Proposal number: 1351/24

**“I am all worn out, I can’t go on”: The underlying mechanisms of autism burnout and its relationship to depression and suicidal ideation and behavior**

**OR**

**Autism burnout: Underlying mechanisms and relationship to depression and suicidal ideation and behavior**

**Scientific abstract**

The term “Burnout”, which was previously used mainly in relation to vocations and parenting, has been recently used in autism research. Indeed, the term “Autism Burnout” (AB) is gaining recognition for its impact on individuals with autism spectrum disorder (ASD). AB is characterized by exhaustion, cognitive disruption, heightened autistic awareness, and withdrawal. However, the antecedents contributing to AB, its potential distinction from, and overlap with, depression, and associations with suicide thoughts and behaviors (STB) remain underexplored. This research seeks to address this gap by examining (a) differences and overlaps between AB and depression (b) how autistic diagnostic characteristics, camouflage of autistic traits, and autistic identity contribute to AB, and (c) the direct and indirect pathways between AB and STB.

The rationale for our proposed research is as follows: First, the new concept of AB is in its initial phases of research. Previous studies suggest communalities between AB and depression and call for differentiation between these terms. Second, autistic people experience various challenges due to their diagnostic characteristics, including their impairments in social communication, repetitive behaviors, and sensory processing differences. These characteristics may result in ongoing difficulties in both socialization and everyday life, and may therefore expose autistic people to elevated risk of burnout. In light of the diagnosis, autistic people may adopt different identities concerning their disability, namely autism identity (AI). While positive AI such as accepting and acknowledging the diagnosis allows better coping with autism related challenges, negative AI such as rejection and engulfment may pose psychological challenges which in turn may result in AB. Moreover, these autistic characteristics are often not well accepted or accommodated by society, which often result in attempts to camouflage one’s autistic traits. Such attempts may request ongoing efforts which may also contribute to AB.

Lastly according to our preliminary studies, AB may have an important contribution to the development of suicide ideation and behaviors, which are proven to be highly prevalent in autistic people.

To address our research questions, we propose a set of 3 studies. **The first study** is a mixed-methods study designed to explore how AB is experienced by autistic people, its prevalence and potential overlaps with and differences from depression. **The second study** is a quantitative study designed to examine what factors contribute to AB. We test the association between autism diagnostic characteristics (e,g,, social communication difficulties, repetitive behaviors, sensory sensitivity) and AB, as well the moderating role of autism identity and social camouflage in this relationship.

**The third study** is a longitudinal study designed to test the associations between AB and STB, and the mediating role of depression and sense of burdensomeness in this relationship. We use self-report questionnaires, structured and semi-structures interview to assess the study variables. Participants for the quantitative studies will include 200 high-functioning autistic adults. Participants in the qualitative study will include 25 autistic adults that have lived experience with burnout.

This is the first research to explore the underlying mechanisms of autism burnout and its relationships with depression and STB. Such knowledge may potentially set the ground for prevention of severe phenomena such as depression and STB in autism, therefore both helping autistic people and decreasing the overload of the mental health system.

\*We are aware of the variety of terms used in relation to “autism”. In this proposal we use the term Autism Spectrum Disorders (ASD) which is used in the DSM-5, and identity-first language.

**Research program**

**1. Scientific background**

Autism spectrum disorder (ASD) is a life-long, pervasive, clinically and etiologically heterogeneous, neurodevelopmental condition. Autism is characterized by impairments in social communication, repetitive behaviors, restricted interests, and altered sensory sensitivities. Symptom expression and functional levels of autism are significantly heterogeneous, including highly variable cognitive and language abilities (American Psychiatric Association, 2013). The prevalence of ASD has risen strikingly in the last two decades (Myers et al., 2019; Tchaconas, 2013). According to the world health organization, about 1 in 100 children has autism, (WHO- reference) and according to current reports by the Centers for Disease Control and Prevention (CDC), 1 in 36 eight-year-olds in the USA is diagnosed with autism (CDC, 2023). Autistic people experience various challenges across their lifespan due to their diagnostic characteristics, including their impairments in social communication, repetitive behaviors, and sensory processing differences.

Due to the characteristics of the disorder, autistic people face various social, emotional, and sensory challenges across their lifespan. Moreover, other people in the social environment are often unaware of their challenges and therefore they often face the need to function within an un-accommodating environment (Davis, 2016). Intensified autism diagnostic characteristics may, on the one hand, entail a greater gap between the environmental conditions and the individual's needs. On the other hand, the disability of high functioning autistic people may be transparent to others, which may result in ignorance of their needs (ref). In an attempt to deal with social norms and expectations, to avoid negative responses from others and to alleviate emotional strain, autistic people may try to 'act normally' and mask their autistic behaviors and differences (Bagatell, 2007, Mesa & Hamilton, 2022). This phenomenon is called social camouflaging. Social camouflaging has been shown to have benefits and costs (Allely, 2019). Although the function of social camouflaging is to integrate into social life and alleviate stress, research has also shown that camouflaging attempts are taxing in energy (Allely, 2019; Tierney, Burns & Kirbey, 2016). Thus, despite potential benefits to social integration, camouflaging can contribute to the depletion of coping resources, stress and mental health problems, and can result in autism burnout and identity confusion (Hull et al., 2021, Mandy, 2019, Tierney, Burns & Kirbey, 2016; Zhuang et al., 2023).

