parents are seen as a collaborative unit who value and respect each other, including their tasks and roles within parenting (Cohen & Weissman, 1984), and work closely together to address their parenting responsibilities (Schoppe-Sullivan et al., 2004). This partnership system represents a central construct for parents to better cope with demands in parenting (Bodenmann, 2000). Hock et al. (2012) work out two phases in relation to the couple relationship of parents to children with ASD: Phase (1) "tag team", which is characterized by the focus on parenting and by distance and conflict, and phase (2) "deeper intimacy and commitment", which brings the parents closer and more intimately together and in which they perceive their relationship as resilient (p. 411).

Other studies show that parents to children with ASD have a lower quality of relationship than other parents (e.g. Brobst, Clopton & Hendrick, 2009), which Siman-Tov and Kaniel (2011) found to lead to higher levels of stress. Children with ASD often require more parental education, care, and supervision, which is why the daily demands are high (see Chapter 3.2). If so many resources are demanded in one domain, another domain, such as caring for the partnership in the form of hedonistic couple activities (Bodenmann, 2003), may be neglected (Buck & Neff, 2012).

In the literature, it is called a spillover effect when behaviors or affects from one domain of life or situation are transferred to another (Engfer, 1988). The spillover effect is known from the professional context: Occupational stress (role as an employed person) and the associated behavior (e.g. irritability) is dynamically transferred from this domain to another domain, such as family life (role as a parent and/or partner) (e.g. Almeida et al., 1999; Conger et al., 1992; Engfer, 1988; Repetti, 1987). According to this concept, the stress experienced by

parents to children with ASD in their role as parents could also be transferred to the partnership and vice versa. Short-term correlations between problems in the parent-child relationship and marital conflicts have been shown in studies (see meta-analysis by Erel & Burman, 1995). If one assumes that people prefer one coping style and use it in different situations (Aldwin, 2009), this could be an explanation for the connection between a low perceived partnership and parental stress. If dysfunctional coping strategies (see Chapter 4.1) are used in one role, they are presumably also used in the other role.

In summary, the coping resources presented and examined in studies I and II relevant to the doctoral dissertation show links to stress in parents to children with ASD in previous studies. From the perspective of the stress models on which this thesis is based (Abidin, 1992; Lazarus & Folkman, 1984), looking at the connection between resources and stress alone is not adequate, but needs to be extended to include the connections to demands. For this reason, an overarching research question is derived in the following Chapter 5, which is to be answered with the help of sub-questions in the three studies relevant to the doctoral dissertation (Sartor et al., 2023a, 2023b; Sartor et al., 2024). In order to facilitate an overarching discussion, the central results of the three studies are presented.

5 Overarching research question and overview of studies relevant to the dissertation

The neurodevelopmental disorder by the name of autism spectrum disorder is characterized by the heterogeneity of its symptoms (Kamp-Becker & Bölte, 2021). ASD often results in a need for extensive and ongoing support, which in most cases is the responsibility of the parents (Jungbauer & Meye, 2008). There are numerous findings from empirical studies that show that parents to children with ASD have to cope with increased and specific demands in everyday life (e.g. O'Nions et al., 2018; Ornstein Davis & Carter, 2008) and experience significantly more stress than other parents (e.g. Hayes & Watson, 2013). For the sake of providing targeted support for parents to children with ASD, empirical findings are needed from a transactional perspective that identify the demands that induce stress. At the same time, it is necessary to focus on the coping resources that help parents to deal with the demands so that the stress is reduced or does not arise in the first place. The above components are often researched in isolation (stress: e.g. Hayes & Watson, 2013; demands: e.g. Larson, 2006; coping resources: e.g. Marciano et al., 2015) or only partially in conjunction with each other (e.g. stress and coping resources: Weiss et al., 2021; stress and demands: Hassan & Inam, 2013; demands and coping resources: Ludlow et al., 2011).

In order to understand how these components are linked, the following overarching question is addressed in this doctoral dissertation: *How are parental stress, everyday demands, and coping resources of parents to children with ASD connected?* Three empirical studies were conducted for this purpose (Sartor et al., 2023a, 2023b; Sartor et al., 2024). These can be found as an overview in Table 2 and in article form in Appendices A, B and C. Lazarus' Transactional Stress Model (Lazarus, 1999; Lazarus & Folkman, 1984; Lazarus & Launier, 1978) was used as the basis for all three studies relevant to the doctoral dissertation. In stress research, it is generally accepted to use this model as a framework (Schwarzer, 2000; Stemmler,

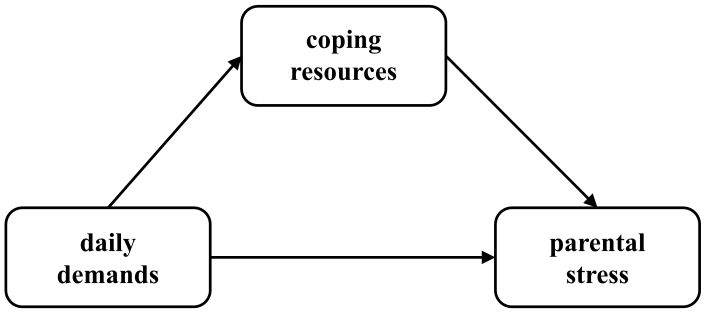
2007). In addition, the use of the most popular psychological stress model offers the advantage that the present results are more comparable with other studies that also used the Transactional Stress Model as a basis. The Parenting Stress Model by Abidin (1992) was used as the measurable specification for parents in all three studies relevant to the doctoral dissertation (see Chapter 3.1), so that both models form the basis for answering the overarching question. The specific questions and the central results of the three studies relevant to the doctoral dissertation are summarized below.

Study I. As a starting point, stress is seen as a product that arises when parents do not consider their perceived resources to be adequate to cope with the demands placed on them within their parental role (see Chapter 3.2). If these theoretical model assumptions are transferred to parents to children with ASD, it can be assumed that the everyday demands of raising, caring for, and looking after a child with ASD cause high parental stress if parents do not appraise their coping resources as adequate or suitable for coping with the demands. Resources that are potentially helpful in coping with the demands can be derived from empirical results from the research landscape. In summary, it can be assumed that coping resources such as the use of functional coping strategies (see Chapter 4.1), high parental self-efficacy (see Chapter 4.2), and a high level of perceived social support (see Chapter 4.3) help parents to cope with everyday demands (see Table 1) and protect them from stress. Furthermore, it can be assumed that the use of dysfunctional coping strategies prevents parents from coping with their demands and thus promotes stress. In order to answer the question of whether the aforementioned resources have a mediating effect on whether stress arises from the everyday demands that parents to children with ASD have to cope with, the theoretical model in study I (see Figure 3) was empirically tested using mediation analyses. For this purpose, data from a questionnaire survey were used (Tröster & Lange, 2019) with $N = 266$ parents to children with ASD who

were affiliated with an autism therapy center. Firstly, the results showed a direct effect of high demands of everyday life influencing parental stress, regardless of the coping resources listed. Secondly, two of the four coping resources proved to be significant mediators that have a mediating influence between demands and stress. High parental self-efficacy helps parents to children with ASD to cope more effectively with demands and protect them from stress. The opposite is true for dysfunctional coping strategies: If parents use dysfunctional strategies (e.g. distraction or denial) to cope with demands, this is partly responsible for parental stress arising from the demands. Contrary to expectations, functional strategies and a pronounced perceived social support did not have a mediating effect (Sartor et al., 2023a).

Figure 3

Schematic representation of the model of study I

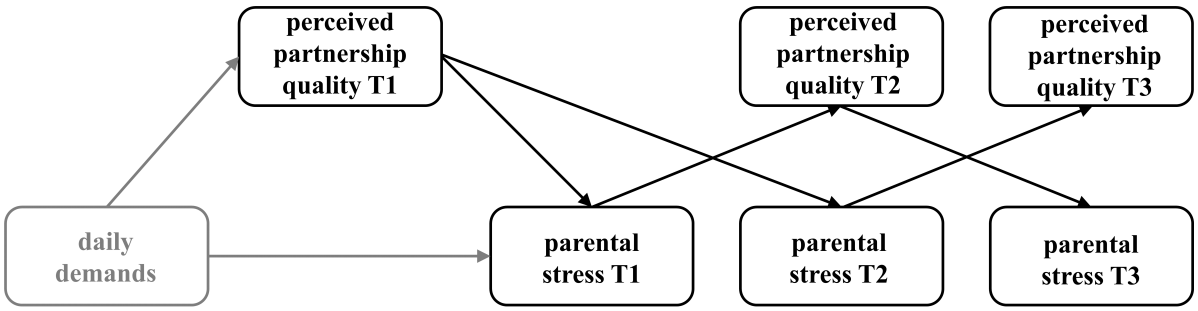


Study II. Study II took a closer look at a resource that has so far been ambivalently associated with stress in research: Perceived partnership quality (see Chapter 4.4). In order to obtain a clearer picture of the connection between the perceived partnership quality and the parental stress of parents to children with ASD, these two constructs were examined in more detail in a longitudinal design. For this purpose, data from $N = 160$ parents to children with ASD were used. By means of a questionnaire, these parents were interviewed at the beginning of their child's therapy in an autism therapy center, as well as four and eight months after the start of therapy (Tröster & Lange, 2019). The aim was to gain insights into the correlation

between perceived partnership quality and parental stress and how these two constructs predict each other in the first eight months of the child's therapy (see Figure 4). To highlight the interaction, a random intercept cross-lagged panel model was calculated. The results only showed a cross-lagged effect in the parent domain (see Chapter 3.1). The perceived partnership quality is thus less associated with the stress resulting from the child's behavior than with the stress resulting from the restriction of parental functions. For those parents whose parental stress decreased during the first four months, this led to a decrease in perceived relationship quality eight months after the start of therapy. The change in stress levels therefore influenced the perceived quality of the partnership. No effects were found in the opposite direction (Sartor et al., 2024).

Figure 4

Schematic representation of the model of study II

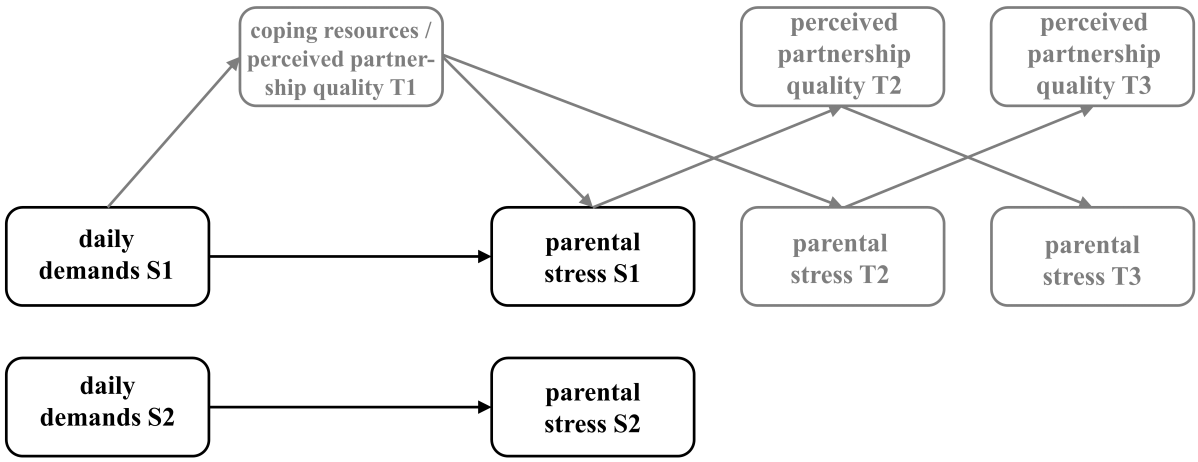


Study III. Overall, there was an increase in parental stress during COVID-19 (Bujard et al., 2021). It was found that parents to children with ASD were more stressed compared to other parents (e.g. Corbett et al., 2021; Kalb et al., 2021; see Chapter 3.2). It is assumed that the pandemic and its effects have made it more difficult to cope with the demands (American Psychological Association, 2020), e.g. through restrictions on therapeutic services (White et al., 2021) or closures of care and educational facilities (Preißmann, 2020). In to the interest of finding out which demands in everyday life have increased due to the pandemic-related changes and which of these are responsible for the increased stress of parents, data was

collected from *N* = 168 parents to children with ASD during the COVID-19 pandemic. These were matched with data from N = 105 parents to children with ASD from before the pandemic (Tröster & Lange, 2019). This made it possible to compare whether there were differences in clarifying stress through the demands (see Figure 5). The results are consistent with previous research findings that both parental stress and all the demands surveyed (see Figure 1) were higher during the COVID-19 pandemic than before the pandemic. At both points in time, the three demands *dealing with the child's problem behavior*, *restriction of the child's personal way of life* and *cooperating with the partner* were consistent in terms of stress. Above all, the child's problem behavior as a demand during the pandemic was responsible for the stress. The demand of dealing with stigmatizing reactions was relevant for the resolution of parental stress before the pandemic, but no longer during the pandemic (Sartor et al., 2023b).

Figure 5

Schematic representation of the study III model



Figures 3, 4, and 5 illustrate the relationship between the three studies relevant to the doctoral dissertation. In the following chapter (Chapter 6), the results of these sub-studies are discussed to answer the overarching question of this thesis.

Table 2

Overview of the three studies relevant to the doctoral dissertation

Study	Title	Authors	Journal	Research question	Methodology
Study I: Sartor et al., 2023a (Appendix A)	*Coping resources and stress due to demands in parents to children with autism spectrum disorders*	Teresa Sartor, Sarah Sons, Jörg-Tobias Kuhn & Heinrich Tröster	Published in: *Frontiers in Rehabilitation Sciences, 4* (1340977), 1–10.	*Do coping resources such as parental self-efficacy expectations, social support, and (dys-)functional coping strategies have a mediating effect on whether everyday demands result in parental stress in parents to children with ASD?*	Mediation analysis
Study II: Sartor et al., 2024 (Appendix B)	*Stress and perceived partnership quality of parents to children with autism spectrum disorder:* *A random intercept cross-lagged panel approach*	Teresa Sartor, Sarah Lange, Jörg-Tobias Kuhn & Heinrich Tröster	Published in: *The Family Journal, 32*(1), 139–148.	*Which interaction between self-reported parental stress and perceived partnership quality of parents to children with ASD exists and how do these two constructs predict each other in the first eight months of the child's therapy?*	Random intercept cross-lagged panel model
Study III: Sartor et al., 2023b (Appendix C)	*Demands and stress before and during the COVID-19 pandemic of parents to children with autism spectrum disorder*	Teresa Sartor, Sarah Sons, Olga Kunina-Habenicht, Heinrich Tröster & Jörg-Tobias Kuhn	Published in: *Frontiers in Psychology, 14* (1212556), 1–11.	*Which demands have increased in the daily lives of parents to children with ASD during the COVID-19 pandemic and which of these are responsible for the increased stress of parents? Are there any differences in clarifying parental stress due to everyday demands before and during the pandemic?*	Simple and multiple linear regression analyses

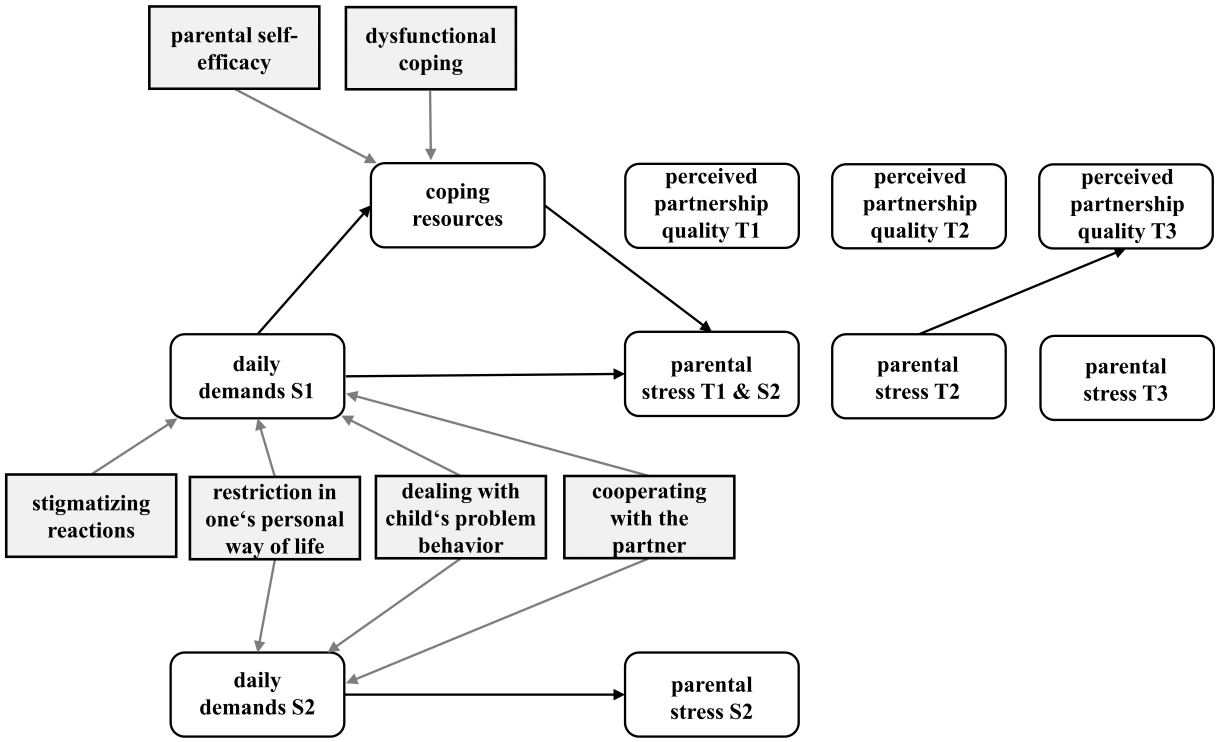
6 Overall discussion

Although there is interest in families to children with ASD, there is still less focus on parents and their stress experience (Kamp-Becker et al., 2020), even though the latter are exposed to extremely high demands and stress (e.g. Hayes & Watson, 2013). There is hence a continuing need for research on this topic in German-speaking regions (Zawacki, 2019). This doctoral dissertation addresses this research gap by focusing on the connections between demands, stress, and coping resources of parents to children with ASD in order to take a more holistic approach. The results from the three studies relevant to the doctoral dissertation are discussed with regard to the assumptions of the models introduced (Abidin, 1992; Lazarus & Folkman, 1984) in order to answer the overarching research question. From this, insights for further research as well as for practical work with parents to children with ASD are derived. Subsequently, limitations of the work and further research implications derived from it are presented.

In the three studies relevant to the doctoral dissertation, various connections between the three broad components of the stress models (stress, demands, and coping resources) could be drawn. In both study I and study III, the basic assumption of the stress models (Abidin, 1992; Lazarus & Folkman, 1984) that everyday demands lead to parenting stress was confirmed in parents to children with ASD (Sartor et al., 2023a, 2023b). In addition, studies I and II showed links between coping resources and stress (Sartor et al., 2023a; Sartor et al., 2024) and between demands and coping resources (study I), supporting the model assumptions. Figure 6 summarizes the central results of the three studies in a joint model.

Figure 6

Schematic representation of the central results of the three studies relevant to the doctoral dissertation summarized in a model



Of all the demands tested (see Table 1), four were found to be significant for parental stress: (1) stigmatizing reactions, (2) restriction in one's personal way of life (only in the parent domain), (3) dealing with problem behavior of the child, and (4) cooperation with the partner (see Figure 6). The demand to organize family life and the demand to maintain social contacts were not significant. High parental stress and demands are even more pronounced in a time of crisis (during the COVID-19 pandemic) (Sartor et al., 2023b), which is consistent with numerous study results (e.g. Manning et al., 2021). Despite the increased demands during a time of crisis, the same demands are still responsible for the stress, except for stigmatizing reactions. It can therefore be concluded that the four demands that result in stress are relatively stable.

(1) Stigmatizing reactions

The typical symptoms of ASD can be conspicuous in everyday social life (e.g. impairment in communication, see Chapter 2), which is why other people often show stigmatizing behavior towards the child with ASD or the family (e.g. Hassan & Inam, 2013; Vollmer et al., 2020). Stigmatization is understood as a multidimensional construct, whereby a norm-deviant characteristic is related to prejudice, stereotypes, and discrimination (Röhm et al., 2019) and arises from negative feelings such as fear, pity, or anger (Fox et al., 2018). Parents to children with ASD often react to stigmatizing behavior with isolation (e.g. Gray, 1993; Kinnear, 2016). During a time of crisis in which contact restrictions and quarantine periods determined everyday life (COVID-19 pandemic), this isolation was natural. During this time, stigmatizing reactions were the only one of the four relevant demands that was no longer informative of stress, although like all other demands, it turned out to be more pronounced (Sartor et al., 2023b). From a transactional perspective (Lazarus & Folkman, 1984), one could conclude that the parents were able to activate resources to successfully cope with these demands during this time, so that no stress resulted from the stigmatizing reactions. Which resources or strategies these could be must be investigated in further empirical studies. By identifying these, targeted support could be provided so that parents could successfully cope with the demand of dealing with stigmatizing reactions even after such a time of crisis. Moving away from the individual-centered approach of how parents can cope with these demands, the general social approach that triggers these demands should also be considered. For example, there should be more education about the disorder of ASD so that stigmatization and the associated isolation of families can be minimized (Minhas et al., 2015).

(2) Restriction in one's personal way of life

Care and educational demands of parents to children with ASD are high, making it difficult for those parents to find time for other activities (Hoogsteen & Woodgate, 2013). This entails restrictions on their personal way of life and reduces time for themselves, such as realizing their own goals, both personally and professionally, or pursuing their own hobbies (Jungbauer & Meye, 2008). Seeing oneself in a role other than that of the child's parent proves to be a challenge in everyday life, which leads to stress in the parent domain (Sartor et al., 2023b). Depending on the severity of the ASD symptoms and the age of the child, the focus is on care, nursing, and the organization of everyday life (Jungbauer & Meye, 2008). This leaves little time and space for fulfilling other roles. In order to provide this time and space, care systems for families with children with ASD need to be rethought and, above all, designed to be reliable and long-term so that families can benefit from them. Due to the great heterogeneity of children with ASD, professional support must be tailored to their needs. Staff must be established over a longer period of time as a fixed structure in the child's everyday life, as sudden changes are difficult to process, especially for a child with ASD due to their disorder (Bagatell, 2016). This implementation requires attractive framework conditions for employees, such as anattractive salary, affiliation with a provider, and further education and training opportunities for the sake of attracting employees to this work. The idea of Minhas et al. (2015), who suggest training community members through interventions due to the shortage of skilled workers, is also conceivable and could be an easier and more cost-effective approach to implement. The disadvantage here, however, is the social cost to the parents to children with ASD of accessing support from their social or neighborhood environment (Diewald, 1991). The price they pay as recipients may be feelings of obligation to return the help (Nestmann, 1988) or feelings of inability to cope with situations without help (Laireiter & Lettner, 1993). This could be the reason

why social support does not mediate helpfully between the demands and parental stress of parents to children with ASD (Sartor et al., 2023a).

(3) Problem behavior of the child

The child's problem behavior, which is characterized by varying degrees of impairment in social interaction and communication as well as repetitive behaviors (see Chapter 2), can be extremely challenging for parents in care and parenting situations (e.g. Ornstein Davis & Carter, 2008). It requires a great deal of patience and tolerance from parents to learn how to deal with their child's behavior (Ludlow et al., 2011). Problem behavior proved to be a particularly important predictor in the clarification of parental stress during the time of crisis (Sartor et al., 2023b), thus confirming previous empirical findings (e.g. Manning et al., 2021). This result can be explained by the intensification of ASD-specific symptoms during the pandemic, which a number of studies from the time showed (Isensee et al., 2022; Stadheim et al., 2022; Vasa et al., 2021). Constantly changing routines due to new official regulations regarding the pandemic (Latzer et al., 2021) and a lack of therapy sessions (White et al., 2021) are possible explanations. Even regardless of crisis situations such as a pandemic, regular and reliable therapeutic support is essential for the child (AWMF, 2021). For this reason, Stadheim et al. (2022) propose hybrid concepts as a solution for continuity in therapeutic work. If digital appointments are established in the routine, this ensures therapy on the one hand (with the exception of therapeutic concepts that require physical presence). On the other hand, such an approach protects the child from a sudden change to a different format (digital sessions) during a time of crisis with contact restrictions in which digital formats are unavoidable. There is still little research into such formats, which is why empirical testing through intervention studies is necessary.

(4) Cooperation with the partner

Cooperation with the parenting partner is a challenging demand for parents to children with ASD (e.g. Jungbauer & Meye, 2008; Siman-Tov & Kaniel, 2011), which increases parental stress (Sartor et al., 2023b). Cooperation with the partner must be distinguished from the perceived quality of the partnership. In contrast to the demand to cooperate with the partner in everyday life with regard to parenting and the organization of everyday family life (e.g. "I argue with my partner about the upbringing of our child."), the perceived quality of the partnership, which describes the subjective quality of the relationship (e.g. "My partner understands my concerns.") has no influence on parental stress, as has been shown longitudinally (Sartor et al., 2024; see Figure 6). Rather, it is the other way around, with parental stress influencing the perceived quality of the partnership. This effect was found at least in the first eight months after the family started to be connected to an autism therapy center. When parental stress is reduced, the parents perceive their partnership quality to be lower in the further course. The parenting alliance (Cohen & Weissman, 1984) can be used as an explanatory approach. Coping with the demands of stressful times seems to bring parents together and strengthen the quality of their relationship (see also Marciano et al., 2015). If the stress is reduced, mutual support is no longer as necessary as in stressful phases. It can be assumed that the parents are strengthened in dealing with their child through therapeutic support at the autism therapy center, such as through psychoeducation or by participating in the child's therapy. Especially, if only one of the two partners accepts these therapy modules, this can lead to an imbalance, which could have a negative impact on the quality of the partnership (Sartor et al., 2024). This hypothesis should be investigated empirically so as to develop suitable strategies and services for practice that counteract this imbalance. The reduction of such differences could be promoted by therapists at a low-threshold level by encouraging the more passive parent to participate more. Explicit offers for

full-time working parents at off-peak times, which, in addition to psychoeducation, also encourage exchanges between parents, could make participation more attractive. Intensive offers such as workshops to provide parents with further training, especially at the start of therapy, could also create a common basis for parents. In addition to ASD-specific topics, couples therapy should also be included in such programs to reflect on and work on communication and cooperation styles (for an overview, see e.g. Schindler et al., 1998). This is because marriage and couples counseling can bring about an improvement in partnership cooperation in parents who experience stress in child rearing (Kröger et al., 2004), which in turn emerged in study III as an important demand for parents to children with ASD (Sartor et al., 2023b). If both partners agree on the goals they are pursuing in the upbringing of their child, it should be easier to cooperate as educational partners (work on strengthening educational partnerships, see for an overview e.g. Stange et al., 2013). The question remains open as to whether cooperation with the partner can mitigate or even prevent stress through a good partnership quality as a resource, as could be modeled from a transactional perspective. Findings to answer this question could be provided by an intervention study.

As described above, the present studies (I and III) were able to confirm that everyday demands lead to stress. However, according to the stress theories of Lazarus (Lazarus & Folkman, 1984) and Abidin (1992), stress only arises from the demands when the available resources are not considered adequate for coping. For this reason, four coping resources associated with stress in parents to children with ASD (see Chapter 4) were examined in terms of whether they mediate between demands and parenting stress: Parental self-efficacy, dysfunctional coping, functional coping, and perceived social support. In line with previous research on the topic (see Chapter 4.2), study I confirms that a high level of parental self-efficacy protects parents to children with ASD from stress. The level of self-efficacy mediates whether or not

stress arises from the demands placed on parents (Sartor et al., 2023a). Their own conviction that they know exactly what their child needs in certain situations helps parents with coping with demands. To strengthen this conviction, education about the disorder is needed so that parents can classify the behavior of their child with ASD (Hess et al., 2004) and cope with the demands of dealing with their child's problem behavior (study III). For this reason, psychoeducation is an important component in interventions for parents to children with ASD (e.g. Sofronoff & Farbotko, 2002). In addition to imparting knowledge and conveying practical parenting skills, it is particularly important to strengthen parents' confidence in their own abilities (Coleman & Karraker, 1998). This can be achieved, for instance, by successfully performing a behavior or observing successful application models (Rammsayer & Weber, 2016). Self-help groups (Shu & Lung, 2005) or discussion groups (Gross et al., 2009) also have a positive effect on parental self-efficacy. More research is needed to further link the influential resource of self-efficacy proven in study I with the relevant demands from study III. For example, it is conceivable that good parental self-efficacy is helpful in coping with the demand *cooperation with the partner*. If parents are convinced that they are adequately competent to resolve situations with their child with ASD and thus have a natural and confident approach to parenting with clear goals, they may find it easier to cooperate with their partner in achieving their child's parenting goals. Kröger et al. (2008) call for the strengthening of parenting skills in interventions to focus not only on the individual level, but also on the couple level. In order to avoid an imbalance between the parents (Sartor et al., 2023a), partnership-based interventions in which self-efficacy is strengthened could be aimed for. Empirical testing is needed to determine whether a joint intervention is effective or whether parents make their belief in their competence dependent on their partner. A modular program containing individual and couple modules would be conceivable, which would have to be designed and evaluated.

In addition to parental self-efficacy, another important mediator between demands and stress is dysfunctional coping (see Figure 6). This includes avoidance behavior such as denial, self-distraction, substance use, or the strategy of losing oneself in negative thoughts, blaming oneself, and venting emotions (Sartor et al., 2023a). As it is assumed that similar strategies are used in different situations (Aldwin, 2009), this could also apply to other demands. Using these strategies in demanding situations, such as dealing with the child's problem behavior or stigmatizing behavior of others, will not lead to successfully coping with the demand in the long term, but will lead to stress instead. The effects of using dysfunctional strategies could also have an impact on the parents' partnership. If parents avoid the challenging demands or get lost in negative thoughts, this could weaken the parenting alliance (Cohen & Weissman, 1984). Open, constructive communication could be beneficial in coping with the demands together and thus strengthen the parenting alliance (Cheatham & Fernando, 2022). It is important that parents are encouraged to reflect on their strategies and that individual effective strategies are developed with therapeutic support. Contrary to expectations (e.g. Muller & Spitz, 2003), it has not been possible to prove that functional strategies mediate between demands and parental stress (Sartor et al., 2023a). It is possible that the functional strategies summarized in study I (positive reinterpretation, planning, acceptance, active coping, humor) are not specific enough for parents to children with ASD. Particularly, the demand of dealing with the problem behavior of the child with ASD is very diverse due to the wide spectrum of this disorder (see Chapter 2). Individual strategies need to be identified that help parents to children with ASD to cope with demands so that they can be supported accordingly. Further research is needed into which strategies help this specific target group in everyday life. The results from study I, for example, support this assumption. The results show that perceived social support, although mentioned as an important resource in the literature (see Chapter 4.3), was not confirmed as a mediating predictor between

demand and stress in parents to children with ASD (Sartor et al., 2023a), which could result from the symptoms. Depending on how pronounced some of the symptoms are (e.g. restricted behaviors, difficulties with changing routines), parents may have limited ability to accept support as children have difficulty adjusting to changing people. It remains to be empirically tested which resources and strategies are needed to cope with the different domains of challenge so that stress does not arise and which symptom manifestations exactly need to be taken into account.

In summary, the findings of the three studies relevant to the doctoral dissertation can contribute an important part to answering the overarching research question of how the everyday demands, coping resources, and stress of parents to children with ASD are related (see Figure 6). The daily demands faced by parents to children with ASD are associated with increased stress (studies I and III), and both demands and stress were particularly high during a time of crisis (study III). In some cases, the stress arises directly from the demands (study I). For parents, it is stressful to pursue their personal needs and goals alongside the care and upbringing of a child with ASD, to deal with stigmatizing reactions from others as well as the child's ASD-specific problem behavior, and to cooperate with their partner regarding child rearing (study III). However, parental stress is also partly mediated by coping resources. Strong self-efficacy helps parents in coping with the everyday demands of raising, caring for, and educating a child with ASD. The use of dysfunctional coping strategies, on the other hand, favors parental stress resulting from the demands (study I). Perceived partnership quality has no influence on parental stress in the first eight months of the child's therapy, but reduced stress predicts lower perceived partnership quality (study II).

Key points regarding practical implication include strengthening parents' confidence in their own abilities (e.g. psychoeducation or learning practical parenting skills) in order to

reinforce their self-efficacy and equip them for dealing with their child's behaviors in everyday life (study I). To counteract an imbalance between parents, to facilitate the demand to cooperate with the partner in parenting (study III) and to increase the perceived quality of the partnership (study II), appropriate offers should be made (e.g. offers at off-peak times for full-time working parents). Ideally, these services should be holistic, low-threshold and offered at an early stage (e.g. at the start of an affiliation with an autism therapy center). An individual analysis of personal demands and the coping strategies used should be carried out so that behavioral patterns tailored to the individual can be developed during therapy and, above all, dysfunctional strategies can be reduced (study I). Designing tailored intervention programs that are reliable and accessible requires high-quality studies on effectiveness first. Even if some connections could be drawn from the three studies, some flanks remain open. Research is needed on the connections between the individual demands and the available as well as other resources (e.g. sense of coherence: Oelofsen & Richardson, 2009; resilience: Pastor-Cerezuela et al., 2020). It also remains to be empirically examined how and which coping resources function during a crisis. It is questionable which resources remain stable and which do not. It is also interesting to see how the three constructs (demands, coping resources and stress) behave after a period of crisis, such as the COVID-19 pandemic. On the one hand, it is conceivable that the stress level will stabilize again after some time, as it did before the crisis. On the other hand, it can be assumed that the children's increased ASD symptoms will not go away easily, so that the high stress level will not decrease without effective therapeutic support – both for the children and for the parents – which is why further research on children with ASD and their parents is essential.

In what follows, the limitations of the three studies relevant to the doctoral dissertation are presented and further research implications are derived from them.

Research limitations

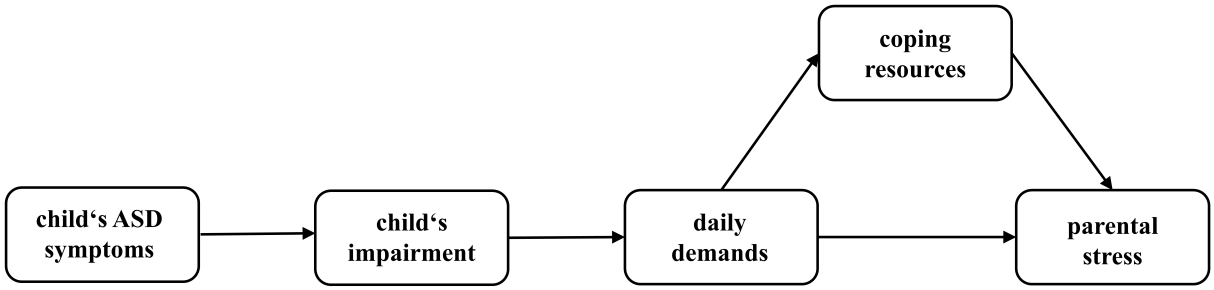
This doctoral dissertation examined the connections between demands, coping resources, and parenting stress in parents to children with ASD, using Lazarus' stress models (e.g. Lazarus & Folkman, 1984) and Abidin's (1992) specification on parents, which takes a transactional view. In research, the use of the Transactional Stress Model of Lazarus and his research group as a basis has met with acceptance (Schwarzer, 2000; Stemmler, 2007). Despite the great influence of the Transactional Stress Model on stress research over the last 40 years, the model has not yet been fully empirically confirmed (Lüdeke, 2018). The main problems cited in empirical testing are the complexity caused by the large number of variables (e.g. Kühlmann, 1982) or the difficulty in proving that a cognitive process precedes all decisions (Zajonc, 1980). However, empirical studies can still confirm the basic assumptions of the model – often applied in a simplified form – in their research (e.g. Kocalevent et al., 2007; Goodarzi et al., 2015; Obbarius et al., 2021), as is also the case in the present doctoral dissertation (Sartor et al., 2023a, 2023b, Sartor et al., 2024). Lazarus (1978) argues for a sharper focus on the process. Studies I and III gained their findings from cross-sectional data, which is why there is no proof of the causality of the individual variables within the stress process. Wysocki et al. (2022) emphasize the great importance of causal structures. To further confirm the findings from the studies, longitudinal study designs should be sought in order to better understand not only inter- but also intra-individual processes.

In the interest of depicting the process even more completely, it would be conceivable to start modeling not with the demands, but with the triggers of the demands. The first level of the Four Level Model (Tröster et al., 2017) begins with the core autistic symptoms that cause impairments in everyday life, which in turn cause the demands. Due to the high variability in ASD symptoms and their severity, as described in the ICD-11 (WHO, 2023), it would make

sense to integrate these into the model (see Figure 7), as the severity of the symptoms has a major influence on parental stress (e.g. Batool & Khurshid, 2015; Lyons et al., 2010; Manning et al., 2021). The extended model could be tested with structural equation modeling, ideally in a longitudinal design with multiple measurement points.

Figure 7

Schematic representation of the extension of the path model used in study I to include the components of the Four Level Model by Tröster et al. (2017)



Furthermore, the development of stress from a transactional perspective is individualized by one's own evaluations (Lazarus & Folkman, 1987), making it difficult to capture all significant variables for the target group under investigation in one model. Thus, it is likely that not all facets of the demands that parents to children with ASD experience on a daily basis when living together with their child with ASD were included in the model in study III. Although the two demands *professional support* and *parent-child relationship* can be derived from the literature as important demands for this target group (see Table 1), these subscales could not be considered in detail due to poor internal consistency. A test standardization for the scale *Parental demands in everyday life* by Tröster and Lange (2019) would be desirable so that the scale can be used validly for further research. It would also be conceivable for the scale to be used as a screening instrument in practice. This would give therapists a direct overview of the parents' demands and enable them to select targeted services.

Regarding the examination of coping resources, it can also be assumed that those included in study I do not cover a complete picture and that there are other resources that support parents to children with ASD in their individual coping with demands, as already mentioned above. Other resources or skills that are specific to parents to children with ASD also need to be looked at, such as an increased appreciation of life or greater inner strength that parents have gained through raising a child with ASD (Schirmer & Alexander, 2015). More research is needed on the positive aspects of living with a child with ASD and the parental resources that can be derived from that. Parents should, in theory, have high self-efficacy because they are experts regarding the unique behaviors of their child with ASD and their child's development and, according to Hess et al. (2004), this is associated with high self-efficacy. However, research shows that parents to children with ASD actually have lower self-efficacy than other parents (e.g. Smart, 2016). Future studies should investigate the question of why these parents do not seem to feel like experts for their children so as to offer support in this regard. Qualitative research approaches could provide deeper and more differentiated insights (Misoch, 2019).