Identity in the context of autism entails unique issues concerning forming self-identity in light of the diagnosis. The concept of “autism identity” is based on the concept of “illness identity”, which is defined as the set of roles and attitudes that people have developed regarding themselves in relation to the illness they are dealing with (Oris et al., 2016; Yanos et al., 2010). Autism identity describes the degree to which autism is included and integrated into the person's sense of self, in an attempt to understand why some people with autism experience difficulties in daily coping, while others manage to face challenges that arise as a result of their autism (Lamash et al., 2023). Accepting and acknowledging the diagnosis allows better coping with the challenges arising from it and leads to better psychological and physical functioning (Karademas et al., 2009; Luyckx et al., 2010). Autism identity refers to four dimensions originally described by Oris et al (2016) regarding illness identity, two of them construct “positive autism identity” and two “negative autism identity”.

Positive autism identity includes “Acceptance” (the person accepts the autism as part of his identity alongside other social roles, without being overwhelmed by it), and “Enrichment (the autism enriches the sense of self and allows the individual to grow as a person). Negative autism identity includes “Rejection” (the autism is rejected as part of the person's identity and is perceived as a threat or unacceptable) and “Engulfment” (the autism dominates the person's identity, and invades for all areas of his life). Previous studies suggest that positive autistic identity is associated with higher self-esteem and better mental health (Cooper, Smith, & Russell, 2017).

In recent years, addressing the intense autism-related stress they experience, people from the autistic community have started to use the term “Autism burnout” (AB; Higgins et al., 2021; Raymaker et al., 2021). The term “burnout” is often used in the literature in relation to occupational burnout and parental burnout (Maslach, Jackson, Leiter,1996; Roskam, Brianda & Mikolajczak, 2018). Its new use in autism relates to overwhelming prolonged or intense stress, and the effort required to navigate a world that is not well-suited to their sensory, social, emotional, and cognitive needs (Higgins et al., 2021; Raymaker et al., 2021). The core characteristic of autistic burnout is exhaustion, while cognitive disruption, heightened autistic self-awareness and withdrawal are additional features of AB (Higgins., 2021).

Autistic adults are at disproportionate risk for developing depression compared to the general population (Hollocks et al., 2018). The pooled estimates of current and lifetime depression prevalence for adults with ASD are 23% and 37%, respectively (Hollocks et al., 2018). Symptoms of depression may include diminished interest or pleasure in activities, fatigue, energy loss, psychomotor slowing or agitation, as well as changes in sleep and appetite, sadness, feelings of worthlessness or guilt, and depression can sometimes result in suicidal thoughts (APA, 2013). Despite the partial resemblance between symptoms of AB and depression the mechanisms of both phenomena fundamentally differ. Specifically, AB is the result of an adaptive mental response to an overwhelming environment and its excessive demands. Whereas the AB symptoms of exhaustion and withdrawal disconnect the person from their environment to cease depletion of mental resources and enable rehabilitation, symptoms of depression reflect a pathological process in which withdrawal from the world and depressive affect result from a disproportional perception of threat (Beck 1979, 2002). Arnold and colleagues (2023) found AB sub-scales to correlate with overall scores of depression, but did not examine the correlations with sub-scales of depression and AB. It should be noted that the occupational literature also shows work-related burnout and depression to be associated but distinct concepts (Tavella et al., 2021; Tavella 2023; Verkuilen et al., 2021). However, due to the partial resemblance of symptoms and insufficient knowledge concerning AB, it can be misdiagnosed as depression. Given that optimal treatments of AB and depression are highly different it is crucial to differentiate between the two. For example, behavioral activation strategies effectively applied for treating depression (Cuijpres, Van Straten, & Warmerdam, 2007) are not suited for treating AB and may exacerbate the situation. Still, despite the mechanistic differences between AB and depression, the previous can transform to the latter or they can co-occur.

Accumulating research has shown that autistic people who are high functioning (HF) are at elevated risk of STB and death by suicide compared to the general population (Hirvikoski et al. [2016](https://link.springer.com/article/10.1007/s10803-017-3274-2%22%20%5Cl%20%22ref-CR24); Newell et al., 2023;). A recent meta-analysis found the pooled prevalence of suicidal ideation in HF autistic people to be 34.2%, and the prevalence of suicidal attempts and behaviours to be 24.3% (Newell et al., 2023). Hirvikoski et al. ([2016](https://link.springer.com/article/10.1007/s10803-017-3274-2#ref-CR24)) reported suicide to be the leading cause of premature death in HF autistic people and that this group has a 9.4 times greater risk of suicide compared to the general population. These studies highlight the urgent need for studying the mechanisms underlying suicidality in the autistic population. While depression is a well-known risk factor for suicidality both among the general population and autistic people (Cassidy 2014, Hedley et al., 2017), AB is a new concept in the autism literature and has yet to be explored as a risk factor for suicidality. AB may cause emotional distress and impair self-image over time, which directly or indirectly via depression may contribute to formation of STB. Notably, in the occupational psychology literature, exhaustion—the core symptom of occupational burnout—has been found to contribute to suicide ideation beyond depression levels (Oh et al., 2023). In addition, AB impairs functioning which may intensify a sense of being a burden for autistic individuals, who have an elevated sense of burdensomeness to begin with (Moseley et al., 2022). Indeed, sense of burdensomeness is a key risk factor for suicide ideation among autistic people and the general population (Joiner, 2005; Moseley et al., 2022). Thus, examining AB as a risk factor for STB in autistic people and assessing the potential direct and indirect pathways between AB and STB will help us to better understand the mechanisms underlying suicidality in the autistic population.

 **Limitations with existing studies**

1. Conceptual limitations: While there is evidence that autistic people are at risk of experiencing depression and STB, there is a lack of examination of the relationships between AB and these phenomena, and no study has provided a conceptualization of a potential pathway between AB and STB.

2. Insufficient focus on the concept of autism burnout: While the term burnout has been used in the literature in relation to vocational stress or parenthood challenges, it has only recently been used in the literature in relation to autism. As a result, research that addresses AB is scarce. Researchers therefore have not yet identified the prevalence of AB nor have they thoroughly investigated its antecedents and its consequences. Beyond understanding how burnout builds up among autistic people, and what the risk factors are for such build up, it is of crucial importance to assess its potential relationships with depression and its potential prediction of STB.

3. Methodological limitations: The few existing studies that address AB have been cross-sectional, and none of them include longitudinal design or prediction. As a result, important questions regarding the ways such factors may interact to impact the mental health and well-being of autistic people are left unanswered. The implementation of a longitudinal study will allow us to study predictive associations between AB and other factors.

**Research aims**

This research will include 3 studies with the following aims:

**Study 1 aims to explore the concept of AB, including examining (a) its prevalence in a sample of high functioning autistic adults, and (b) overlaps and differences between autistic burnout and depression symptoms.** Although the new concept “autism burnout” is theoretically distinguished from depression, some of the symptoms of the two concepts overlap while others remain distinct, thus we wish to test their similarities and differences. Furthermore, according to our preliminary results it is of high priority to distinguish the two as professionals may often confuse them, while treatment of AB and depression highly differ. To address this aim we will use a mixed-methods approach including both a quantitative and a qualitative study.

1.1 First, we will conduct a qualitative study in which we will explore the conceptualization of AB from the subjective perception of autistic adults. We will use in- depth interviews, which will allow learning from the lived experience of autistic individuals that have experienced burnout and/or depression and hear in their words if and how the two are similar, distinct, or connected.

1.2 Second, we will conduct a quantitative study will assess the prevalence of AB in a sample of autistic adults. We will then further explore overlaps and differences in sub-components of autistic burnout (exhaustion, withdrawal, cognitive disruption, heightened autistic self-awareness) and depression (depressive affect, somatic symptoms, positive affect, interpersonal relations).

**Study 2 aims to examine the association between autism diagnostic characteristics and AB, and the moderating role of autism identity and camouflage of autistic traits on the relationship between autism diagnostic characteristics and AB.** This study will assess autism diagnostic characteristics, as well as camouflage and autistic identity and their contribution to AB.

**Study 3 aims to explore the relation between burnout and STB in autism.**

The goal of this study is to explore the relationship between AB and STB, while looking at direct and indirect connections (via depression and burdensomeness) between AB and STB over time.

With these studies we intend to deepen our understanding of burnout among autistic people and to delve into the mechanisms of autism burnout and its relationships with depression and suicidal ideation and behavior.

**Expected significance of the proposed study**

We believe that the knowledge gained from the proposed research will promote positive autistic identity and awareness of autistic experiences among the autistic community, professionals, and the society in general.

First, these studies will deepen our conceptual understanding of AB, by exploring it from the point of view of autistic people and identifying its boundaries. This understanding can be used to validate the subjective experiences of autistic people and assist in bringing them into awareness. Such knowledge can also be translated into clinical guidelines for the differential diagnosis of AB and depression, which is critical as the therapeutic actions differ between the two. Second, the studies will shed light on potential antecedents of AB, i.e., factors that contribute to the buildup of burnout among autistic people and that are related to their core diagnostic criteria, autism identity, and camouflage efforts. This knowledge may have clinical implications: due to understanding and addressing the underlying mechanisms, clinicians may help to mitigate burnout among autistic people. Finally, the study will illuminate a unique and underexplored mechanistic pathway that puts autistic individuals at risk for suicide. Such understanding may help address AB as one of the factors to consider in suicide risk assessment and treatment.

Taken together, these studies will provide valuable knowledge to both autistic individuals and professionals working with autistic people. Such knowledge may be translated to inform suicide prevention, which may save lives.

**Working hypothesis and research questions**

**Study1:** Study 1(a) is a qualitative study that will address several research questions in an open ended manner: How do autistic adults experience AB? How does AB affect their mental health/well-being? How is the experience of AB similar to or different from depression?

In study 1(b) we will examine the prevalence of AB and the commonality with, and distinctions between, sub-components of AB and depression. Specifically, we hypothesize that:

H1: The subscale of AB-exhaustion will be strongly linked and overlapping with the subscale of depression-somatic symptoms.