In addition, it cannot be conclusively ruled out that the non-significant coping resources (functional coping and social support) are not mediators between demands and stress for parents to children with ASD. Particularly in the case of perceived social support, more specific definitions could help to gain further insights into the links. It may first be necessary to clarify which form of social support is actually useful for parents due to their child's ASD symptoms in order to have a relieving effect. In order to generate findings in this regard, methodological social network analyses would be conceivable, with which social relationships between different people and their effects can be analyzed (Gamper, 2020).

Selection effects should be mentioned as methodological limitations. This doctoral dissertation refers to parents, although mothers are primarily represented in the data. Studies report

gender differences, such as different coping styles between mothers and fathers to children with ASD (Hastings et al., 2005) or higher stress levels in fathers compared to mothers (Rivard et al., 2014). It would be interesting to consider gender-specific differences in the models. To this end, the factor of how much of the care work is managed by the parent surveyed should be included to adequately compare parenting stress. For the sake of including the gender factor, fathers must be recruited more successfully for participation. The encouragement suggested above to reduce the imbalance between the parents and to motivate the parents who were less involved in the child's therapy could also increase the chances of both parents participating in the study.

Another selection effect lies in the drop-out in the longitudinal design in study II. Those parents who felt less stressed on average were more likely to drop out of the study (Sartor et al., 2024). On average, the results can therefore be interpreted more in favor of the parents who reported more parental stress. On the one hand, this is primarily the group that needs the most support; on the other hand, the studies should represent all parents to children with ASD as closely as possible. For further research, it is important to successfully collect longitudinal data with as few drop-outs as possible. Apparently, the least stressed parents need to be motivated most to take part in further measurement points. It is assumed that the issue is not as acute for this group because it affects them less than the highly stressed parents (Tröster & Lange, 2019). In addition to transparent communication of the study objectives and the importance of participation, material incentives such as enclosed gifts can also increase participation rates (e.g. Diekmann & Jann, 2001).

The last methodological limitation is the self-report method. Methods that depend on self-reporting can be susceptible to social acceptability effects (Döring & Bortz, 2016; Nederhof, 1985). Respondents' desire to appear as good parents can distort the completion of

questionnaires. As perceived stress and coping with stress are subject to intrapsychic processes, self-assessment survey methods are still the best alternative, as these processes can only be observed from the outside to a certain extent. Nevertheless, a mixed-method design in which additional information is collected through supplementary methods, such as the diary method, could be helpful (Kahneman et al., 2004), e.g. to avoid retrospective bias and thus further complete the knowledge on the connections between demands, coping resources, and parental stress of parents to children with ASD.

7 Conclusion

In order to connect the dots between parental stress, demands, and coping resources in parents to children with ASD, three studies were conducted as part of this doctoral dissertation, which build on the findings of previous studies and contribute to clarification with their different foci. Despite the aforementioned limitations, the results of this doctoral dissertation can provide insights into the development and management of stress in parents to children with ASD and thus identify needs for action in practice as well as indications for further research approaches. The results speak in favor of a holistic view of parents' stress experience, demands, and coping resources in order to provide the best possible support for parents, as these constructs show predictive links with each other (Sartor et al., 2023a, 2023b, Sartor et al., 2024). Parents to children with ASD are exposed to considerable demands and stress, which become even more evident during crisis situations. The demands clarify the stress, some of which is mediated by coping resources. Strong parental self-efficacy helps parents to cope with the demands, whereas dysfunctional coping strategies inhibit coping, resulting in stress. These findings follow the basic outlines of the Transactional Stress Model (Lazarus & Folkman, 1984) and Abidin's (1992) Parenting Stress Model. Nevertheless, further holistic research is needed to validate the links further empirically (see Chapter 6, Research limitations). It is of great relevance to transfer the results into practice-oriented research and to focus on the support structures. The individual needs of parents to children with ASD must be taken into account in the structures in order to create the best possible framework conditions for the families so that they can shape their own lives and successfully cope with the demands.

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Appendix A: Study I

Sartor, T., Sons, S., Kuhn, J.-T., & Tröster, H. (2023a). Coping resources and stress due to demands in parents to children with autism spectrum disorders. *Frontiers in Rehabilitation Sciences, 4*(1240977), 1–10. https://doi.org/10.3389/fresc.2023.1240977

frontiers | Frontiers in Rehabilitation Sciences

TYPE Original Research
PUBLISHED 06 October 2023
DOI 10.3389/fresc.2023.1240977

OPEN ACCESS

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RECEIVED 15 June 2023
ACCEPTED 19 September 2023
PUBLISHED 06 October 2023

CITATION
Sartor T, Sons S, Kuhn J-T and Tröster H (2023) Coping resources and stress due to demands in parents to children with autism spectrum disorder.
Front. Rehabil. Sci. 4:1240977.
doi: 10.3389/fresc.2023.1240977

Coping resources and stress due to demands in parents to children with autism spectrum disorder

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Introduction: Parents to children with autism spectrum disorder (ASD) are exposed to numerous demands in their daily lives and exhibit high levels of stress. The present study aims to find out which coping resources are mediators that help parents cope with these demands and which of those coping resources amplify or reduce stress arising from the demands. Studies often only focus on the connection between coping resources and stress without taking the demands into account at the same time.
Methods: For this reason, a mediation model was set up to answer the research question. Data from a German questionnaire survey with $N = 266$ parents who have children with ASD (two to 23 years old) were used. Subjectively perceived demands in everyday life (scale "Parental demands in everyday life"), parental stress ("Parental Stress Inventory", based on Abidin's parenting stress model) and the following coping resources were collected: parental self-efficacy beliefs ("Parents' sense of competence questionnaire"), available social support of parents (scale "Availability of social support") and parental coping strategies (German version of the Brief COPE).
Results: An exploratory factor analysis revealed four mediators: dysfunctional coping, functional coping, social support, and self-efficacy. The use of dysfunctional behavior and parental self-efficacy were found to be significant mediators that mediated between daily demands and parental stress. A direct effect of demands on parental stress was also found, implying partial mediation. The two factors of functional coping and support were not found to be significant mediators.
Discussion: Key findings indicate that parental stress resulting from the daily demands of parenting children with ASD can be reduced by high parental self-efficacy and increased by dysfunctional coping. For practice, it can be deduced that dysfunctional coping strategies of parents to children with ASD should be reduced and parental self-efficacy should be strengthened in order to reduce stress which arises from the multiple demands in everyday life.

KEYWORDS

autism spectrum disorder, ASD, parental stress, parental demands, coping resources

1. Introduction

1.1. Demands and stress of parents to children with ASD

1.1.1. Parental stress

Parents to children with autism spectrum disorders (ASD) exhibit higher levels of stress than other parents [e.g., (1–3)]. Based on the transactional stress model (4, 5), parental stress arises from the discrepancy between parents' demands and resources. Thus, it arises when parents perceive the resources available to them as inadequate for

coping with the demands. Parents to children with ASD experience multiple demands in their daily lives (6), especially from the child's behavior and characteristics (7). In his parenting stress model, Abidin (8) calls this source of stress the child domain. This includes, among other stress sources, the inability to adapt to the environment [e.g., through restricted repetitive behavior of children with ASD; (9)]. These behavioral dispositions of the child result in special demands the parents are confronted with in their interaction with the child. In contrast, the parent domain reflects the stress resulting from the limitations of parental functions needed to cope with the educational demands. They include the restrictions on parents' personal lives that they experience as a result of their role as parents, or feelings of guilt when parents are not always emotionally available to their child (8). Results show that both domains are associated with psychovegetative stress symptoms and self-reported stress (10).

1.1.2. Parental demands in everyday life

Day by day, parents to children with ASD have to cope with a variety of demands, which are associated with the role those parents take in different fields of everyday parenting (11). These parental demands result from the symptomatology of ASD [e.g., persistent deficits in social interaction or communication; (9)] as a profound developmental disorder and lead to impairments in almost all areas of life (12). These impairments create high demands on the caregivers, usually parents [e.g., (13)]. Tröster and Lange (6) have described the daily demands of parents to children with ASD in eight areas (see **Table 1**). The demand of organizing family life can be an extensive task with a child with ASD being a family member, as the child's disorder makes it particularly relevant for structures to be in place (14). A further demand is cooperating with the partner and maintaining the relationship (15) as well as keeping and strengthening the parent-child relationship (16). In addition, there are demands to maintain a social life (17) but also to fulfill one's own needs (18). There is also a lot of organizing and communicating to do outside of the family's daily routine, such as with funding agencies, therapists, or childcare facilities (19). Furthermore, parents are often faced with stigmatizing reactions in the social environment which they have to deal with (20). Managing the problem behavior of the child with ASD [e.g., restricted repetitive behavior; (21)] may prove to be a permanent demand in everyday life (17). In the study by Tröster and Lange (6), problematic behavior of the child in education was shown to be the most important predictor of stress in the child domain for parents to children with ASD. In the parent domain, balancing personal needs and interests with parental demands was shown to be predictive of stress.

TABLE 1 Subscales of the "Parental demands in everyday life" scale.

Parental demands	Example item	α
Organization of family life (5 items)	*Joint family activities require a lot of preparation.*	.73
Professional support (2 items)	*There are disputes with cost bearers when it comes to covering the costs of supporting my child.*	.54
Social participation (2 items)	*I find little time to spend with my friends.*	.80
Cooperation with the partner (4 items)	*Coordinating with my partner about the tasks in raising and caring for our child is difficult.*	.79
Parent-child relationship (4 items)	*I find it difficult to put myself in my child's shoes.*	.69
Personal way of life (5 items)	*I have to give up things that I enjoy doing.*	.90
Stigmatizing reactions in the social environment (7 items)	*In our circle of acquaintances, I experience misconceptions and prejudices towards my child.*	.73
Problem behavior of the child in education (12 items)	*My child is hypersensitive or hyposensitive to certain stimuli.*	.75

Subscales of the "Parental demands in everyday life" scale (6) including a sample item and internal consistency (Cronbach's alpha) for each scale.

1.2. Resources for coping with stress

In order to prevent stress from occurring in the first place, resources are necessary that enable or facilitate coping with the demands of parenting. Three resources have shown to be essential: self-efficacy, social support, and coping strategies.

1.2.1. Parental self-efficacy

Self-efficacy, according to Bandura (22), is a person's subjective conviction regarding his or her own competencies, meaning that a person is convinced that his or her own competencies are sufficient to cope with upcoming challenges. Educational self-efficacy can be seen as parents' conviction that they are able to cope with the demands of parenting in the best possible way (23). For parents to children with ASD, research indicates a negative relationship between self-efficacy and parenting stress [e.g., (6, 24–26)]. Strong parental self-efficacy among parents to children with ASD may positively affect coping with challenging ASD-typical demands (27) and could protect against the development of parental depression (25). Daulay et al. (28) findings show an association between the severity of stereotypical and social abnormalities of the child with ASD and their parents' self-efficacy. A comparative study by Smart (29) shows that parents to children with ASD in particular have low self-efficacy compared to other parents, for example parents to children with Down syndrome or emotional behavioral disorders, which can be used as an explanation for a high stress level among parents to children with ASD.

1.2.2. Available social support

Available social support represents another resource. Social support fulfills three functions: the (1) informational, (2) emotional, and (3) instrumental support (30). Exchanges among parents (informational) about experiences, for example, can be profitable since they offer an opportunity to ask another parent for advice. Social support can also facilitate emotion regulation when there is someone to talk to about thoughts and feelings. One example of instrumental social support is having access to someone who will provide childcare if needed. Knowing that social support is available can reduce stress in childrearing [e.g.,

(10)]. Stress can be prevented by parents' confidence that they will find support in their social network when they need it (31). Studies agree that available social support is an important resource for parents to children with ASD [e.g., (32–34)]. For example, Siman-Tov and Kaniel (35) use path analyses to show that social support facilitates coping with stress that arises from parenting a child with ASD.

1.2.3. Coping strategies

In addition, there are different strategies to cope with demands and deal with stressful situations which can be either functional, i.e., conducive to health, or dysfunctional, i.e., hazardous for health (36). Functional strategies such as exercising or performing relaxation exercises have shown to be preventive for burnout syndrome (37), whereas withdrawing and playing computer games, for example, are cited as dysfunctional because they promote the occurrence of the above stress disorder. According to the systematic review by Vernhet and colleagues (38), unlike parents to neurotypically developing children, parents to children with ASD use less social support and are more likely to use avoidance strategies to cope with demands. For example, avoidance behaviors manifest themselves in distractions such as watching television or by parents waiting it out in hopes that the problem will go away (39). Studies show that those parents to children with ASD who use dysfunctional behaviors such as active avoidance of problems exhibit higher levels of stress [e.g., (6, 40)], whereas active coping has been shown to be a stress-reductive strategy among parents to children with ASD (41). In active coping behaviors, parents perceive the stress-inducing demands and attempt to change them by taking action to address them (42).

To our knowledge, there is no study which examined the relationship between all three of these within a single mediation model: daily demands, coping resources, and parenting stress of parents to children with ASD. The focus is either on relationships between demands and parental stress (see Section **1.1**) or on relationships between coping resources and parental stress (see Section **1.2**). In the present study, the three aforementioned areas will be examined together to determine whether stress of parents to children with ASD arises from demands, and whether parental self-efficacy, social support, and coping strategies have a mediating effect of the stress level resulting from those demands. It was hypothesized that self-efficacy, available social support as well as functional coping strategies have a relieving effect, whereas dysfunctional coping strategies are hypothesized to increase parental stress.

2. Methods

2.1. Analytic strategies

Various parental coping strategies, social support, and self-efficacy were considered as potential mediators. In a first step, an explorative factor analysis of the various potential mediators was carried out with the aim of combining them into factors (see Section **2.3**). The cutoff value was set at a factor loading of .30 because Hair et al. (43, p. 129) defined a factor loading of .30–.40 as "minimally acceptable". Subsequently, multiple mediation analyses were calculated, in which demands were entered as an independent variable and parental stress as a dependent variable. The mediation analyses were conducted using R version 4.1.1 (44) and the lavaan package (45). The comparative fit index (CFI; cutoff value close to .95), the Tucker-Lewis index (TLI; cutoff value close to .95) and the root mean square error of approximation (RMSEA; cutoff value close to .06) were used as fit indices (46).

2.2. Data collection and sample

The data stems from the German research project "ELKASS" [Parents to Children with Autism Spectrum Disorders; (6)], which was developed in cooperation with the German Autism Association ("Autismus Deutschland e.V., Bundesverband zur Förderung von Menschen mit Autismus") and ten autism therapy centers throughout Germany. Data collection took place between December 2015 and March 2017 and was reviewed for compliance with ethical guidelines prior to commencement. All parents surveyed were fully informed of the voluntary nature, anonymity, and intended use of the data prior to their participation and signed the consent declaration. $N = 266$ parents to children with ASD whose children had just started support in an autism therapy center were surveyed. Thus, the inclusion criterion was that the parents and their child were affiliated to a cooperating autism therapy center. Further inclusion or exclusion criteria were not specified. The therapists distributed the paper-based questionnaire and collected it again in an anonymized letter and forwarded it to the research group, who entered the information digitally into a data set and processed it for the analyses. The questionnaire was in German. The parents who participated in the survey questionnaire were aged between 24 and 63 years ($M = 41.4$ years, $SD = 7.47$ years) and the majority were mothers (86.1%). Most of them were married (72.6%) and almost a quarter (23.7%) described themselves as single parents. Their children were predominantly male (83.2%) and were between two and 23 years old ($M = 10.2$ years, $SD = 4.0$ years). Half of the children (50%) were diagnosed with at least one comorbid disorder in addition to their ASD (see **Table 2**). Information on diagnoses was requested from the therapists. Despite the wide age range, in what follows, we refer to them as children because they are their parents' children regardless of age, and this group is the focus of this research.

2.3. Materials

2.3.1. Parental demands in everyday life

The construct of parental demands was assessed with the scale "Parental demands in everyday life" by Tröster and Lange (6). The scale comprises a total of 41 items, which can be assigned to eight

TABLE 2 Diagnosis and comorbid disorders of children with ASD.

	n	%
Diagnosis		
Asperger syndrome (F84.5)	127	47.7
Childhood autism (F84.0)	83	31.2
Atypical autism (F84.1)	32	12.0
Other diagnosis[a]	16	6.0
Comorbid disorders (three most frequent)[b]		
Hyperkinetic disorder (F90.-)	47	17.7
Specific developmental disorder of speech and language (F80.-)	20	7.5
Specific developmental disorder of motor function (F82.-)	17	6.4

Diagnosis and the three most frequently cited comorbid disorders with ICD-10 codes (21) of $N = 266$ children (deviations due to missing values).
[a]The remaining category (7.8%) included, e.g., Pervasive developmental disorder, unspecified (F84.9) or cases where no firm diagnosis had yet been made.
[b]Other comorbid disorders included e.g. Other behavioral and emotional disorders with onset usually occurring in childhood and adolescence (F98.-) or Mixed specific developmental disorders (F83).

areas of demand. The items contain typical statements that describe the demands of parents in their everyday lives. The parents rated these with a four-point scale (1 = "never/rarely" to 4 = "very often"), depending on how often they experience the described situation. The eight subscales, the number of items and the Cronbach's α are shown in **Table 1**. In addition, an example item can be found for each case.

2.3.2. Parental stress

Parental stress was measured with two instruments: the "Parental Stress Inventory" ("Eltern-Belastungs-Inventar"; EBI) and the Symptom List "Physical Complaints" [both (10)]. The symptom list Physical Complaints, which comprises a total of 14 items, records psychovegetative stress symptoms. The parents indicated on a five-point scale (1 = "never/almost never" to 5 = "very often") how often they suffered from physical complaints, such as headaches/migraines, sleeping disorders or gastrointestinal complaints, in the past week. The scale showed good internal consistency of Cronbach's $\alpha = .87$. The Parenting Stress Inventory is a screening instrument based on the parenting stress model by Abidin (47) that measures different sources of stress for parents (10). The inventory of 48 items overall is divided into two domains (see **Table 3**): The parent domain consists of seven subscales that capture the stress resulting from the tasks parents have to cope with in their role as parents. The child domain comprises five subscales of stress resulting from the child's characteristics and behavior. In the present investigation, Cronbach's α reliabilities in the two domains were high (parent domain: $\alpha = .93$; child domain: $\alpha = .88$). All items are answered on a five-point scale from 1 = "does not apply at all" to 5 = "fully applies". The validity of the instrument was predominantly demonstrated with mothers of children and adolescents with disabilities and chronic illnesses (10).

2.3.3. Parental self-efficacy beliefs

Parents' self-efficacy beliefs regarding the effectiveness of parenting children with ASD were assessed using Miller's (48) "Parents' sense of competence questionnaire". The scale uses

TABLE 3 The parent and child domain subscales of the EBI.

	Example item	α
Parent domain		
Health	*I don't have as much energy anymore to do things that I used to enjoy.*	.85
Depression	*I sometimes feel like it's actually my fault when my child does something wrong.*	.81
Parental Attachment	*It sometimes takes a while for parents to develop a feeling of closeness and warmth for their child.*	.73
Parental Competence	*Some things in raising my child are harder for me than I expected.*	.81
Role Restriction	*I sometimes feel constrained by the responsibilities of being a mother/father.*	.85
Isolation	*I don't have as much interest in other people as I used to.*	.76
Spouse	*Since I had the child, I don't do as much together with my partner.*	.80
Child domain		
Demandingness	*I have the impression that my child needs more attention and care than other children.*	.75
Acceptability	*I sometimes have the impression that my child is not as open to other people as other children.*	.52
Adaptability	*My child often reacts very strongly when something happens that he doesn't like.*	.78
Distractibility/ Hyperactivity	*I often feel exhausted because my child is so active.*	.71
Mood	*My child often wakes up already in a bad mood.*	.80

Presented are the subscales of the EBI (10), each with an example item and the internal consistency (Cronbach's alpha).

seven items to survey parents' sense of self-efficacy in raising their child (example item: "I am meeting my personal expectations about how I care for my child"). The scale was also answered by parents using a four-point scale ranging from 1 = "not true" to 4 = "completely true". Cronbach's α in the present sample was $\alpha = .75$.