H2: The subscales of AB-withdrawal and sub-scale of depression-social-problems will be strongly linked.

H3: The remaining subscales of AB, i.e., AB-cognitive disruption and AB-heightened autistic self-awareness, will not be strongly related to depression subscales.

H4: The depressive affect subscale of depression will not be strongly related to AB sub-scales.

Study 2: H5: Autism diagnostic characteristics, namely social communication difficulties, repetitive and restricted behaviors and interests, and hypo/ hyper sensitivity to sensory stimuli, will show a predictive association with AB.

H6: A higher tendency to camouflage autistic traits will moderate the association between autistic diagnostic characteristics and AB.

H7: Autistic identity will moderate the association between autistic diagnostic characteristics and AB. Specifically, positive autistic identity (awareness and enrichment) will have a buffering effect, whereas negative autistic identity (rejection and engulfment) will have strengthen the association between autistic diagnostic characteristics and AB.

Study 3: AB will have both direct and indirect (mediated via depression and sense of burdensomeness) connections to STB.

Fig 1. The proposed research by studies



**2. Research design and methods by study**

Because of the subjective nature of the constructs under investigation, we will investigate them through first-hand accounts rather than observations or caregivers’ reports, and we will use self-report measures and structured and semi-structured interviews. Although it is possible that autistic people with various levels of functioning may experience autism burnout and depression, only those who are cognitively able are capable of self- report. Moreover, the literature suggests that autistic people who are cognitively able are more prone to STB. Therefore, the current study will address autistic people who are cognitively able (i.e., ASD level 1). The main inclusion criterion for all studies will be a formal diagnosis of ASD, with no intellectual impairment, from a clinical psychologist or psychiatrist, according to DSM-5 criteria (APA, 2013). Proficiency in Hebrew will be required as well. Individuals with co-morbidities of psychosis or drug abuse will be excluded from the study. Participants will be recruited using advertisements placed on social networks and in relevant organizations, such as "Alut", "Asperger Israel", "Reim", and "Bait Ehad" centers.

Data for studies 1b, 2 and 3 will be collected together. Participants will be requested to complete a demographic questionnaire constructed specifically for this research.

***Study 1*** is a mixed-methods study designed to explore how AB is experienced, its prevalence, and potential overlaps with and differences between AB and depression symptoms. It includes a initial qualitative phase aimed at further unpacking the relatively new concept of AB, followed by a quantitative phase aimed at identifying the relationship between AB and the term “depression”.

Study 1a is an exploratory qualitative study designed to voice the lived experience of autistic individuals who have experienced AB. Twenty-five autistic adults will participate in in-depth, semi-structured interviews regarding their experience of AB.

**Measures**

*The Autism-Spectrum Quotient* (AQ; Baron-Cohen et al. [2001](https://link.springer.com/article/10.1007/s10803-020-04699-7%22%20%5Cl%20%22ref-CR8)*),* is an autism screener and has been translated to Hebrew. The psychometric properties of the Hebrew version have been examined, and it was found to be a reliable instrument for screening for autism (Golan et al., 2022). AQ quantifies autistic traits in adults and is used to define autism severity. The 50 items are rated on a 4- point scale. We will use the AQ to screen out people who are not autistic.

*Interviews.* In-depth, semi structured interviews autistic young adults will be used to investigate their AB experience, the extent to which it is similar or different from their depression experience, the factors they perceive as promoting or inhibiting AB, and how it affects their behaviors and participation in everyday life.

**Procedure:**

Participants will be recruited via social media and online autism community forums. The call for participation will invite formally diagnosed autistic people who have experienced AB. Following recruitment, autism diagnosis will be confirmed using The Autism-Spectrum Quotient (AQ), short form.

Interviews will be conducted by the researchers in a session lasting approximately one hour, by zoom or face to face according to each participant’s preference, and the location of the interview will be determined according to the convenience of the participants.

Interviews will be recorded and transcribed. Thematic analysis will be used to identify, analyze, and report key themes that emerge from the interviews.

Participants will receive gift-vouchers as compensation for their time.

Study 1b is a quantitative study that will examine the sub-categories of symptoms of AB and depression.

**Participants** will include 200 autistic adults (autism level 1) that are eligible to give consent. **Measures**:

*Autistic Burnout Severity Items* (ABSI; Arnold et al., 2023), a 20-item scale composed of four factors: exhaustion, withdrawal, cognitive disruption, and heightened autistic self-awareness, will be used to assess AB.

*The Center for Epidemiological Studies Depression Scale* (CES-D) (Radloff, 1977), a 20-item inventory comprised of four subscales (depressive affect, positive affect, somatic complaints, and interpersonal problems), that has been used with autistic adults (Kawai et al., 2023), will be used to assess depression.

**Procedure:** Participantswill be recruited via social media and online autism community forums. Following recruitment, participants will receive information about the study and will be asked to sign consent forms. Data collection will be done by zoom or face to face according to each participant’s preference. While participants fill-out self-report measures a member of the research team will be available to help clarify and answer questions. Participants will receive gift vouchers as compensation for their time. Members of the autistic community in Israel will serve as advisors on this project and will assist in recruitment and interpretation of results.

**Analytic strategy:** Exploratory Factor Analysis of the 4 subscales of ABSI and 4 subscales of CES-D will be utilized to explore subscales loading on factors. **Power analysis**: The sample size should be at least 20 times the number of variables: 8 x 20 = 160 (Price, 2016).

***Study 2*** is designed to examine the relationship between autism diagnostic characteristics (social communication difficulties, repetitive behaviors, and sensory sensitivity) and AB, and the moderating role of autism identity and social camouflage on this relationship. **Participants** will be identical to study 1b.

**Measures**:

*Autism Diagnostic Observation Schedule* (ADOS-2; Lord et al., 2012), which is viewed as the gold standard for the observational assessment of autism spectrum disorders (ASDs), is a semi-structured, standardized assessment instrument that includes a number of play-based activities designed to obtain information in the areas of communication, reciprocal social interactions, and restricted and repetitive behaviors associated with a diagnosis of ASD. The ADOS-2 contains five modules, each requiring 40–60 minutes to administer. Module 4, which is constructed for verbally fluent older adolescents and adults, will be used to assess Autistic diagnostic characteristics.

*The Camouflaging Autistic Traits Questionnaire (CAT-Q)* (Hull et al., 2019n), a 25-item scale, will be used to assess social camouflaging.

*Autism Identity Questionnaire* (Lamash and Meyer, 2022, adapted from the Illness Identity questionnaire (AIQ); Oris et al., 2016; 2018) is a self-report, 25-item measure, comprised of four dimensions (1) Rejection of autism as part of one's identity, (1) Engulfment - autism dominates the person's identity, (3) Acceptance of autism as part of identity alongside other social roles, and (4) Enrichment experiences due to autism as part of identity.

AB will be assessed in an identical way to study1b.

A **power analysis**, conducted with an anticipated effect size of 0.3, power level of 0.8, probability level of 0.5, and 8 predictors, showed a minimal sample size to be n=59. However, due to the requirements of study 3 a larger number of participants will be recruited.

**Procedure** will be similar to study1b. **Analytic strategy:** data will be analyzed using Multiple Regression Modeling, with AB as the predicted variable. Moderation analysis will be performed using PROCESS macro for SPSS Model 1 (Hayes, 2018). A simple slopes analysis will be used to test the significance of moderation effects.

***Study 3*** is a longitudinal study designed to test the pathways between AB and STB.

**Participants:** 200 HF adult autistic individuals (identical to study1b).

**Measures**: Depression and AB will be assessed using the measures mentioned in study 2.

*Columbia Suicide Severity Rating Scale* (C-SSRS; Posner et al., 2011) is a clinical rated interview which is comprised of 5 items assessing severity of recent suicide ideation and a section on suicide behavior during lifetime that has been already used in studies with autistic participants (Schwartzman, Muscatello & Corbett, 2023). It will be used to assess STB.

*The Interpersonal Needs Questionnaire* (INQ; Joiner et al., 2009), burdensomeness subscale, which includes 6 items, will be used to assess sense of burdensomeness. It has been previously used with autistic adults (Moseley et al., 2022).

**Procedure**: At baseline data collection is similar to study 1b. If the session is too long for any participants an additional session will be scheduled within the subsequent two weeks. For participants who have active suicidal ideation safety interventions will be implemented by PI JB and referrals for psychotherapy and/or psychiatry services will be provided. Participants will be re-evaluated at 6 months’ follow-up.

**Analytic strategy:** Structural Equation Modeling (SEM) will be used to examine the direct and indirect paths (mediated via depression and burdensomeness) between the observed variables of AB and STB. Levels of AB, depression and burdensomeness at baseline will be used to predict STB six months later.

**Power analysis** was conducted for SEM with an assumed effect size of 0.3, statistical power of 0.8, probability level of 0.05, with 43 latent variables (AB, depression, burdensome, STB) and 11 observed variables (see Fig 2). The minimum sample size required for the model is n=119. Considering expected attrition rates, and the need for a larger sample for study 1b, we will recruit 200 participants.

**Table 1.** Overview of proposed studies

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|   | Aim | N | Data collection method/Measures | Analytical approach | Baseline  | Follow-up |
| Study 1a | Lived experiences from autism community members | 25 | In depth interviewsAQ  | Thematic analysis | + | - |
| Study 1b | Overlaps and differences in symptoms of AB and depression | 200 | ABSICES-D | Factor analysis | + | - |
| Study 1 | Antecedents of AB  | 200 | ADOS-2CAT-QAutism Identity questionnaireABSI | Regression model | + | - |
| Study 3 | Examining the pathways between AB and STB over time  | 200 | ABSICES-DINQC-SSRS | Structural equation modeling | + | + |

\* Preliminary collaborations of the researchers with members from the autistic community helped shape this grant proposal, as the topic and the variables of focus in the current study were initially raised by our community partners. The current research will be conducted according to the community-based participatory research (CBPR) principals. That is, autistic community members will take part in planning and advising on how to carry out and interpret the study and its results.

Two community experts provided support letters for the current proposal and will serve as consultants throughout the study.