2.3.4. Available social support of parents

The scale "Availability of social support" (10) was used to survey available social support. The scale depicts how well parents perceive the availability of their social support, which is surveyed with nine items in three areas [(1) Informational support: "Through my circle of friends and acquaintances I often get good tips (e.g., good doctor, events)"; (2) Instrumental support: "I know some people I could ask for support if I were in financial need"; (3) Emotional support: "I have some good friends with whom I can talk about personal problems"]. Internal consistency was very good (Cronbach's $\alpha = .91$). The response format of the items comprised four grades (1 = "not true" to 4 = "completely true").

2.3.5. Parental coping strategies

In order to survey different coping strategies, the German translation of the frequently used instrument Brief COPE (42); German translation by (49) was used. According to Carver (42), of the total 28 items, two items each are assigned to one of the 14 subscales, which represent different habitual coping strategies: denial (e.g., persuading oneself that the situation is not so bad), self-blame (e.g., blaming oneself for being responsible for the

situation), self-distraction (e.g., occupying oneself with other things), venting emotions (e.g., showing others one's own feelings), substance use (e.g., drinking alcohol to feel better about oneself), positive reframing (e.g., looking at the positive side of a situation), planning (e.g., considering what would be the right thing to do in a situation), acceptance (e.g., accepting that certain things cannot be changed), active coping (e.g., being proactive to change the situation), humor (e.g., making jokes about the situation), use of emotional support (e.g., accepting consolation from other people), use of instrumental support (e.g., asking other people for advice), behavioral disengagement (e.g., not dealing with the situation), religious coping (e.g., finding support in one's own faith). This structure has been used previously in studies of parents to children with ASD (50). In the present study, a 15th subscale ("negative thoughts and reactions") was used, which was developed as an addition by Tröster and Lange (6). The coping strategy "negative thoughts and reactions" also contains two items and represents the parents' negative thoughts resulting from the child's behavioral problems (example item: "I thought that my child was deliberately trying to provoke me."). The items of the Brief COPE and the additional subscale are answered with a four-point scale (1 = "does not apply at all" to 4 = "applies very much").

3. Results

3.1. Exploratory factor analysis

In order to assess the dimensionality of coping strategies, the structure of the subscales of the Brief COPE (42); surveyed with the German translation by (49) was examined by means of an exploratory factor analysis (principal component analysis with Promax rotation). The scale "availability of social support" (10) was included in the analysis due to its content-related fit. Knowing that there is social support of a network that one can fall back on in case of need may encourage parents and was thus regarded as a potential coping strategy.

A parallel analysis clearly showed three factors above the threshold in the principal component analysis. By means of the EFA, a total of 38.6% of the variance could be extracted on the basis of three factors with an eigenvalue >1 (see **Table 4**). The three factors that emerged were (1) dysfunctional coping, (2) functional coping and (3) support.

3.1.1. Factor 1: dysfunctional coping

The factor "dysfunctional coping" was shown by strategies such as denial, self-blame, negative thoughts, or substance use. Self-distraction could also be assigned here, which was probably used as a displacement strategy. The "venting" strategy, which was assigned to dysfunctional coping in the analysis, also included statements such as "I've been expressing my negative feelings". Especially in child rearing, omitting negative moods towards the child can lead to feelings of guilt, so this strategy probably did not lead to a reduction in stress. The factor "dysfunctional coping" was therefore characterized by the fact that those parents to children with ASD had and gave free rein to negative feelings towards the child as well as towards themselves based on self-blame. They denied the stress they experienced and repressed it through distraction or alcohol and drugs. This factor accounted for 13.8% of the total variance.

TABLE 4 Results of the exploratory factor analysis.

Coping strategies	Factor 1	Factor 2	Factor 3	h^2
Denial	.682			.410
Self-blame	.650			.421
Negative thoughts and reactions[a]	.636			.358
Self-distraction	.456			.276
Venting emotions	.419			.262
Substance use	.337			.144
Positive reframing		.753		.501
Planning		.649		.507
Acceptance		.559		.268
Active coping		.546		.366
Humor		.440		.180
Use of emotional support			.872	.824
Availability of social support			.599	.363
Use of instrumental support			.494	.529
Explained variance in %	13.8	14.0	10.8	

Factor loadings and communalities (h^2) of the exploratory factor analysis with the subscales of the Brief COPE (42); surveyed with the German translation by (49) and the "Availability of social support" scale (10).
[a]The subscale "Negative thoughts and reactions" is a development of Tröster and Lange (6).

3.1.2. Factor 2: functional coping

The second factor "functional coping" consisted of the subscales positive reframing, planning, acceptance, active coping and humor (14% variance clarification). The parents who used these functional behaviors as coping strategies seemed to approach the demands placed on them actively, so that they positively reinterpreted the situation for themselves, dealt with it in detail or also accepted the situation as it was and made the best of it. Humor can be understood as a displacement mechanism, but it can also lighten up a situation so that it is not treated too seriously and doggedly ("I've been making fun of the situation").

3.1.3. Factor 3: social support

The third factor "social support" was characterized by three forms of support: emotional, instrumental, and available social support. Parents who applied these strategies for themselves used their social contacts to experience emotional support as well as practical support. They felt certain that they could theoretically receive support if they ever needed it. The subscale "behavioral disengagement" could not be included in the EFA due to unacceptable reliability (Cronbach's $\alpha = .20$). The subscale "religious coping" showed loadings that were too small on the support factor (<.3), which is why it was not included in the factor.

3.2. Mediation analysis

The three coping strategies dysfunctional coping ($M = 1.71$, $SD = 0.46$), functional coping ($M = 2.61$, $SD = 0.57$) and social support

($M = 2.34$, $SD = 0.71$) as well as the resource self-efficacy ($M = 2.97$, $SD = 0.44$) were included in the analysis as a total of four mediators. In addition to the basic assumption that stress arises from the demands that cannot be met or are difficult to meet, it is assumed that the four mediators affect the influence of the demands on stress. It is assumed that the use of dysfunctional behavior to cope with demands makes it more difficult and thus leads to stress, and that the use of functional strategies as well as social support and a pronounced self-efficacy facilitate coping.

Three models are shown that differ only in the dependent variable. Here, stress is distinguished in the three facets of parent domain (PD), child domain (CD), and psychovegetative stress symptomatology (PS). **Figure 1** presents the results of the mediation analyses. Model fit of the three models was good: PD: χ^2 (15) = 410.22, $p < .001$, CFI = 1.0, TLI = 1.0, RMSEA = .00; CD: χ^2 (15) = 389.92, $p < .001$, CFI = 1.0, TLI = 1.0, RMSEA = .00; PS: χ^2 (15) = 248.79, $p < .001$, CFI = 1.0, TLI = 1.0, RMSEA = .00.

The direct path from demands to stress shows up significantly in all three models ($c_{PD} = .54$, $p < .001$, $SE = .080$; $c_{CD} = .61$, $p < .001$, $SE = .077$; $c_{PS} = .17$, $p < .001$, $SE = .011$). Thus, there seems to be a direct influence of daily demands on stress across all domains. The total effect has higher path coefficients than the direct effect in all models, indicating partial mediation ($c'_{PD} = .69$, $p < .001$, $SE = .074$; $c'_{CD} = .69$, $p < .001$, $SE = .067$; $c'_{PS} = .33$, $p < .001$, $SE = .097$). Partial mediation shows that stress in all three models arises largely from demands. Yet, it is also in part dependent on resources used. Indeed, it seems to be crucial for the stress of parents whether dysfunctional coping strategies are used to cope with the demands of everyday life ($a1*b1_{PD} = .12$, $p < .001$, $SE = .042$; $a1*b1_{CD} = .05$, $p = .038$, $SE = .035$; $a1*b1_{PS} = .06$, $p = .043$, $SE = .049$). The more demands occur, the more likely parents are to use dysfunctional behavior to cope, and this results in an increased occurrence of stress. The degree of parental self-efficacy also seems to mediate the effects of demands on stress to some extent ($a4*b4_{PD} = .03$, $p = .018$, $SE = .023$; $a4*b4_{CD} = .03$, $p = .042$, $SE = .018$; $a4*b4_{PS} = .04$, $p = .028$, $SE = .029$). When demands are high, self-efficacy decreases and, thus, stress increases. In terms of the resource, a pronounced self-efficacy provides relief. Engagement in functional coping ($a2*b2_{PD} = .00$, $p = .976$, $SE = .019$; $a2*b2_{CD} = .02$, $p = .166$, $SE = .020$; $a2*b2_{PS} = .03$, $p = .083$, $SE = .027$) and social support ($a3*b3_{PD} = .00$, $p = .828$, $SE = .008$; $a3*b3_{CD} = -.01$, $p = .360$, $SE = .020$; $a3*b3_{PS} = .02$, $p = .108$, $SE = .023$) do not appear to substantially mediate the effect of demands on experienced stress. Although in the model of self-reported psychovegetative stress symptomatology paths a and b each show significant coefficients for both mediators (see **Figure 1**), the indirect effect is not significant.

4. Discussion

The present study investigated the extent to which coping resources mediate the influence of everyday demands on stress experienced by parents to children with ASD. In the direct pathway as well as in the indirect pathways, there were no differences between the three dependent stress variables. Thus, the results of the models are discussed uniformly for the three stress domains surveyed (parent domain, child domain, psychovegetative stress symptoms) instead of separately.

The results confirm that the high demands of everyday life experienced by parents to children with ASD lead to stress. The direct effect shows that stress also arises from the demands independently of the coping resources collected in this study. According to transactional stress theory (4, 5), stress arises when there is a discrepancy between demands and perceived resources. It can be assumed that other coping resources that were not surveyed in this study should have been included as mediators. Possible mediators that studies have shown to be associated with parental stress include resilience [e.g., (51)] and sense of coherence [e.g., (52)].

The expectation that parental self-efficacy protects against stress arising from the demands placed on parents can be confirmed based on the results. The belief that they know best what exactly their child with ASD needs in certain situations ["If anyone knows the answer to what is wrong with my child, it is me"; (48)] and being able to meet these needs of their child seems to help parents cope with the demands of everyday life.

A larger mediation effect than in self-efficacy was shown for dysfunctional coping in the present models. Using dysfunctional coping strategies such as denial, self-blame, self-distraction, venting emotions, substance use, or negative thoughts makes it more difficult for parents to cope with the demands, which translates into increased stress levels. Dysfunctional strategies are not constructive or solution-oriented strategies. From ignoring the demand, as by denying, self-distraction or taking drugs, a demand (e.g., care of the relationship between parent and child, partnership or organization of family life, see **Table 1**) can be coped with only with difficulty. Stress arises as a consequence. It is also not helpful if parents get lost in negative thoughts and blame themselves.

Contrary to expectations based on studies indicating a link between functional coping and lower perceived stress (53), using a functional behavior to cope with demands does not appear to have any mediating influence on stress. Thus, parental stress arises from demands independent of the application of positive reframing, planning, acceptance, active coping, or humor. Possibly the functional strategies captured by the Brief COPE are not appropriate for the specific demands of parents with ASD children or they are too imprecise and would have to be adapted to typical situations in the everyday life of this target group.

In the study by Robinson and Weiss (33), both perceived and received social support were associated with lower stress among parents to children with ASD. The mediator "social support" in the present study was also composed of the two components of perceived social support (scale: Availability of social support) and received social support (subscales Brief COPE: Use of emotional support and Use of instrumental support). However, no effects could be shown regarding social support having an influence on whether stress arises from the demands of parents. For social support to be helpful in coping with demands, social contacts must be present and maintained. Studies show that parents to

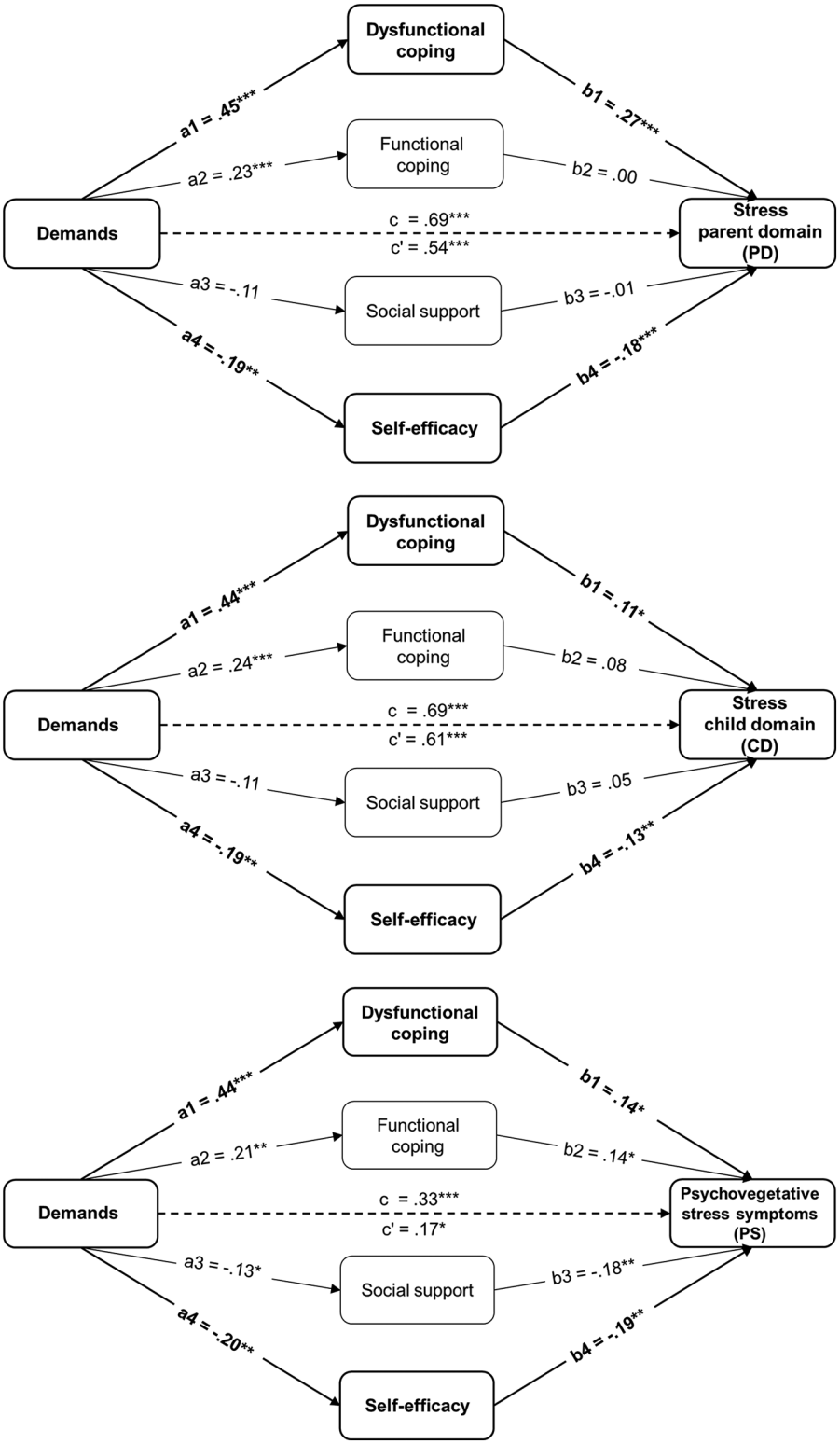

FIGURE 1
Results of the three mediation models. The three mediation models show demands as independent variable (IV), four mediators (dysfunctional coping, functional coping, social support, and self-efficacy), and stress as dependent variable (DV). The models differ in the domains of stress (parent domain, child domain, and psychovegetative stress symptoms). Path coefficients: c = total effect, c' = direct effect, a = relationship between IV and mediator, b = relationship between mediator and DV. The significant indirect effects are shown in bold print. *$p < .05$, **$p < .01$, ***$p < .001$.

children with ASD, unlike other parents, use less often strategies to seek social support (38). In addition to the relieving function, the use of social support is associated with costs (54). Hierarchical structures that arise between the giver and the receiver of support can give rise to feelings of inferiority on the part of the receiver as well as feelings of inability, which can threaten self-worth (55). Feelings of obligation to return the support received or to be indebted to the other may also arise (56), which may discourage parents to children with ASD from seeking and accepting social support. Another explanation for the lack of effect in the present study is that such support, which would help parents cope with everyday demands, was not explicitly surveyed: for example, parents to children with ASD might benefit less from the opportunity to receive practical childcare support, because implementing this support requires first investing effort so that a child can be cared for by another person (e.g., practicing fixed routines with the child). Having another caregiver can also be stressful for the child, which in turn transfers to the parent. Parents would therefore likely benefit from long-term, dependable social support. To prevent feelings of imbalance, support groups could come together. Support groups are a good example here that this type of support can be helpful (57). Parents have the opportunity to support each other in an emotional way, but also to exchange information. Here they can share their experiences and feel self-efficacious by talking about issues they are familiar with: Parenting a child with ASD.

In practical work with families to children with ASD, parental self-efficacy should be strengthened in a professional setting using empirically tested interventions. For example, Sofronoff and Farbotko (58) evaluated an intervention program aimed at parents to children with Asperger's syndrome that had a demonstrable positive effect on the self-efficacy of parents and especially mothers. The intervention program is designed to increase parents' self-efficacy by improving their ability to better understand and manage their child's problem behavior. By better understanding towards their child's behaviors, they feel more confident in their response and more competent in their parenting role. A practical implication that would support this would be for parents to attend the child's therapy sessions. This way, the parents learn how to deal with the child's behavior and can apply this themselves to feel more confident and competent in everyday situations.

In summary, the diverse everyday demands of raising children with ASD lead to stress. The hypothesis that self-efficacy, social support, as well as functional coping strategies have a relieving effect on parents to children with ASD, while dysfunctional coping strategies increase parental stress, was partially confirmed. The daily demands are mainly influenced positively by parental self-efficacy and negatively by dysfunctional coping strategies. Above all, the practice should therefore strengthen the self-efficacy of parents to children with ASD by setting up low-threshold offers that do not involve even more organizational challenges and stress for parents. In addition, parents should be given professional support for reflecting on their coping strategies in an attempt to then gradually reduce dysfunctional strategies for coping with parental demands. The aim here is to reduce or even prevent the buildup of stress.

5. Limitations

Using mediation analyses with cross-sectional data is controversial [e.g., (59)], so the results must be interpreted carefully. Nevertheless, the results can contribute to research when used to test existing causal theories. Wysocki et al. (60) demonstrate the importance of causal structures. In the present study, transactional stress theory (4, 5) serves as the causal structure to answer the research question using a mediation model.

It should be noted that the present sample size ($N = 266$) for the mediation analysis used, with a power level of 0.8 and a significance level of .05, can only identify effects above size .25. For smaller effects, according to the a-priori sample size calculator by Soper (61), a much larger sample would have been necessary (e.g., for anticipated effect size = .1, the minimum sample size to detect effect is $N = 1.713$). However, in order to achieve such sample sizes, larger, multi-centric projects are necessary in the future.

One limiting factor is that the data were collected via self-report by parents. Although anonymity was granted, it is unclear to what extent there is a social acceptability bias when parents are guided by how ideally stress should be handled (62). For example, questions about substance use (Substance use subscale) may make some individuals feel ashamed to state that they use alcohol or other substances (63). As mentioned above it is questionable whether other potential mediators should have been included in the model. The parental demands could have also been expanded, as only the parental demands in everyday life regarding the upbringing of the child with ASD were surveyed here. Although it is difficult to accurately cover everyday demands of different families because the realities of families' lives are heterogeneous, additional parental demands could have been included, such as household chores. In addition, the sample shows heterogeneity both because of the very wide age range of the children and because of the diagnosis and symptomatology of the children and adolescents with ASD. Future studies should focus on capturing the severity of ASD symptoms, as these may condition differences in parents' experience of stress [e.g., (64)]. Likewise, differences between mothers and fathers should have been considered, as studies show that mothers and fathers to children with ASD differ in their coping styles (40). In the present study, more than 85% of the parents interviewed were mothers, so the results cannot be interpreted in terms of gender without limitations. Not only should gender be taken into account, but more importantly, the amount of care work done by the parent being interviewed. It is likely that the demands on parents to children with ASD increased by life events like during the COVID-19 pandemic [e.g., higher caregiving demands due to quarantine; e.g., (65)]. Whether the present results will still be consistent then or whether different coping patterns will emerge to deal with the new demands remains to be investigated.

Data availability statement

The datasets presented in this article are not readily available because the data will be used for further analyses and publications. Requests to access the datasets should be directed to TS, teresa.sartor@tu-dortmund.de.

Ethics statement

Ethical approval was not required for the studies involving humans because the procedure of the study was officially reviewed by a legal division from both a legal and Ethical point of view and found to be unobjectionable. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

TS: idea for writing this manuscript, data curation, data analysis, writing and revising of the draft (lead). SS: data collection, data curation, revising of the draft. J-TK: supervision, revising of the draft. HT: supervision, project administration, data collection, data curation, revising of the draft. All authors contributed to the article and approved the submitted version.

Acknowledgments

We would like to thank all the contributors to the research project "ELKASS": the parents who participated, the therapists at the autism therapy centers and the project staff. We would also like to thank the sponsors who made the study possible: the German Autism Association and the participating autism therapy centers.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Appendix B: Study II

Sartor, T., Lange, S., Kuhn, J.-T., & Tröster, H. (2024). Stress and perceived partnership quality of parents to children with autism spectrum disorder: A random intercept cross-lagged panel approach. *The Family Journal, 32*(1), 139–148. https://doi.org/10.1177/10664807231198093

Article

The Family Journal: Counseling and Therapy for Couples and Families
2024, Vol. 32(1) 139-148

DOI: 10.1177/10664807231198093
journals.sagepub.com/home/tfj


Stress and Perceived Partnership Quality of Parents to Children With Autism Spectrum Disorder: A Random Intercept Cross-Lagged Panel Approach

Teresa Sartor, Sarah Lange, Jörg-Tobias Kuhn, and Heinrich Tröster

Abstract

Parents to children with autism spectrum disorder (ASD) experience increased levels of stress compared to other parents. However, it has been difficult to clarify how this parental stress affects the quality of parent partnership, and how stress and partnership quality predict each other longitudinally. Stress and perceived partnership quality of 160 parents to children with ASD who started therapy in an autism therapy center were surveyed at three measurement points. To find out about within-person effects, a random intercept cross-lagged panel model was used. The results showed that a decrease in stress level over the course of therapy led to a decrease in partnership quality. The theory of the parenting alliance can be used to explain these results: coping with demands in parenthood during stressful times seems to tie parents together and strengthen their relationship. Implications for therapeutic practice, such as the use of marriage and family counselors to support the parents' partnership during their child's autism therapy are presented.

Keywords

parental stress, perceived partnership quality, parenting alliance, autism spectrum disorder, ASD, cross-lagged panel, longitudinal model

Stress of Parents to Children With Autism Spectrum Disorder

Autism spectrum disorder (ASD) leads to limitations in almost all areas of life, which is why parents are permanently challenged to support their children (e.g., Mancil et al., 2009). The majority of persons with ASD are dependent on social and professional support throughout their lives (Müller-Teusler, 2008), although the severity of the impairment varies (Brobst et al., 2009). Hence, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) no longer differentiates between various subtypes of ASD but speaks of a spectrum of disorders (American Psychiatric Association, 2013).

Parents to children with ASD show increased stress levels, as shown in the meta-analysis by Hayes and Watson (2013). They reported that parents to children with ASD experience more stress than parents to children without disabilities. Also, compared with parents to children with learning and attention disorders (Chad-Friedman et al., 2022) or intellectual disability or Down syndrome (Hayes & Watson, 2013), parents to children with ASD report higher stress. It seems, therefore, that the symptoms of ASD are particularly demanding for parents, which in turn is associated with an increased stress level. In general, parental stress occurs when the available parental resources of dealing with the demands of raising their child are insufficient or overused (Tröster, 2011). In his Parenting Stress Model (1995), Abidin explains the separation of stress into three major domains: The parent domain, the child domain, and the domain of situational and demographic life stress. The parent domain includes stress resulting from limitations of parental functioning (e.g., the role restriction of parents) and the child domain includes stress resulting from the characteristics and behavior of the child (e.g., the restricted adaptability of the child). Life stress implies the stress experienced outside the parent-child relationship. These can be stressful situations such as the death of a relative. According to Hoffman et al. (2009), the stress of parents to children with ASD manifests itself primarily in those stress areas of the Parenting Stress Index (PSI; Abidin, 1995) that result from the child's behavior and characteristics. These findings are supported by the results of Sarimski (2016) who found a significantly

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higher level of stress in the child domain for parents to children with ASD than for parents to children with intelligence impairment.

Perceived Partnership Quality and Stress

Parental stress arises from the fact that, in the parents' own appraisal, their resources do not adequately meet the demands of parenthood (Tröster, 2011). This mastering of demands can be facilitated by resources. One resource that could reduce the stress of parents to children with ASD is a functioning relationship with their partner. Cooperation with and the support of partners can help to cope with parental demands (e.g., Laux & Schütz, 1996). Studies have found that parents to children with ASD experienced a lower stress level when they were satisfied with their partnership quality (e.g., Siman-Tov & Kaniel, 2011). It can be assumed that a high level of partnership quality is accompanied by a lower parental stress level. This association can have a direct (practical support with the child in everyday life) or an indirect impact (improvement in general well-being) on parenthood (Domsch & Lohaus, 2010). Wiedebusch and Seelhorst (2014) found that parents to children with developmental delays rely on the emotional support and assistance of their partner as a coping response for their stress.

The fact that stress levels are higher in parents to children with behavioral disorders than in parents to typical children has been demonstrated in numerous studies (e.g., Johnston & Mash, 2001), as has the association between childhood behavioral disorders and marital conflict (e.g., Cummings & Davies, 2002). However, the results on partnership quality and ASD are inconsistent. On one hand, there are results showing that the partnership quality is lower among parents to children with ASD than among parents to typically developed children (e.g., Brobst et al., 2009). On the other hand, studies report that parents to children with ASD feel more closely connected due to the challenging task of bringing up a child (Marciano et al., 2015). If we look at the divorce rate as an indicator, the study by Hartley et al. (2010) shows that parents to children with ASD are more likely to get a divorce. However, this was refuted by Freedman et al. (2012) because after controlling for relevant covariates such as symptom severity or mother's mental health there is no longer evidence that parents to children with ASD are more likely to get divorced.

The *spillover effect* might be descriptive for the results of low partnership quality among parents to children with ASD. According to the spillover effect, when the stress level in one area of life (domain) is high, it can be dynamically transferred to other areas of life (e.g., Bolger et al., 1989). In our case, this means that if there is stress in parenthood, it is transferred to the partnership leading to the parents being stressed and therefore less satisfied in this area as well. This could be explained by the possibility that parents are so stressed by the demands of parenting that they no longer have the capacity to handle the demands that a partnership entails. The stress requires so many resources in one domain that there are none left for the other (Buck & Neff, 2012). In everyday practice, a deterioration of the quality of relationships due to a lack of time for hedonistic activities between couples could be a reason (Bodenmann, 2003). Given the high level of care required for a child with ASD, this phenomenon would not be unexpected. Another explanation for an observed *spillover effect* is the assumption that people develop a coping style so that they repeatedly resort to similar coping strategies in different situations (Aldwin, 2009). For example, if problem situations are approached with a dysfunctional coping strategy such as "avoidance," as in the area of child education (e.g., an undesirable behavior of the child), it is likely that the parent will also use this strategy in other areas such as conflicts in the partnership. In this example, the situation would probably become worse rather than leading to a solution, which would then be seen in both areas.

However, stress could also work in a positive way, improving the partnership. The findings which argue for a strengthening of the partnership resulting from stress can be explained by the *parenting alliance* (Cohen & Weissman, 1984). The parenting alliance represents a mutual support system based on partnership, which is seen as central to coping with the challenges of education (Bodenmann, 2000). Gabriel and Bodenmann (2006) explain the strengthening of the relationship of parents to children with behavioral problems with a common perception of the problems in education or child behavior. The shared stressful situation ties both partners closer together as they decide to face the challenges together. In addition to satisfaction with the partnership, it seems to be important for a strong parental alliance of parents to children with disabilities that the partner participates in the caregiving for the child (Abdo & Fischer, 2003). Parents to children with ASD report that while caring for the child is time consuming, they find a relational bond as a couple by caring for the child together (Marciano et al., 2015).

Based on the above contradictory research findings on the relationship between parental stress and partnership quality of parents to children with ASD, the aim was to examine these two constructs longitudinally in order to gain insight into whether there is an inter-relationship between self-reported parental stress and perceived parental partnership quality and whether these two constructs can predict each other longitudinally. In this context, a longitudinal model was used (random intercept cross-lagged panel model; RI-CLPM; Hamaker et al., 2015), which allows a more clearcut interpretation of cross-lagged and autoregressive paths as described below.

Method

Research Design

Data were collected in the research project "ELKASS" (*Parents to children with autism spectrum disorders: demands, stress, and resources*; Tröster & Lange, 2019). The longitudinal study resulted from a cooperation with therapists from autism therapy centers who perceived a need for research on the topic of stress experienced by parents to children with ASD.

All participants were informed about all contents of the project and about anonymity and voluntariness ahead of their participation. The ethical guidelines were officially examined.

Parents to children with ASD who had started an outpatient therapy in one of ten cooperating autism therapy centers throughout Germany during the survey period were assessed with a questionnaire at three points in time. Each therapy center consists of a multi-professional team that works according to the guidelines of the German Autism Association. In accordance with the research question, only those parents who lived in a partnership were selected for the sample. Similarly, parents to children in adolescence and young adulthood were excluded due to better comparability. Therefore, only parents whose children were 12 years old or younger are part of the sample. Only parents who started therapy in one of the cooperating therapy centers were included in the study. The first test was carried out at the beginning of the therapy. One hundred and sixty parents participated in the first testing, 98 parents (61.3%) in the second, and 59 (36.9%) in the third. There were 4 months between each test.

Participants

Parents to Children With ASD. The following sample information is based on 160 parents (137 mothers). Parents' age ranged from 24 to 62 years ($M = 39.67$ years, $SD = 6.96$ years). German nationality was stated by 85.7% of all participating parents and 13.1% were of other nationalities such as Turkish (3.7%) or Russian (1.9%). Eleven nationalities other than German were mentioned (1.2% missing data). The highest educational degree parents reported was a university or college degree (28%) followed by 27.3% of parents who had obtained their general or subject-related qualification for university entrance, 29.8% reported having a secondary school certificate, 9.9% had passed lower secondary education, and 3.1% had left school without a degree (1.9% missing data).

In addition to supporting the children, the therapists in the therapy centers worked with the parents of almost all families (96.9%) by offering regular parent talks (94.9%) or by supporting the parents through psychoeducation (84.5%). 57% of the parent talks were attended by both parents together (41.9% by the mothers alone). The therapy centers enabled parents to attend the child's therapy session, which 39% of parents took advantage of (78.1% mothers alone, 18.8% both parents together). Other therapy programs that the parents accepted from the therapy center were systemic therapy (26.8%), behavioral therapy (22.7%), crisis intervention (18.6%), and Marte Meo therapy (7.2%), which is a developmental support concept based on video analysis of everyday situations (Baeriswyl-Rouiller, 2008). The autism therapy center also organizes support groups for parents, which were accepted by 7.7% of the parents.

Children With ASD. The ages of the children (138 male) of the parents interviewed ranged from 2 to 12 years ($M = 7.68$ years, $SD = 2.69$ years). Information on ICD-10 diagnoses of the children was provided by the therapists at the therapy centers. In addition to the diagnosis ASD, other comorbid disorders were diagnosed. More than half of the children (51.9%) with ASD had at least one or more comorbid disorders. The diagnoses as well as the frequency of comorbid disorders and the four most frequently indicated comorbid disorders are shown in Table 1.

During the second measurement, the therapists were asked about the therapy offered. Outpatient therapy usually took place once a week (89.8%) with one-to-one sessions (96.5%), which lasted one and a half hours on average ($M = 1.47$ h, $SD = 0.47$ h). In most cases, support took place in the therapy center (83.1%). The individualized support of the children was carried out with multi-method therapy approaches tailored to the needs of the clients, namely children with ASD. The three most frequently used therapy methods by the therapists were working through problems via conversations (30%), the TEACCH approach (27.5%; Treatment and Education of Autistic and related Communication Handicapped children;

Table 1. Diagnoses and Comorbid Disorders of Children With ASD According to ICD-10 Codes.

	n	%
Diagnosis		
Asperger syndrome (F84.5)	69	43.1
Childhood autism (F84.0)	58	36.3
Atypical autism (F84.1)	17	10.6
Other diagnosis[a]	7	4.4
No diagnosis yet	5	3.1
Missing data	4	2.5
Number of comorbid disorders		
No comorbid disorder	70	43.8
One comorbid disorder	51	31.9
Two comorbid disorders	19	11.9
Three or more comorbid disorders	13	8.1
Missing data	7	4.4
Four most frequently mentioned types of comorbid disorders[b]		
1. Disturbance of activity and attention (F90.0)	23	14.4
2. Specific speech articulation disorder (F80.-)	14	8.8
Expressive language disorder (F80.1)	3	1.9
Receptive language disorder (F80.2)	3	1.9
Other developmental disorders of speech and language (F80.8)	1	0.6
Developmental disorder of speech and language, unspecified (F80.9)	4	2.5
F80.- (not specified)	3	1.9
3. Specific developmental disorder of motor function (F82)	14	8.8
4. Mixed specific developmental disorders (F83)	9	5.6

Note. The data refer to $N = 160$ children with ASD at the start of therapy at the autism therapy center.

[a]Pervasive developmental disorder, unspecified (F84.9).

[b]Other types of comorbid disorders, for example, mild mental retardation (F70), epilepsy (G40), nonorganic enuresis (F98.0) were not mentioned more than seven times.

Reichler & Schopler, 1976), and behavioral therapy methods (18.1%).

Materials

The two constructs of stress and perceived partnership quality were assessed using self-report data from parents to children with ASD who had completed a questionnaire in German.

Parental Stress. The Parent Stress Inventory ("Eltern-Belastungs-Inventar," EBI; Tröster, 2011), which is based on Abidiń's Parenting Stress Model (Abidin, 1995), was used to measure the stress level of parents to children with ASD. Many studies have suggested the EBI's usefulness as a multidimensional screening method for recording parental stress (e.g., Irlbauer-Müller et al., 2017; Sarimski, 2017). The EBI consists of 12 subscales with four items each. Every subscale belongs to either the child or parent domain. The child domain records the sources of stress resulting from the child's characteristics and behavior. Five subscales are defined within the child domain: adaptability (example item: "My child reacts intensely when something happens that it doesn't like."), mood (example item: "I sometimes have the feeling that my child constantly places demands on me."), hyperactivity/distractibility (example item: "I often feel exhausted because my child is so active."), acceptability (example item: "My child does some things that bother me."), and demandingness (example item: "My child does some things that challenge me a lot."). Aspects of stress resulting from the challenges of the parental role are measured by way of the parent domain in the following seven subscales: depression (example item: "It depresses me when I notice that I react irritably to my child."), role restriction (example item: "To do justice to my child, I have to limit myself more than I had imagined."), social isolation (example item: "Since I became a mother/father, it has been more difficult for me to make new social contacts."), health (example item: "I no longer have as much energy to do things I used to enjoy."), parental competence (example item: "Some aspects connected to raising my child are harder than I expected."), parental attachment (example item: "In some situations I wish I could better empathize with what is going on in my child."), and partnership (example item: "Since I had the child, I don't do as much together with my partner."). The 48 items in total are answered on a five-point Likert scale ("does not apply at all" to "applies exactly," high values = high stress). The EBI was normed for mothers aged 20–53 years of infant and preschool-aged children. The gender ratio of children was approximately balanced. In previous German studies, the measurement instrument has been used with parents to children with ASD (Rabsahl, 2016; Sarimski, 2017; Tröster & Lange, 2019). The EBI normative sample achieved a Cronbach's alpha of $\alpha = .91$ in the child domain and $\alpha = .93$ in the parent domain.

Table 2. Descriptive Statistics and Bivariate Correlation (Pearson) Between Perceived Partnership Quality and Parental Stress.

Variable	*M*	*SD*	α	Partnership T1	Partnership T2	Partnership T3	Stress parent domain T1	Stress parent domain T2	Stress parent domain T3	Stress child domain T1	Stress child domain T2	Stress child domain T3
Partnership T1	2.09	.67	.83	1								
Partnership T2	2.24	.74	.86	.32**	1							
Partnership T3	2.25	.69	.87	.62***	.14	1						
Stress parent domain T1	3.16	.75	.93	.34***	.31**	.36**	1					
Stress parent domain T2	3.12	.77	.95	.46***	.38***	.46***	.83***	1				
Stress parent domain T3	3.33	.69	.92	.34**	.15	.57***	.73***	.85***	1			
Stress child domain T1	3.52	.67	.87	.04	.12	.23	.63***	.60***	.58***	1		
Stress child domain T2	3.53	.67	.89	.25*	.27**	.26	.63***	.70***	.59***	.81***	1	
Stress child domain T3	3.67	.69	.91	.06	.12	.33*	.56***	.62***	.72***	.75***	.80***	1

Note. Partnership = Perceived partnership quality measured by the partnership scale of the EFS; Stress parent domain = Parental stress measured by the EBI parent domain; Stress child domain = Parental stress measured by the EBI child domain; T1 = Time 1: At the beginning of the therapy; T2 = Time 2: four months after the start of therapy; T3 = Time 3: eight months after the start of therapy; *$p < .05$ **$p < .01$ ***$p < .001$.

The scaleś reliability calculated in this sample throughout all three measurement points ranged from $\alpha = .87$ to .95 (see Table 2). The means of the child and parent domains were used for the following calculations.