**3. Preliminary results supporting the rationale and feasibility of the proposed study**

Two recent studies provide preliminary results that form the basis of the current proposal. Neither of these studies have been published yet. Study 1 was the first Israeli survey on STB in autistic people. It included quantitative information about suicide ideation, suicide attempts, and seeking help among autistic adults without ID. The survey was developed with autistic community members. The Suicidal Behaviors Questionnaire-Autism Spectrum Conditions (SBQ-ASC; Cassidy et al., 2021) was used to assess suicide ideation and attempts, The Autism Quotient (AQ; Baron-Cohen et al., 2001) was used to evaluate levels of autistic traits. A total of 93 autistic adults ages 18 to 70 years (M=34.49, SD= 10.96) participated in this study. Results indicated that 96.8% of participants have experienced suicide ideation at some point during their lives; 67.7% reported having suicide thoughts during the past 12 months. See figure 3 for frequency of suicidal thoughts levels during lifetime. See figures 4 and5 for the frequency and duration of suicidal thought during the past year.

Two thirds of participants reported attempting suicide during their lifetime, and 4.3% attempted suicide during the past year. Forty percent reported disclosing STB to a family member or spouse, 35% reported disclosing to a friend and 44% reported disclosing to a professional. 15% reported they feared disclosing STB, and 5.3% reported they did not have anyone to tell.

Study 2 was a qualitative study that included 2 focus groups, each composed of 5 community members that are experts by personal experience. Groups discussed “what are important topics to study in the field of suicide prevention among the autistic community?” The community experts identified autistic burnout and camouflage to be two key factors that contribute to suicidal risk in autistic people, but which not enough is known about. It is therefore important that we study these factors. Several quotations from the participants in the focus group illustrate this theme:

“*Professionals who treat autism don’t know enough about autism, and don’t know anything about autistic burnout. They confuse it with depression, but it is different and it should be treated differently… it leads to suicide*” (M).

“*Understanding autistic burnout is important to suicide prevention as it can rapidly lead to suicidal thoughts. That’s what happened to me, I didn’t understand why I was so worn out and couldn’t go on. Connecting to the autistic community abroad … and learning about burnout saved my life*” (S).

“*So many autistics are burned-out… as the world is not well suited for us, on every level even the intensity of light and sound, so you are not sure if you have a place in this world, with your room being the only place you can control and that can really create a will to disappear from the world*” (E).

The preliminary findings from these two studies support for the feasibility and rationale for the proposed program of research. Study 1 demonstrates that members of the autistic community have an elevated suicide risk. However, we did not measure potential risk factors for suicidality such as burnout, autism identity, and camouflage. Study 2 pointed to AB as highly relevant to understanding suicide risk in autistic people.

|  |  |  |
| --- | --- | --- |
| Fig 5. Duration of suicidal thought among those who experiences suicidal ideation during the past year (n=58) | Fig 4. Frequency of suicidal thoughts among those who experiences suicidal ideation during the past year (n=58) | Fig 3. Frequency of suicidal thoughts levels during lifetime (n=93) |



**Ethical considerations**

Participants will be autistic individuals without intellectual disabilities, who are over the age of 18 and do not have a guardian. Identifying details, email addresses, and phone numbers will be kept separate from the data. We will use standardized questionnaires that have been widely used in previous studies. Furthermore, previous studies indicate that the assessment of suicide thoughts and behaviors does not have an iatrogenic effect on study participants (DeCouamp & Schumann, 2018). However, given the sensitivity of study 3 which assess STB, in case suicide risk is detected primary safety planning will be provided by PI JB who is a clinical psychologist and an expert in suicide prevention. Any participants deemed to be at risk of suicide will be referred to receive follow-up professional care.

**4. Available resources**

Dr. Benatov and Prof. Gal are researchers at the University of Haifa. Together they bring complementary expertise and knowledge to the current proposal. Both researchers have strong connections with the autistic community in Israel, and train and teach students who work with autistic people. Prof. Gal is an occupational therapist and an Autism expert. She heads the occupational therapy department and the Autism Laboratory at the University of Haifa. She has investigated sensory features, pain perception, autism identity, and repetitive behaviors in autism. She co-authored the Springer book “Repetitive and Restricted Behaviors and Interests in Autism Spectrum Disorders: from Neurology to Behavior” (2021). She has authored over 100 publications and has been involved in the organization of various autism conferences, and presentations. Prof. Gal has supervised numerous graduate students, most of whom have conducted research on ASD.

Dr. Benatov is an expert in mental health, depression, and suicidality. She is a faculty member at the department of special education at the University of Haifa, and is also a research fellow at Geha Mental Health Center. She is co-founder of the Collaborative Lab for Suicide Prevention among the Autistic Community and recently co-organized a conference on suicide prevention in autistic individuals held in Israel. In addition, Dr. Benatov is a clinical psychologist, experienced in clinical suicide risk assessment and psychotherapeutic treatment. She serves as a consultant and an instructor for the National Suicide Prevention Program in Israel. She has methodological experience in collecting and analyzing longitudinal data (Benatov et al., 2021). She has published 30 peer-reviewed publications and has given numerous conference presentations. Dr. Benatov is experienced in leading research teams and has supervised doctoral and master’s students.