Perceived Partnership Quality. The partnership scale of the parental stress questionnaire of Domsch and Lohaus ("Elternstressfragebogen," EFS; 2010) was used to survey three areas of partnership: (a) the satisfaction with the partnership (example item: "There are some aspects of the partnership I would like to change"), (b) the support by the partner (example item: "My partner relieves me of the task of raising the child"), and (c) the agreement on educational issues (example item: "Regarding issues of education, my partner and I are in complete agreement"). The three areas are understood as "perceived partnership quality" because they only describe the subjective perception of a partner. In what follows, the construct will be referred to as "partnership quality" for convenience. The seven items were measured on a four-point Likert scale (from "applies exactly" to "does not apply," high values = high quality). The ESF was normed with parents of children attending kindergarten ($M = 35.8$ years, $SD = 5.3$ years) as well as grades one through six in school ($M = 39.9$ years, $SD = 5.2$ years). The questionnaire was predominantly completed by the parent who was the primary caregiver of the child, which was the mother 91.4% of the time in the kindergarten sample and 92.2% of the time in the school sample. The internal consistency of the partnership scale was $\alpha = .84$ in the kindergarten sample and $\alpha = .83$ in the school sample. The ESF has been used in other studies for parents to children with ASD (e.g., Niemczyk et al., 2019). In our sample Cronbach's Alpha proved to be good with $\alpha = .83$ to .87 in the different measurements (see Table 2). The mean of the seven items was used for the model calculations.

Statistical Analysis

To answer the research question, we used an RI-CLPM, which estimates between- and within-person effects separately. Numerous comparisons between the conventional CLPM and the RI-CLPM (e.g., Hamaker et al., 2015) show that controlling for stable between-person differences is important because estimated cross-lagged effects and autoregressive effects change in significance and magnitude when moving from CLPM to RI-CLPM. The CLPM assumes that the level of the two variables considered is the same in the population. However, it is implausible to assume that all parents have the same stress level and perceive their partnership quality to be equally high. Therefore, two random intercepts are used in the RI-CLPM in order to eliminate the between-person effects and, thus, to be able to clearly interpret the within-person effects.

A CLPM serves to analyze the interaction between different variables over time. This involves two or more different variables measured at two or more points in time. However, the results of the CLPM in some studies show biased estimates in the analysis of mutual effects of longitudinal data due to the confounding of interindividual and intraindividual effects (e.g., Bailey et al. 2020; Hamaker et al., 2015). In order to allow not only for temporal stability but also for interpersonal stability overall survey periods, random intercepts have to be included (Hamaker et al., 2015). In this way, time-stable, unobserved third-party variables can be controlled (Kühnel & Mays, 2019). In longitudinal data, the results must be considered separately at two different levels: the within-person level and the between-person level. In several studies comparing a CLPM and an RI-CLPM, the results show that especially the autoregressive effects (see Figure 1: α and δ) in the RI-CLPM are often insignificant and rather small, compared to the classic CLPM (e.g., Bailey et al., 2020; Kühnel & Mays, 2019). The RI-CLPM considers estimates for both within-person and between-person differences, although the following section

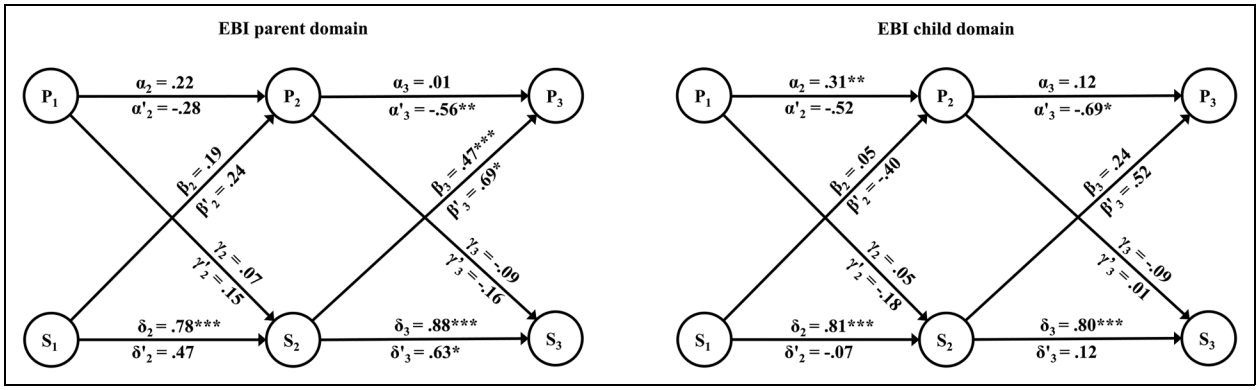

Figure 1. CLPM and RI-CLPM include the factors perceived partnership quality and parental stress. *Note.* Standardized parameter estimates with the CLPM are presented above the arrows and those with the RI-CLPM below the arrows, additionally marked with an apostrophe. P1 to P3 = perceived partnership quality for the three measurements; α_2 and α_3 = autoregressive parameters of perceived partnership quality; γ_2 and γ_3 = cross-lagged parameters of perceived partnership quality; S1 to S3 = parental stress for the three measurements; δ_2 and δ_3 = autoregressive parameters of parental stress; β_2 and β_3 = cross-lagged parameters of parental stress; *$p < .05$, **$p < .01$, ***$p < .001$.

will focus primarily on within-person effects to answer the underlying research question.

The calculations were computed using the lavaan package (Rosseel, 2012) with version 4.1.1 of R (R Core Team, 2021). The model fit was evaluated with the following fit indices: comparative fit index (CFI), Tucker–Lewis index (TLI), and the root mean square error of approximation (RMSEA; e.g., Hu & Bentler, 1999). The handling of missing data was implemented with the full information maximum likelihood (FIML) estimation. In this procedure, the parameters for the sample are estimated by maximizing the likelihood function. The missing values are estimated in such a way that the distribution appears as plausible as possible for the observed data. Before applying the RI-CLPM, bivariate correlations were calculated to get an overview of the associations of parental stress and perceived partnership quality.

Results

Bivariate Correlations

Descriptive statistics and bivariate correlations between the EBI parent and child domain and partnership quality across the three measurements are reported in Table 2. There were positive correlations between the parent and the child domain of $r = .56$ and $r = .83$, $p < .001$. Over the course of the three measurement dates, the partnership scale correlates between $r = .32$, $p = .002$ and $r = .62$, $p < .001$. The main associations between parental stress and partnership quality are to be found in the parent domain, ranging from $r = .31$, $p = .002$ to $r = .57$, $p < .001$. The higher the stress in the parent domain, the better the quality of the partnership was perceived. In the child domain, there were no or only weak indications of connections between the two constructs ($r = .04$, $p = .667$ to $r = .27$, $p = .009$).

CLPM and RI-CLPM

For comparison, the parameter estimates for the CLPM and the RI-CLPM are shown in Figure 1. In order to better differentiate the results from RI-CLPM, they are marked with an apostrophe in the following part. The RI-CLPM fits the data significantly better than the CLPM, as shown by the fit-indices CFI and RMSEA and the likelihood-ratio-test in both domains ($p < .001$): parent domain CLPM: x^2 (4) = 27.69, $p < .001$, CFI = .91, TLI = .65, RMSEA = .19; parent domain RI-CLPM: x^2 (1) = .04, $p = .846$, CFI = 1.0, TLI = 1.06, RMSEA = .00; child domain CLPM: x^2 (4) = 36.58, $p < .001$, CFI = .84, TLI = .39, RMSEA = .23; child domain RI-CLPM: x^2 (1) = .25, $p = .618$, CFI = 1.0, TLI = 1.06, RMSEA = .00.

EBI Parent Domain. High autoregressive paths were found in the parent domain using the CLPM ($\delta_2 = .78$, $p < .001$, $SE = .064$ and $\delta_3 = .88$, $p < .001$, $SE = .071$), which were less pronounced ($\delta'_3 = .63$, $p = .026$, $SE = .241$) or no longer present ($\delta'_2 = .47$, $p = .063$, $SE = .236$) in the RI-CLPM. The autoregressive paths in the partnership quality showed no significant effects in either model (CLPM: $\alpha_2 = .22$, $p = .050$, $SE = .121$; RI-CLPM: $\alpha'_2 = -.28$, $p = .171$, $SE = .234$). While α_3 had an insignificant positive value in the CLPM ($\alpha_3 = .01$, $p = .951$, $SE = .116$), the path showed a negative prediction in the RI-CLPM ($\alpha'_3 = -.56$, $p = .004$, $SE = .178$). At the within-person level, the negative autoregressive effect in the RI-CLPM suggests that for those parents for whom partnership quality is high at T2, compared with their own average partnership quality, it is likely that partnership quality at T3 is below their own average. Both models showed a positive cross-lagged effect in path β_3 (CLPM: $\beta_3 = .47$, $p < .001$, $SE = .117$; RI-CLPM: $\beta'_3 = .69$, $p = .021$, $SE = .338$). At the within-person level, the positive path (β'_3) showed that those parents who rated their stress lower than their own average at T2 tended to perceive their partnership quality to be worse than their own average four months later (T3). Increased stress appears to have a positive impact on the partnership. β_2 showed no effect in both models (CLPM: $\beta_2 = .19$, $p = .080$, $SE = .102$; RI-CLPM: $\beta'_2 = .24$, $p = .301$, $SE = .270$). Also, there were no cross-lagged effects in either CLPM or RI-CLPM that are based on partnership quality (CLPM: $\gamma_2 = .07$, $p = .349$, $SE = .076$ and $\gamma_3 = -.09$, $p = .198$, $SE = .070$; RI-CLPM: $\gamma'_2 = .15$, $p = .350$, $SE = .149$ and $\gamma'_3 = -.16$, $p = .299$, $SE = .106$). Contrary to expectations, partnership quality does not seem to reduce parental stress. On the between-person level in the RI-CLPM no significant correlation was found (.39, $p = .104$, $SE = .061$).

EBI Child Domain. In the child domain, there were no cross-lagged effects in either CLPM or RI-CLPM (CLPM: $\beta_2 = .05$, $p = .659$, $SE = .114$; $\beta_3 = .24$, $p = .083$, $SE = .139$; RI-CLPM: $\beta'_2 = -.40$, $p = .547$, $SE = 1.251$; $\beta'_3 = .52$, $p = .139$, $SE = .561$; CLPM: $\gamma_2 = .05$, $p = .462$, $SE = .061$ and $\gamma_3 = .01$, $p = .894$, $SE = .078$; RI-CLPM: $\gamma'_2 = -.18$, $p = .721$, $SE = .330$ and $\gamma'_3 = -.15$, $p = .510$, $SE = .159$). In the autoregressive paths, a significant effect from T1 to T2 was found in CLPM in partnership quality ($\alpha_2 = .31$, $p = .002$, $SE = .109$), which was no longer present in the RI-CLPM ($\alpha'_2 = -.52$, $p = .290$, $SE = .585$). In the path from T2 to T3, there was an insignificant effect in CLPM and a significant effect in RI-CLPM (CLPM: $\alpha_3 = .12$, $p = .373$, $SE = .121$; RI-CLPM: $\alpha'_3 = -.69$, $p = .011$, $SE = .242$). The CLPM showed significant autoregressive effects in the child domain, which were no longer present when using the RI-CLPM (CLPM: $\delta_2 = .81$, $p < .001$, $SE = .063$; $\delta_3 = .80$, $p < .001$, $SE = .091$; RI-CLPM: $\delta'_2 = -.07$, $p = .924$, $SE = .718$; $\delta'_3 = .12$, $p = .924$, $SE = .718$). Similarly, on the between-person level in the RI-CLPM no significant effect was found (.20, $p = .143$, $SE = .042$).

Discussion

We investigated how parental stress and partnership quality of parents to children with ASD impact each other during the first eight months of support at the autism therapy center using

longitudinal data and modeling techniques. Almost no substantial bivariate correlation and no cross-lagged effects were found between the quality of the partnership and the stress resulting from the characteristics and behavior of the child (child domain). It seems, that the parental stress resulting from the child's behavioral problems, in particular ASD-related symptoms, has no connection with the quality of the partnership. Rather, a connection was found between the partnership and the stress resulting from limitations or an overload of parental functioning (parent domain).

Similar to other research on and with CLPM and RI-CLPM (e.g., Bailey et al., 2020; Hamaker et al., 2015), different results are shown in the two models, especially in the autoregressive effects where, for example, effects occurring in CLPM are no longer statistically significant in RI-CLPM. In the following part, only those results of RI-CLPM will be discussed since this model fits the data better according to fit indices.

The results show no negative association between parental stress and partnership quality over the course of their child's first 8 months of therapy. The assumption that parents require many resources for their child every day (e.g., time and energy for care work), which are then no longer available to them for the partnership (e.g., time for common activities as a couple) cannot be confirmed. The findings at within-person level suggest that if the parental stress level decreases during the course of therapy, partnership quality is perceived to be deteriorating as the therapy continues. The theory of the parenting alliance (Cohen & Weissman, 1984) can be used as an explanation here. Coping with demands in parenting in stressful times ties parents together and strengthens their relationship (Marciano et al., 2015). Both parents form a unit to tackle the challenges of parenting together with each parent supporting the other. Therefore, when the stress reduces and mutual support is not as urgently needed, the partnership is perceived to have a lower quality than at a time of severe stress. One reason for this could be that parents then perceive their relationship to be less of a team. It can be assumed that the effects found between stress reduction and deterioration of partnership quality are generated by the therapy program. If the parents have gained more confidence and self-efficacy in handling their child and the ASD symptoms through the therapeutic programs at the autism therapy center (e.g., through parent talks, psychoeducation or involvement in the child's therapy), they might thus be less dependent on the support of their partner. In this regard, an imbalance between the partners could arise especially if only one of the parents has participated in the programs offered by the therapy center (57% of parent talks and 18.8% of child's therapy sessions attended together). Thus, the active parent develops new skills in dealing with the child and its disorder whereas the other parent does not, so that the parenting alliance is weakened. In addition, the parents might have learned to reflect on their different roles (parents, relationship partners) due to the support in the therapy center. While issues in the partnership were overshadowed when parental stress was high, they appear when stress decreases. Possibly the parents rediscover their role as partners in a romantic relationship and the associated challenge of a partnership, while their functional role as parents, in which they are acting as an alliance, takes a back seat. As described above, the ESF partnership scale consists of, among other things, support from the partner and agreement on educational questions. It could be that new educational issues have arisen during the course of therapy where the parents disagreed and therefore the agreement in education part of the scale was given a lower rating.

Those parents whose partnership quality initially improved in the first four months after the start of therapy (between measurements one and two) are likely to perceive a reduced partnership quality after eight months (measurement three). It can be hypothesized that the parents are generally more optimistic at first, because the therapy has started and they are excited about the newly gained support, which has an effect on the quality of the partnership. This initial euphoria might subside in the further course of the therapy and explain the effect.

During the first four months of therapy, there seemed to be no effects since neither the autoregressive pathways nor the cross-lagged pathways between the first two survey dates showed effects. Only in the later course of therapy changes appeared to occur and influences became evident. Therefore, a longer period of time should be determined in follow-up studies to be able to make more reliable statements.

Implications for Counselors

The results of the present study suggest a need for action in practice, which is not only relevant for autism therapists, but also for marriage and family counselors.

In practical work with families, it may be beneficial to encourage parents to participate together in the therapy program in order to counteract an imbalance and a weakened parental alliance between them. Autism therapists could involve parents as a team in their child's therapy so that newly acquired skills or routines can be implemented by both parents equally in everyday life. Those parents could thus continue to perceive themselves as an alliance going through the process of their child's therapy together. In this context, it appears reasonable to offer additional support structures especially geared toward fathers since they are underrepresented in the programs offered by the therapy centers. Autism therapists could also be trained by marriage counselors to analyze parental partnership quality so that they can identify needs among families. If the quality of the partnership is perceived to be low, therapists should point out options to parents as to what support and therapy services are available locally and establish contacts with these. Marriage or family counselors should then be used to provide adequate support for parents. From the present results, it can be deduced that the quality of the partnership deteriorates after the parental stress subsides in the first months of therapy. Often, the beginning of the child's therapy marks the end of a long waiting period, which is stressful for the whole family (Jungbauer & Meye, 2008). In this new process, parents need to be seen and cared for not

only as parents, but also as a couple, so that their parenting relationship (or alliance) as well as their relationship as partners can be strengthened. A possible starting point is open and successful communication between the partners so that their cohesion is strengthened again (Cheatham & Fernando, 2022). This requires trained therapeutic professionals and an available adequate offer. An issue that may arise is that many parents to children with ASD have little time for such programs due to the increased care load. One possibility would be to expand the range of services offered by the autism therapy centers to include couple therapy carried out by marriage or family counselors as staff members, so that families could receive holistic care at the centers without having to visit different practices. It is important to research the topic of stress of parents to children with ASD because empirical evidence shows the urgency for policymakers. Based on these empirical results, new structures can be developed to support families of children to ASD holistically and centrally by the state by creating and funding new family therapeutic services. However, it is important to also note that parents to children with ASD develop substantial strengths from their parenting such as resilience or hope, and experience enrichment in their lives through their child with ASD (Bayat, 2007; Kozachuk et al., 2022; Phelps et al., 2009). Therefore, in both practice and research, apart from focusing on challenges to parenthood, a focus on resources is imperative to fully map the needs of parents to children with ASD.

Limitations

The major limitation of the study is the large drop-out between the first and third measurement point, the latter of which showed only 36.9% of the initial sample. This fact may especially have an impact on the significance of the lagged effects estimates. The reasons for the dropout from the study could not be fully elucidated. Some parents no longer took their child to the autism therapy center for various reasons (e.g., successful completion of therapy, termination of therapy due to external circumstances). Other no longer wanted to participate in the study for unknown reasons. In this context, parents with increased stress taking part in the study might create a selection effect. Especially those parents who feel stressed are more motivated to participate in a study on this topic and, above all, to finish it, as they find the topic important and recognize the relevance of the research on it. The drop-out of parents perceiving lower stress levels from the study then results in lower mean stress levels at the first measurement point compared to the later points. Thus, at T2 and T3, the mean stress level would increase due to the omission of parents who are generally less stressed. There may also be biases in the quality of the partnership. It can be assumed that those parents who stay together despite the high demands and stress due to child characteristics (e.g., ASD symptoms) have a strong partnership.

Furthermore, fathers are underrepresented in the present study. Rivard et al. (2014) showed in their study that fathers of children with ASD have higher stress levels than mothers. This could be related to the fact that in families where parents adopt traditional gender roles, fathers are less involved in active care and educational work and therefore benefit less from therapy and counseling services. For further research it would therefore be desirable to have a more balanced sample in terms of gender and to consider the extent and nature of each parent's involvement in child parenting. Both of these aspects would enable an examination of gender-specific effects. In addition, it would have been useful to collect data from both partners rather than one in order to make clearer statements about perceived partnership quality.

Another limitation of the study is the scale used to measure the quality of the partnership. In the ESF, the scale used is a subscale in the larger context and comprises only seven items. The construct of the perceived partnership could have been surveyed in more detail and in all its facets. There are numerous research results on the connection between dyadic coping and marital quality (e.g., Bodenmann et al., 2006). Parental coping strategies were not explicitly taken into account in the analyses. In this case, it would have been particularly interesting to know whether the parents use interpersonal and/or dyadic coping strategies. Longitudinal study results by Bodenmann (1997) showed that stress triggers an increased risk of break-up both directly and indirectly through individual and dyadic coping. Dyadic coping has also been identified as an important resource for parents to children with childhood behavioral problems and represents an important resource for coping with the demands of parents to children with behavioral problems (Gabriel & Bodenmann, 2006). This component should be considered in future studies in order to enable a specific support, for example, in the form of couples therapy offers for parents to children with ASD.

Regarding the chosen method, it should be noted that in the RI-CLPM time-invariant confounders but no time-variable confounders can be controlled by the random intercepts. Thus, for causal interpretations, the control of time-variable confounders, such as the severity of autism symptoms, would be necessary. Studies show that the severity of autism symptomatology (Lyons et al., 2010), the number of comorbid disorders (Zablotsky et al., 2013), and the point in time the diagnosis has been received (Rivard et al., 2014) can influence parental stress. These variables should be considered in future research.

In summary, the representativeness of the sample of this field study is limited. Nevertheless, it must be noted that practitioners deal with such a heterogeneous clientele on a daily basis, which is why the results are relevant.

Acknowledgments

We would like to thank the parents who participated in our longitudinal study "ELKASS" for their commitment, as well as the therapists from the ten cooperating autism therapy centers for their support during the process of data collection during the study. The study was funded by the German Autism Association and the participating autism therapy centers.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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Appendix C: Study III

Sartor, T., Sons, S., Kunina-Habenicht, O., Tröster, H., & Kuhn, J.-T. (2023b). Demands and stress before and during the COVID-19 pandemic of parents to children with autism spectrum disorder. *Frontiers in Psychology, 14*(1212556), 1–11.

https://doi.org/10.3389/fpsyg.2023.1212556

frontiers | Frontiers in Psychology

TYPE Original Research
PUBLISHED 03 October 2023
DOI 10.3389/fpsyg.2023.1212556

OPEN ACCESS

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RECEIVED 27 April 2023
ACCEPTED 19 September 2023
PUBLISHED 03 October 2023

CITATION
Sartor T, Sons S, Kunina-Habenicht O, Tröster H and Kuhn J-T (2023) Demands and stress before and during the COVID-19 pandemic of parents to children with autism spectrum disorder.
Front. Psychol. 14:1212556.
doi: 10.3389/fpsyg.2023.1212556

Demands and stress before and during the COVID-19 pandemic of parents to children with autism spectrum disorder

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Introduction: Parents to children with Autism Spectrum Disorder (ASD) face diverse daily demands that can lead to stress. The aim of this study was to examine to which extent stress in parents to children with ASD can be explained by daily demands before and during the COVID-19 pandemic (after lockdowns; first half of 2022), and whether there are differences between the two time periods in this regard.

Methods: Data from parents to children with ASD living in Germany from two independent questionnaire studies (before the pandemic: $N = 168$, during the pandemic: $N = 105$) were matched for comparability. Simple and multiple linear regression analyses were used to answer the research question.

Results: Parental stress as well as all demands examined showed higher levels during the COVID-19 pandemic than before. Significant predictors of parental stress before and during the COVID-19 pandemic were (1) the daily demands to deal with the child's problem behavior, (2) the restriction of one's personal way of life, and (3) the challenge to cooperate with the partner. During the COVID-19 pandemic, the child's problem behavior was particularly relevant. It was also found that the demand to deal with stigmatizing reactions did not explain parental stress during the COVID-19 pandemic whereas before the pandemic it had been a significant predictor.

Discussion: Although parental stress and the demands of daily life increased during the pandemic, most of the stress can be explained by the same demands. It is suggested that the increased levels may be due to an increase in the child's ASD symptomatology, which is why it is advisable to install therapeutic and care structures that prepare children with ASD for future crises.

KEYWORDS

parental stress, parental demands, COVID-19 pandemic, autism spectrum disorder, ASD

1. Introduction

1.1. Parents to children with ASD: demands and stress

Numerous studies consistently show that parents to children with autism spectrum disorder (ASD) experience higher levels of stress than parents of neurotypical children (e.g., Hayes and Watson, 2013). During the COVID-19 pandemic, parents report high levels of stress compared to non-parents (e.g., Bujard et al., 2021). Among parents, parents to children with ASD are shown to experience even higher levels of stress (e.g., Kalb et al., 2021). This raises the question of which factors are responsible for the high level of stress examined and which daily demands

placed on parents to children with ASD increased during the COVID-19 pandemic that may help explain their increased levels of perceived stress.

The demands that parents to children with autism spectrum disorder (ASD) face in their daily lives are enormous and multifaceted (O'Nions et al., 2018), even without a pandemic. These demands result in large part from the symptoms of ASD, which according to the DSM-5 are characterized by social communication impairments and restricted repetitive behavior and/or interests. Symptom severity is mapped on a continuum (American Psychiatric Association, 2013). The symptoms lead to impairments in the living arrangements of the child with ASD, which in turn requires a high level of support for the parents (Mancil et al., 2009). In what follows, we present everyday demands of parents to children with ASD that have been found to be significant in the literature (see Table 4, Tröster and Lange, 2019). Parents must deal with their child's problematic behaviors (e.g., impaired communication) on a day-to-day basis, which presents challenges in daily interactions and parenting (*problem behavior of the child in education*; e.g., Ludlow et al., 2011), while maintaining a bond with their child, which can be particularly challenging for children with ASD (*parent–child-relationship*; e.g., Teague et al., 2019). Due to the symptoms typical of ASD, parents sometimes have to deal with stigmatizing reactions in public or in their social environment (*stigmatizing reactions in the social environment*; e.g., Woodgate et al., 2008; Vollmer et al., 2020). A commonly exhibited way of dealing with this demand is avoidance, which can lead to isolation (Minhas et al., 2015), and which in turn impacts social participation. On a day-to-day basis, it is difficult for parents to maintain social contacts on top of all family-related demands (e.g., Woodgate et al., 2008), as maintaining a social relationship involves effort and expectations (*social participation*; Diewald, 1991). Apart from maintaining social relationships outside the family, parents also need to maintain the relationship with their partner. They often face the challenge of perceiving themselves as lovers on top of the parental role (*cooperation with the partner*; e.g., Hock et al., 2012), because organizing family life can take a lot of time, especially for parents with children with ASD, as structures in everyday life are particularly important for them (*organization of family life*; e.g., Larson, 2006; Habermann and Kißler, 2022). This includes finding and coordinating appropriate professional support, such as making applications, organizing and keeping appointments (*professional support*; e.g., Vollmer et al., 2020). In addition, parents are left with little time and space for their personal needs, such as hobbies or their own careers (*personal way of life*; e.g., Hoogsteen and Woodgate, 2013).

These numerous high demands are reflected in the stress experience of parents to children with ASD. According to Lazarus' transactional stress theory, stress must be viewed in terms of a reciprocal person-environment relationship, focusing on cognitive appraisals and coping in the stress process (Lazarus and Launier, 1978; Lazarus and Folkman, 1984; Lazarus, 1999). Using Abidin's (1995) parenting stress model, which "represents an explication of a specific application of Lazarus and Folkman's general theory" (Abidin, 1992, p. 410), parental stress can be accounted for as follows: Parental stress occurs when parents are confronted with demands in their parenting that they cannot cope with using their available resources (Abidin, 1992; Tröster, 2011). In the parenting stress model, two main sources of stress are distinguished: first, the parent domain is outlined, which includes the stress that arises from the limitation of parental functions, making it more difficult for parents to cope with the demands of their parenting role, such as a dysfunctional partnership, social isolation, or unstable health; second, the child domain is described as the stress that results from a child's characteristics and behaviors, such as a limitation in adaptability or the child's hyperactivity or mood (Abidin, 1995). Especially in the child domain, parents to children with ASD show higher levels of stress than parents to children without disabilities (Hoffman et al., 2009; Tröster and Lange, 2019) and likewise than parents to children with other disabilities (e.g., intelligence impairment or Down syndrome, Hayes and Watson, 2013).

1.2. Parents to children with ASD during the COVID-19 pandemic

Although parents were generally more stressed during the pandemic (e.g., Bujard et al., 2021), studies show that parents to children with ASD, in contrast to parents with neurotypical children, experience significant stress during the pandemic (Corbett et al., 2021; Kalb et al., 2021) and these parents report more symptoms of depression and anxiety than parents to typically developing children (Wang et al., 2021). This may be related to the specific demands that parents experience as a result of their child's autism diagnosis, which may be compounded by the general demands of the COVID-19 pandemic.

Since the beginning of the COVID-19 pandemic in Germany in March 2020 (World Health Organization, 2020), most people's daily lives have been affected by health-related pandemic measures, e.g., restriction of social contacts (Federal Ministry of Health, 2021). For parents, the closure of childcare facilities and educational institutions was particularly challenging, requiring children to be cared for and schooled at home (OECD, 2021; Stadheim et al., 2022). The results of a study from 2020 showed that parental satisfaction during the pandemic in Germany was lower than before the pandemic in all areas surveyed, such as childcare or family life (Huebener et al., 2020), and parents felt more stressed than non-parents (Bujard et al., 2021). Broadening the view, similar findings emerged in other countries. In the American Psychological Association 2020 study, parents were found to be significantly more stressed than non-parents during the pandemic, especially in the pandemic-related aspects. The group of children with ASD and their families appeared to be particularly impacted by the pandemic because of its potential to exacerbate ASD symptoms (Bellomo et al., 2020; White et al., 2021). In a study in Germany and Austria by Isensee et al. (2022), almost 50% of parents reported an increase in symptoms in their child with ASD already at the onset of the pandemic. The study by Vasa et al. (2021) also reported that over half of the children with ASD either developed new psychiatric symptoms during the pandemic or had their pre-existing psychiatric conditions exacerbated. Colizzi et al. (2020) showed that more than one-third of children with ASD had their preexisting behavioral problems aggravated during the pandemic. An increase in mood symptoms, maladaptive behaviors (Stadheim et al., 2022) and sleep disturbances, a reinforcement of ritualized behaviors, and a decrease in motivation for social interaction were also evident in children with ASD (Latzer et al., 2021). In addition, children with ASD showed increased pandemic anxiety at the beginning of the pandemic (Hall et al., 2023). According to White et al. (2021), the greater expression of ASD symptoms could be explained by the frequent or prolonged interruption of therapy. Amplification may also result directly from the day-to-day realities of the pandemic. Children

with ASD had particular difficulties in adapting to the new daily routines and patterns that the pandemic brought with ever-changing regulations (Latzer et al., 2021); at the same time, their parents longed for stability and normalcy (Stadheim et al., 2022). The increased severity of ASD in turn has an impact on parental stress: the more severe the symptoms of ASD, the more stressed parents feel during the pandemic (Manning et al., 2021) and the more intrafamilial conflicts increase (e.g., physical violence or aggression; Isensee et al., 2022). Results show that parents to children with ASD report difficulty in coping with the daily demands regarding the child in particular (Colizzi et al., 2020).

It can be summarized that parents to children with ASD were highly stressed and the numerous demands in their daily lives that they had to cope with were intensified by the COVID-19 pandemic. Most studies to this point relate to the lockdown phases of the COVID-19 pandemic and not (yet) to the immediate post-strict phase period (see Procedures section for details on chronology). The aim of this study is to fill this research gap to some extent and to help clarify the increased stress experienced by parents to children with ASD during the COVID-19 pandemic, post-lockdown period, by answering the question of which demands in daily life explain this increased stress. Based on existing results surveyed during the pandemic (e.g., Colizzi et al., 2020), we hypothesize research that daily demands and parental stress during the pandemic are higher than before (H1). Due to the increase in symptoms during the pandemic (e.g., Manning et al., 2021; Isensee et al., 2022), we postulate as our second research hypothesis (H2) that parental stress is mainly explained by the need to deal with the child's behavior on a daily basis. Similarly, living a personal lifestyle (H3) and the need to organize family life (H4) are hypothesized to have a predictive influence due to the increased care needs of parents as a result of closed care institutions (e.g., Huebener et al., 2020; Stadheim et al., 2022). Two samples were compared to answer the research question. Details of the statistical analyses will be outlined below.

2. Method

2.1. Procedures

Two samples were used in this study: one sample of parents to children with ASD before and one during the COVID-19 pandemic in Germany. The first sample (hereafter referred to as S1) was collected as part of the research project "ELKASS" (Parents to children with autism spectrum disorders: Demands, stress and resources; Tröster and Lange, 2019) from December 2015 to March 2016. The second sample (hereafter S2) was collected between April and June 2022 during the ongoing COVID-19 pandemic. At the end of March 2022, according to the government, the onset of a new phase of the pandemic began: the removal of most protective measures (Federal Government of Germany, 2022a). In most regions, there were no general contact restrictions (e.g., regarding the number of people allowed to meet in private) during the survey period, educational institutions were open, and most recreational facilities were open (Federal Government of Germany, 2022b). Differences in the survey method arose in that S1 was surveyed exclusively with a paper-pencil survey at the ten cooperating autism therapy centers that were requested via the German Autism Association. In S2, in addition to printed questionnaires, an online questionnaire was shared among distributors of therapy centers, institutions, and social media groups to be independent of renewed closures of institutions or stricter contact restrictions. All paper questionnaires were sent to the researcher in anonymized covers via the cooperating institutions Some autism therapy centers from S1 also sent the questionnaire to their members at the S2 time point. Therefore, it cannot be excluded that individual participants took part in both surveys. Due to the assurance of anonymity, participating parents were not asked about the institution they visited. An official review by an ethics committee was carried out in advance, the result of which being a positive vote without any restrictions.

2.2. Participants

S1 is composed of $N = 168$ parents to children with ASD who had just started support at an autism therapy center. In S2, $N = 105$ parents to children with ASD participated during the COVID-19 pandemic. The subjects were largely mothers (S1 = 86.9%; S2 = 96.2%) who reported to be of German nationality (S1 = 85.1%; S2 = 93.3%). The age of the parents interviewed ranged from 24 to 62 years (S1: $M = 39.43$, $SD = 6.58$; S2: $M = 39.95$, $SD = 5.5$) and they had between one and six children (S1: $M = 1.92$, $SD = 0.88$; S2: $M = 2.12$, $SD = 0.91$). Their child with ASD was between 2 and 12 years old (S1: $M = 8.0$, $SD = 2.67$; S2: $M = 7.91$, $SD = 2.61$) and most of them were male (S1: 87.5%; S2: 74.3%). Additional sociodemographic information of the parents as well as the diagnoses of the child with ASD can be found in Table 1. Retrieved information on the situation at home during the pandemic is shown in Table 2.

2.3. Materials

S1 and S2 received the same questionnaire. The questionnaire measured parenting stress and parenting demands in everyday life. In addition, the questionnaire collected sociodemographic information. In S2, additional pandemic-related information was collected.

2.3.1. Parental stress

The stress of parents to children with ASD was assessed with the "Eltern-Belastungs-Inventar" (EBI; Tröster, 2011), which is a German version of the Parenting Stress Index (PSI) of Abidin (1983). The 48 items are assigned to a total of 12 subscales (see Table 3), which in turn belong to either the child domain (five subscales) or the parent domain (seven subscales). The child domain is defined by the stress resulting from the child's behavior and characteristics. The parent domain is defined by the stress resulting from the limitations of parental functions needed to cope with the educational demands. The items were answered by the parents on a five-point scale (1 = "does not apply at all" to 5 = "applies exactly"). Cronbach's alpha was very good for the normative sample in the two domains (child domain: $\alpha = 0.91$, parent domain: $\alpha = 0.93$; Tröster, 2011, p. 32). The internal consistencies as well as an example item for each subscale are shown in Table 3.

2.3.2. Parental demands in everyday life

The parental demands in everyday life were surveyed with the scale by Tröster and Lange (2019). The scale measures behavioral,

TABLE 1 Socio-demographic data.

	S1		S2	
	n	%	*n*	%
Diagnosis of the child with ASD				
Childhood autism (ICD-10, F84.0)	61	36.3	37	35.2
Atypical autism (ICD-10, F84.1)	20	11.9	21	20.0
Asperger syndrome (ICD-10, F84.5)	80	47.6	35	33.3
Pervasive developmental disorder, unspecified (ICD-10, F84.9)	3	1.8	4	3.8
Autism spectrum disorder (DSM-5, 299.0)	4	2.4	8	7.6
Parenting situation				
Single parent	40	23.8	13	12.4
Two-parent families	128	76.2	92	87.6
Employment situation				
Working full-time	33	19.6	15	14.3
Working part-time	70	41.7	54	51.4
Studying	5	3.0	3	2.9
At home (e.g., parental leave, housewife/househusband)	60	35.7	33	31.4
Educational attainment				
University degree	46	27.4	41	39.0
High school	48	28.6	28	26.7
Intermediate secondary school	52	31.0	31	29.5
General secondary school	16	9.5	5	4.8
No qualification	6	3.6	0	0.0
Professional support measures[1]				
None	78	46.4	48	45.7
Educational counseling center	28	16.7	19	18.1
Parent training	24	14.3	17	16.2
Self-help group	21	12.5	19	18.1
Other (e.g., family assistance, psychotherapy, social pediatric center)	42	25.0	26	24.8

Sociodemographic data for the two samples S1 = 168 (before the pandemic) and S2 = 105 (during the pandemic). Data differ due to missing values.
[1]Multiple selections were possible.

cognitive, and social–emotional demands of parents, which are divided into eight subscales (see Table 4). A total of 41 items are answered on a four-point scale from 1 = "never / rarely" to 4 = "very often" according to how often a situation occurs in everyday life. Because the instrument is not yet standardized, the internal consistencies of the present samples are reported. The overall scale had very good reliability in both samples (S1: $\alpha = 0.92$, S2: $\alpha = 0.94$). Example items are illustrated in Table 4, as well as the good internal consistency of the individual subscales. The two subscales parent–child relationship and professional support were excluded from all analyses due to their unacceptable Cronbach's alpha.

2.4. Data analyses

R version 4.2.1 (R Core Team, 2021) was used for all analyses.

2.4.1. Matching

In a first step, S1 and S2 were matched for better unbiased comparison, using the following sociodemographic data of parents and children with ASD: age of parent interviewed, gender of parent, parenting status (single parent or not), educational achievement, employment situation, number of children, age of child with ASD, gender of child with ASD, diagnosis of child with ASD, comorbidity of child with ASD. A propensity score matching (PSM; Pan and Bai, 2015) with full matching was applied and the package "MatchIt" (Ho et al., 2011) was used.

2.4.2. Multiple imputation

For the dependent variables (parental stress) and the independent variables (demands) together, a total of 5% of the values were missing. These were treated under the assumption of missing at random (MAR) and imputed using the R-package "mice" with a number of 20 imputations and 10 iterations per imputation (van Buuren and

TABLE 2 Situation at home during the pandemic.

	S2	
	n	%
Places of work during the COVID-19 pandemic[1]		
Mainly/exclusively at the workplace	42	40.0
Balanced	10	9.5
Mainly/exclusively from home	14	13.3
Time child had to be cared for at home during pandemic		
Up to 1 month	9	8.6
Up to 4 months	38	36.2
Up to half a year	25	23.8
Over half a year	28	26.7
Childcare at home during pandemic[2]		
None	6	5.7
Other parent/partner	30	28.6
Family/friends/acquaintances	21	20.0
Interviewed parent him−/herself (e.g., working from home, parental leave)	104	99.1
Urgent care in facilities (e.g., schools and daycare centers)	21	20.0
Other (e.g., self-paid care, school assistance)	5	4.8

Retrieved information about the situation at home during the pandemic from S2 ($n = 105$). Data differ due to missing values.
[1]Only employed persons;
[2]Multiple selections were possible.

TABLE 3 Parent and child domain subscales of the EBI.

Parent domain	Example item	α
Isolation	*Since I became a mother/father, it is more difficult for me to make new contacts.*	*0.63*
Depression	*It depresses me when I realize that I am reacting irritably to my child.*	*0.75*
Health	*Lately I do not feel as fit and efficient as I used to.*	*0.75*
Spouse	*Because of the child, some problems arose in my partnership.*	*0.80*
Role restriction	*In order to do justice to my child, I have to limit myself more than I imagined.*	*0.82*
Parental attachment	*In some situations, I wish I could better empathize with what is going on in my child.*	*0.61*
Parental competence	*Some things in raising my child are harder for me than I expected.*	*0.83*
Child domain		
Adaptability	*My child sometimes has a hard time adjusting to changes in routine or home environment.*	*0.77*
Acceptability	*My child does some things that bother me.*	*0.70*
Demandingness	*My child is doing some things that are taking a toll on me.*	*0.68*
Mood	*When playing, my child is often impatient and gets angry quickly.*	*0.70*
Distractibility/Hyperactivity	*My child has more difficulty than other children in concentrating and paying attention.*	*0.75*

Presented are the subscales of the EBI, each with an example item and the internal consistency (Cronbach's alpha) for each subscale from the normative sample (Tröster, 2011). Each subscale includes four items.