Table 2. Timeline of the proposed research

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Pre-preparation: ethics approval and personnel recruitment and training | Data collection Study 1a | Data collection Study 1b, Study 2, and baseline of Study 3 | Data collection Study 3 follow-up and preliminary analysis | Analysis of all data, refinement of results and write-up of findings |
| Oct – Dec 2024 | Jan – Apr 2025 | May – Nov 2025 | until May 2026 (6 months follow-up from baseline)  | June – Oct 2026 |

 5. **Expected results and Pitfalls**

The study is expected to shed light on the newly-used term “autism burnout”, its relation to depression, its antecedents, and its contribution to STB. In the future, we expect to use this basic knowledge to develop a comprehensive theory of suicide risk in autistic people and apply it to the development of effective suicide prevention interventions for autistic people that targets constructs that are specifically relevant for this population.

As many of the study variables tap highly subjective concepts we will use self-report questionnaires. In order to address the potential challenges of completing sensitive questionnaires we will use standardized measures that have been used with autistic individuals in previous studies. To ensure that participants understand the questions a member of the research team will be present during data collection to assist and explain questions if needed. In addition, a post-doctoral researcher and a doctoral student who are experienced in working with autistic individuals will be members of the research team.

An additional potential pitfall is the longitudinal design in study 3, as some participants may drop out of the study between data collection points. To address this pitfall, the sample size will be larger than that required by power calculations. Moreover, we will contact participants telephonically to schedule meetings in person or via zoom for time 2. Lastly, compensation will be given upon completion of participation in the study.

\* The PIs connections with autistic community forums in Israel are mainly comprised of Jewish secular individuals, thus the study might not have a representative sample of religious-ethnic minority groups in Israel.

 References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed). American Psychiatric Association.

Allely, C. S. (2019). Understanding and recognising the female phenotype of autism spectrum disorder and the “camouflage” hypothesis: a systematic PRISMA review. Advances in Autism, 5(1), 14-37.

Arnold, S. R., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N. (2023). Towards the measurement of autistic burnout. *Autism*, 13623613221147401.

Arnold, S. R., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N. (2023). Confirming the nature of autistic burnout. *Autism*, 13623613221147410.

Bagatell, N. (2007). Orchestrating voices: Autism, identity and the power of discourse. *Disability & Society*, *22*(4), 413-426.

Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E: The autism-spectrum quotient (AQ): Evidence from asperger syndrome/high-functioning autism, malesand females, scientists and mathematicians. Journal of Autism and Developmental Disorders 2001 31:5-17.

Beck, A. T. (Ed.). (1979). *Cognitive therapy of depression*. Guilford press.

Beck, A. T. (2002). Cognitive models of depression. *Clinical advances in cognitive psychotherapy: Theory and application*, *14*(1), 29-61.

Benatov, J., Brunstein Klomek, A., & Chen-Gal, S. (2021). Bullying perpetration and victimization associations to suicide behavior: a longitudinal study. *European child & adolescent psychiatry*, 1-8.

Cassidy, S. A., Bradley, L., Cogger-Ward, H., & Rodgers, J. (2021). Development and validation of the suicidal behaviours questionnaire-autism spectrum conditions in a community sample of autistic, possibly autistic and non-autistic adults. *Molecular autism*, *12*(1), 46.

Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry*, *1*(2), 142-147.

Center of disease control (CDC). (2023). Autism prevalence higher, according to data from 11 ADDM communities. News release. CDC. March 23, 2023.

Cooper, K., Smith, L. G., & Russell, A. (2017). Social identity, self‐esteem, and mental health in autism. *European Journal of Social Psychology*, *47*(7), 844-854.

Cuijpers P, Van Straten A, Warmerdam L. Behavioral activation treatments of depression: a meta-analysis. Clin Psychol Rev. 2007;27: 318–26.

Davis, L. J. (2016). The disability studies reader. Routledge.

Gal, E, Yirmiya, N. (Eds). (2021) Repetitive and Restricted Behaviors and Interests in Autism Spectrum Disorders: from neurology to behaviour. Springer.

Hayes, A. F. (2018). Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach (Methodology in the Social Sciences) (2nd ed.). New York, NY: The Guilford Press.

Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C. (2017). Brief report: Social support, depression and suicidal ideation in adults with autism spectrum disorder. Journal of Autism and Developmental Disorders, 47, 3669-3677.

Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating# AutisticBurnout. *Autism*, *25*(8), 2356-2369.

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), 232-238.

Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological medicine*, *49*(4), 559-572.

Hull, L., Levy, L., Lai, M. C., Petrides, K. V., Baron-Cohen, S., Allison, C., ... & Mandy, W. (2021). Is social camouflaging associated with anxiety and depression in autistic adults? *Molecular autism*, *12*(1), 1-13.

Joiner, T. (2005). *Why people die by suicide*. Harvard University Press.

Joiner, T. E., Jr., Van Orden, K. A., Witte, T. K., Selby, E. A., Ribeiro, J., Lewis, R., & Rudd, M. D. (2009). Main predictions of the interpersonal psychological theory of suicidal behavior: Empirical tests in two samples of young adults. Journal of Abnormal Psychology, 118, 634 – 646.