Groothuis-Oudshoorn, 2011). For the imputation, the same socio-demographic data were used as for the matching (see above) and additionally the variables included in the analysis (stress and demands).

2.4.3. Regression analyses

To determine whether differences exist in the demands or stress of parents to children with ASD before and during the COVID-19 pandemic, the two matched groups (S1 and S2, independent variables) were compared in the demands and the two stress domains (dependent variables) using simple linear regression analyses. Multiple linear regression analyses were then used to examine which demands are significant in elucidating parental stress (main effects), and whether differences in predictor importance between the two groups were apparent (interaction effects). In this analysis, the stress domains were used as dependent variables and the different demands as independent variables.

TABLE 4 Subscales of the "Parental demands in everyday life" scale.

Demands	Example item	α S1	α S2
Problem behavior of the child in education (BC), 12 items	*My child has a hard time adjusting to new situations.*	*0.72*	*0.79*
Stigmatizing reactions in the social environment (SR), 7 items	*I have to justify my child's conspicuous behavior to other people.*	*0.89*	*0.88*
Social participation (SP), 2 items	*I have to limit my social contacts.*	*0.82*	*0.86*
Cooperation with the partner (CP), 4 items	*There is little time for joint activities with my partner.*	*0.78*	*0.85*
Organization of family life (FL), 5 items	*Joint activities with the family are difficult to realize.*	*0.74*	*0.85*
Personal way of life (PL), 5 items	*I do not have the time to deal with other things.*	*0.87*	*0.90*
Parent–child relationship (PCR), 4 items[1]	*I find it difficult to establish emotional closeness with my child.*	*0.43*	*0.48*
Professional support (PS), 2 items[1]	*Coordinating with teachers, therapists,* etc. *on the proper care for our child is difficult.*	*0.37*	*0.24*

Presented are the subscales of the "Parental demands in everyday life" scale (Tröster and Lange, 2019), each with an example item and the internal consistency (Cronbach's alpha) for each subscale in the two samples of the present study. The two subscales parent-child relationship and professional support were excluded from all analyses due to their unacceptable Cronbach's alpha.

TABLE 5 Results of simple linear regression analyses.

	B	*SE*	*t*	*p*	*d*	R^2_{adj}
Stress parent domain	0.39	0.09	4.17	<0.001	0.55	0.06
Stress child domain	0.37	0.08	4.60	<0.001	0.60	0.07
Organization of family life (FL)	0.55	0.09	6.24	<0.001	0.55	0.13
Stigmatizing reactions (SR)	0.26	0.09	3.00	0.003	0.55	0.03
Social participation (SP)	0.24	0.11	2.09	0.037	0.44	0.01
Personal way of life (PL)	0.26	0.10	2.62	0.009	0.51	0.02
Cooperation with the partner (CP)	0.36	0.10	3.72	<0.001	0.50	0.05
Problem behavior of the child (BC)	0.38	0.06	6.34	<0.001	0.81	0.13

Dependent variables: stress and demands; independent variable: sample (S1 and S2).

3. Results

Before the regression analyses could be used to answer the research question, the two samples were matched for better comparability. Propensity score matching using the 1:1 nearest neighbor method did not yield acceptable results, such that the full matching method (Hansen, 2004; Stuart and Green, 2008) with distance gml and probit regression was applied. This method could achieve a satisfactory balance: After matching, all standardized mean differences for the covariates were below 0.18. According to Cochran and Rubin (1973), the difference should be lower than 0.25, which is thus fulfilled. Further, after propensity score matching, no significant differences in sociodemographic data used for matching (see chapter Statistical Analysis) between S1 and S2 remained ($p > 0.05$). Full matching allowed all cases from the sample to be included, and no cases had to be discarded.

The results of the simple linear regression analyses with demands and stress as the dependent variable and sample as the binary independent variable showed significant differences in all demands and both stress domains concerning to the time of the survey (see Table 5). The sample surveyed during the COVID-19 pandemic reported both higher demands in daily life and higher parental stress. According to Cohen's classification (Cohen, 1988), the effect sizes are in the medium range, with the exception of the demand social participation, where a small effect was found, and the demand problem behavior of the child, where a large effect was present. Tables 6, 7 present the results of multiple regressions with stress as the dependent variable and demands as the independent variables. In the parent domain, significant main effects were shown in the demands of stigmatizing reactions, personal way of life, cooperation with the partner, and problem behavior of the child (adj. $R^2 = 0.59$). In the demand stigmatizing reactions, an additional significant interaction effect was found, suggesting that the significance of this predictor differed between the two samples. Further testing showed that the demand stigmatizing reactions was only a significant predictor of stress in the parent domain during the COVID-19 pandemic, but no longer during the pandemic ($B = 0.50$, $p > 0.05$). In the child domain, similar significant main effects were found in the following demands: stigmatizing reactions, cooperation with the partner, and problem behavior of the child (adj. $R^2 = 0.50$). The negative interaction effect in the demand stigmatizing reactions was also found, similar to the

TABLE 6 Results of multiple regression analysis: parent domain.

	B	SE	t	p
Sample	0.18	0.37	0.48	0.634
Organization of family life (FL)	−0.04	0.08	−0.51	0.610
Stigmatizing reactions (SR)	0.33	0.08	4.03	<0.001
Social participation (SP)	−0.11	0.08	−1.37	0.172
Personal way of life (PL)	0.54	0.09	5.66	<0.001
Cooperation with the partner (CP)	0.34	0.07	5.32	<0.001
Problem behavior of the child (BC)	−0.24	0.10	−2.36	0.018
Sample × FL	0.08	0.13	0.67	0.503
Sample × SR	−0.26	0.12	−2.08	0.037
Sample × SP	0.25	0.13	1.86	0.063
Sample × PL	−0.28	0.15	−1.84	0.066
Sample × CP	−0.05	0.10	−0.50	0.619
Sample × BC	0.21	0.18	1.19	0.233

Dependent variables: stress in the parent domain; independent variables: demands and sample (S1 and S2); with interaction effects.

TABLE 7 Results of multiple regression analysis: child domain.

	B	SE	t	p
Sample	−0.19	0.36	−0.54	0.587
Organization of family life (FL)	0.05	0.09	0.61	0.545
Stigmatizing reactions (SR)	0.35	0.08	4.28	<0.001
Social participation (SP)	0.06	0.09	0.73	0.464
Personal way of life (PL)	0.01	0.09	0.14	0.889
Cooperation with the partner (CP)	0.20	0.07	2.96	0.003
Problem behavior of the child (BC)	0.24	0.10	2.41	0.016
Sample × FL	−0.01	0.13	−0.06	0.954
Sample × SR	−0.33	0.12	−2.71	0.007
Sample × SP	−0.18	0.13	−1.40	0.161
Sample × PL	0.25	0.15	1.73	0.084
Sample × CP	−0.08	0.10	−0.78	0.438
Sample × BC	0.35	0.17	2.05	0.040

Dependent variables: stress in the child domain; independent variables: demands and sample (S1 and S2); with interaction effects.

parent domain. The main effect during the COVID-19 pandemic was not significant either upon further analysis ($B = 0.15$, $p > 0.05$). In addition, a second significant interaction effect was found in the demand problem behavior of the child. It can be inferred from the positive sign that this predictor is especially important during the pandemic for the explanation of the stress.

4. Discussion

The present study addressed the questions of the extent to which stress in parents to children with ASD before and during the COVID-19 pandemic is associated with their daily demands, and whether there are differences between the two time points. For this purpose, two non-longitudinal matched samples were compared before and during the pandemic.

The results show higher levels of all demands examined and both stress domains at time S2 than at S1. This confirms our H1. Thus, parents to children with ASD experience higher everyday demands and experience more stress during the COVID-19 pandemic. This finding is consistent with other study results (e.g., Colizzi et al., 2020). However, the fact that all demands are higher does not mean they cause the increased stress levels during the COVID-19 pandemic. The results show that there are few significant differences in predictors of stress before and during the pandemic. Differences appeared (1) in both stress domains in the demand stigmatizing reactions, which was no longer important for stress during the pandemic, and (2) in the demand problem behavior of the child, which was especially important for stress in the child domain during the pandemic, which confirms H2. Findings from other studies showed that ASD symptomatology increased in children with ASD during the pandemic (e.g., Latzer et al., 2021; Vasa et al., 2021;

Isensee et al., 2022; Stadheim et al., 2022). This may serve as an explanation for the present finding on the problem behavior of the child, because it can be assumed that the demand of having to deal with the child's autism-specific behavior in daily life increases when symptoms increase, resulting in more stress and thus supporting the findings of Manning et al. (2021). The pandemic may have increased problematic behaviors, e.g., due to a lack of therapy sessions (White et al., 2021). Further, constant changes of the pandemic (e.g., parents working from home; Latzer et al., 2021) may have increased problematic behaviors. Rehearsed responses to the child's problem behavior as well as routines in daily life can be difficult to maintain due to the constantly changing infection control regulations (e.g., closure of institutions or contact restrictions), which is why therapeutic support seems particularly necessary at a time like that. Stadheim et al. (2022) identify deficits in educational and therapeutic service systems for children with ASD and suggest a hybrid form for service delivery to ensure continuity. A practice of digital appointments can prepare the child for further crises and also ensure regular therapy if the child cannot appear on site for other reasons (e.g., transportation problems, vacation). This requires structures such as technical equipment on both sides, service and families at home (Isensee et al., 2022), as well as trained media competence. Such structures need to be discussed politically among service providers.

In addition to the child's problem behavior as a demand, only one other difference emerges between the demands that elucidate parental stress: the demand in daily life to cope with stigmatizing reactions emerges as an important predictor of stress in both the child and parent domains before the pandemic. In contrast, this demand no longer affects stress during the COVID-19 pandemic, although the demand - like all others - shows higher levels than before the pandemic. In response to stigmatizing their own child with ASD, parents often use avoidance by isolating themselves (Minhas et al., 2015). As a demand, stigmatizing reactions in the social environment would be expected to no longer be relevant to that extent due to reduction in contact with fellow individuals during the pandemic. The result of an increased level of stigmatizing reactions can be explained by increased symptoms, in that the child's behavior is more noticeable to strangers and the parents therefore fear more stigmatizing reactions, because higher severity of disability is more associated with rejection (Miller et al., 2009). Despite the increased demand to manage these reactions, this does not lead to more stress during the pandemic. It is possible that parents focused on other demands and paid less attention to other people's reactions. In relation to the stress models of Lazarus and Folkman (1984) and Abidin (1992), it is conceivable that parents may have developed new strategies to deal with this stigma during the pandemic (e.g., impression management; Voysey, 1972). Accordingly, they would consider their resources or strategies to be sufficient to handle this demand. The assumption that parents developed new strategies to deal with stigmatizing reactions from others during the pandemic would need to be investigated in further studies. In addition, it should be investigated what these strategies are and whether they continue to protect parents in the long term, after the pandemic.

Apart from that, no differences were found in which demands clarify the stress. The demands during the pandemic are higher, but before and during the pandemic the same demands are responsible for the emergence of parental stress. In addition to the two demands mentioned above (problem behavior of the child and stigmatizing reactions), the limitation in personal way of life in both the child and parent domains is explanatory for stress at both time points. The result confirms H3. Due to the high level of caregiving required, time for personal activities and taking on a role other than parent of a child with ASD can be very difficult (Hoogsteen and Woodgate, 2013). During the pandemic, there are many restrictions on recreational activities and, thus, families spend most of their time at home. It is conceivable that especially parents to children with ASD want to minimize the risk of infection as much as possible since their child belongs to the vulnerable group of the COVID-19 pandemic (Karpur et al., 2021). A hospital stay for the child in a foreign environment and a lack of routines is unthinkable, which brings about even stricter isolation. System-changing measures, such as emergency care systems (possibly digital) during crises should be politically reconsidered. These would need to be practiced over time and established as a fixed structure so that children with ASD can benefit from this offer, rather than experiencing a sudden change that they have difficulties coping with.

Stress in the parent domain is additionally influenced by the demand of cooperating with a partner both before and during the COVID-19 pandemic. Parents to children with ASD must coordinate care and nurturing of the child on a large scale (Hock et al., 2012). The challenge of fulfilling the role as (parenting) partner and of coordinating and agreeing with the partner about the child's upbringing and care seems to be a present demand in the daily life of parents to children with ASD, leading to stress in the parent domain. Isolation and quarantine periods may have led to increased potential for conflict in the partnership (Waddel et al., 2021; Overall et al., 2022). In the balancing act of caring for children and working from home, there is less time to discuss issues calmly as a couple. During the pandemic, many parents cared for children during the day and pursued their professional activities from home in the evenings (Beno, 2021). In the therapeutic setting, parents should be enabled to perceive the cooperation with the partner as a resource and not as a burden. If parents perceive themselves as a parenting alliance (Cohen and Weissmann, 1984) and master the challenges of daily life with a child with behavioral problems together, this can strengthen the relationship (Gabriel and Bodenmann, 2006). In turn, a good partnership relationship can reduce stress of parents to children with ASD (e.g., Siman-Tov and Kaniel, 2011).

All other demands surveyed showed higher levels during the pandemic than in the before-pandemic sample, but they had no relevance for stress. Establishing and maintaining social contacts seems to have become more difficult in times of the pandemic, presumably due to regulations and recommendations to restrict contact and by the self-imposed isolation due to the child's risk status. It has not been demonstrated that stress results from this demand. Apart from all the positive aspects, establishing and maintaining social relationships costs time and energy (Diewald, 1991). During the pandemic, the focus may have shifted to more pressing issues.

H4 could not be confirmed by the present results. Although family organizational demands were reported to be higher during the pandemic, they do not explain the increased stress levels of parents. In particular, due to the many ever-changing pandemic regulations, it could be difficult to organize family life, such as spending time together as a family. It may be that the immediate reward – family time together (Stadheim et al., 2022) – is worth organizing and therefore does not directly cause stress. For children with ASD, routine is an important

building block in daily life (Bagatell, 2015), so if it is well organized, the child also benefits and presumably their behavior reflects that.

In general, the results show that some increased demands during the pandemic led to stress and thus, according to the stress models mentioned above (Lazarus and Folkman, 1984; Abidin, 1992), resources appeared to be insufficient to cope with the demands. It needs to be investigated in subsequent research which resources exactly are overused in this context. Possible coping resources that have already been shown to be effective in the literature among parents to children with ASD, such as parental self-efficacy (e.g., Giallo et al., 2013; Weiss et al., 2013; Tröster and Lange, 2019), social support (e.g., Siman-Tov and Kaniel, 2011; Robinson and Weiss, 2020; Weiss et al., 2021), or functional coping strategies, such as active coping (e.g., Wang et al., 2013), should be taken into account in further research.

5. Limitations

Although propensity score matching was a step in the right direction toward comparability, there is no real longitudinal study available and the results should not be interpreted causally as such. For S2, no information is available on the stress level before the pandemic. Therefore, it is possible that the parenting stress or demands were already higher in S2 than in S1 before the pandemic. Nevertheless, the exploratory results ran important findings.

This study focused only on the general demands of the daily lives of parents to children with ASD as possible predictors for elucidating parental stress. Specific predictors directly resulting from the COVID-19 pandemic could have been included in the analyses. For example, the additional teaching role that parents had to take on during school closures. ACCORDING to previous studies, this appears to be a major challenge for parents and a potential stressor (e.g., Eckert and Kamm Jehli, 2021). In addition, the inclusion of heterogeneity and severity of ASD symptoms would be useful in future studies to provide a more nuanced view, as severity has an impact on parental stress, as shown, for example, in the study by Manning et al. (2021).

An important next step would be to use the influence of parental coping strategies and resources for clarification to allow a more comprehensive picture of reality. In general, stress research is always tainted with a negative view of the families studied. Therefore, resources of parents as well as resources of children with ASD should be focused on. Thus, not only challenges but also opportunities of the COVID-19 pandemic would be discussed. It could be assumed that children with ASD may also benefit from the changing conditions of the pandemic, such as being able to attend classes from home as a safe place (Nashef, 2020) or no longer having to sit on a stimulus-crowded school bus. Fumagalli et al. (2021) note that children with ASD report a more positive mood during the first few weeks of the pandemic compared to neurotypical children. Many children with ASD and their families may also benefit from slowing down their daily routines (Eckert and Kamm Jehli, 2021). In the study by Stadheim et al. (2022), some parents reported and valued a strengthened cohesion within their family during the pandemic. In the period after the pandemic, new structures in the home environment could be pursued. Empirical studies need to pick up here and investigate which factors are helpful for families to maintain this sense of cohesion. During the intensive time spent together throughout the pandemic, new structures were formed that many families would not want to miss (Pavlopoulou et al., 2020). In the post-pandemic period, the new structures in the home environment could be followed up. Empirical studies need to pick up here and investigate which factors are helpful for families to maintain these positive aspects.

6. Practical implications

In summary, the COVID-19 pandemic can be described as a time of crisis for parents to children with ASD. Both daily demands and parental stress were heightened. Studies show that families with members with ASD did not feel adequately addressed during the pandemic (Pavlopoulou et al., 2020). Support to reduce stress-inducing demands should first prioritize working with families. Child care support should be secured so that stress caused by personal limitations as well as the lack of opportunity to work on the partner relationship can be reduced. To mitigate reinforcement of the child's problem behavior, regular therapeutic support should also be available during a pandemic. Alternatives (such as online therapy sessions) have already been developed during the COVID-19 pandemic (Kaku et al., 2021). In addition to focusing on the increased demands themselves due to the pandemic, ways how these demands are handled should also be addressed since, among other reasons, it is sometimes difficult or impossible to address the demands directly (e.g., the pandemic containment regulations that cannot be influenced). Therefore, families should receive therapeutic guidance on how to cope with and manage the new or increased demands or consequences of the pandemic (e.g., how to repeatedly practice new routines with the child), so that they are prepared for future times of crisis (Stadheim et al., 2022). The question of which coping strategies work under which circumstances for parents to children with ASD for the pandemic-related demands so that they experience less stress should be empirically evaluated.

Data availability statement

The datasets presented in this article are not readily available because the data will be used for further analyses and publications. Requests to access the datasets should be directed to teresa.sartor@tu-dortmund.de.

Ethics statement

The studies involving humans were approved by "Gemeinsame Ethikkommission der Fakultäten 11–17 der TU Dortmund." The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

TS: idea for writing this manuscript, data collection S2, data curation S1 and S2, data analysis, writing and revision of the draft (lead). SS: data collection S1, data curation S1, and revision of the

draft. OK-H: project administration S2 and revision of the draft. HT: project administration S1, data collection S1, data curation S1, and revision of the draft. J-TK: supervision, project administration S2, and revision of the draft. All authors contributed to the article and approved the submitted version.

Acknowledgments

We would like to thank all parents who participated in our two surveys and shared their experiences. In addition, we would like to thank all the employees and cooperation partners (e.g., autism therapy centers) who supported us in the data collection. Last but not least, we would also like to thank the supporter of the first study "ELKASS" (German Autism Association and the ten participating autism therapy centers).

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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