Karademas, E. C., Tsagaraki, A., & Lambrou, N. (2009). Illness acceptance, hospitalization stress and subjective health in a sample of chronic patients admitted to hospital. *Journal of Health Psychology*, *14*(8), 1243-1250.

Kawai, H., Kishimoto, M., Okahisa, Y., Sakamoto, S., Terada, S., & Takaki, M. (2023). Initial Outcomes of the Safe and Sound Protocol on Patients with Adult Autism Spectrum Disorder: Exploratory Pilot Study. International journal of environmental research and public health, 20(6), 4862.

Lamash, L., & Meyer, S. (2022). Work-Related Self-Efficacy and Illness Identity in Adults with Autism. *International journal of environmental research and public health*, *20*(1), 122.

Luyckx, K., Duriez, B., Klimstra, T. A., & De Witte, H. (2010). Identity statuses in young adult employees: Prospective relations with work engagement and burnout. *Journal of Vocational Behavior*, *77*(3), 339-349.

Maslach C, Jackson SE, Leiter MP (1996). "MBI: The Maslach Burnout Inventory: Manual". Palo Alto: Consulting Psychologists Press.

Mandy, W. (2019). Social camouflaging in autism: Is it time to lose the mask? *Autism*, *23*(8), 1879-1881.

Mesa, S., & Hamilton, L. G. (2022). “We are different, that’sa fact, but they treat us like we’re different-er”: understandings of autism and adolescent identity development. *Advances in Autism*, *8*(3), 217-231.

Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., Cassidy, S., & Baron-Cohen, S. (2022). The relevance of the interpersonal theory of suicide for predicting past-year and lifetime suicidality in autistic adults. Molecular autism, 13(1), 1-17.

Myers, S. M., Voigt, R. G., Colligan, R. C., Weaver, A. L., Storlie, C. B., Stoeckel, R. E., ... & Katusic, S. K. (2019). Autism spectrum disorder: Incidence and time trends over two decades in a population-based birth cohort. *Journal of Autism and Developmental Disorders*, *49*, 1455-1474.

Newell, V., Phillips, L., Jones, C., Townsend, E., Richards, C., & Cassidy, S. (2023). A systematic review and meta-analysis of suicidality in autistic and possibly autistic people without co-occurring intellectual disability. *Molecular autism*, *14*(1), 1-37.

Oh, D. J., Shin, Y. C., Oh, K. S., Shin, D. W., Jeon, S. W., & Cho, S. J. (2023). Examining the links between burnout and suicidal ideation in diverse occupations. Frontiers in public health, 11.

Oris, L., Rassart, J., Prikken, S., Verschueren, M., Goubert, L., Moons, P., ... & Luyckx, K. (2016). Illness identity in adolescents and emerging adults with type 1 diabetes: introducing the illness identity questionnaire. *Diabetes Care*, *39*(5), 757-763.

Oris, L., Luyckx, K., Rassart, J., Goubert, L., Goossens, E., Apers, S., ... & Moons, P. (2018). Illness identity in adults with a chronic illness. *Journal of clinical psychology in medical settings*, *25*, 429-440.

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied psychological measurement*, *1*(3), 385-401.

Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., ... & Nicolaidis, C. (2020). “Having all of your internal resources exhausted beyond measure and being left with no clean-up crew”: Defining autistic burnout. *Autism in adulthood*, *2*(2), 132-143.

Roskam, I., Brianda, M. E., & Mikolajczak, M. (2018). A step forward in the conceptualization and measurement of parental burnout: The Parental Burnout Assessment (PBA). Frontiers in psychology, 9, 758.

Schwartzman, J. M., Muscatello, R. A., & Corbett, B. A. (2023). Assessing suicidal thoughts and behaviors and nonsuicidal self-injury in autistic and non-autistic early adolescents using the Columbia Suicide Severity Rating Scale. *Autism*, 13623613231162154.

Tchaconas, A. (2013). The Evolving Role and Nature of Gene Mutations in the Neuropathology of Autism Spectrum Disorders. *Columbia Undergraduate Science Journal*, *7*(1).

Tierney, S., Burns, J., & Kilbey, E. (2016). Looking behind the mask: Social coping strategies of girls on the autistic spectrum. Research in Autism Spectrum Disorders, 23, 73-83.

Tavella, G., Hadzi-Pavlovic, D., Bayes, A., Jebejian, A., Manicavasagar, V., Walker, P., & Parker, G. (2023). Burnout and depression: Points of convergence and divergence. *Journal of Affective Disorders*, *339*, 561-570.

Tavella, G. (2023). *Self-diagnosed burnout: an examination of its definition, symptoms, and relationship with clinical depression* (Doctoral dissertation, UNSW Sydney).

Verkuilen, J., Bianchi, R., Schonfeld, I. S., & Laurent, E. (2021). Burnout–depression overlap: Exploratory structural equation modeling bifactor analysis and network analysis. *Assessment*, *28*(6), 1583-1600.

Yanos, P. T., Roe, D., & Lysaker, P. H. (2010). The impact of illness identity on recovery from severe mental illness. *American journal of psychiatric rehabilitation*, *13*(2), 73-93.

 Zhuang, S., Tan, D., Reddrop, S., Dean, L., Maybery, M., & Magiati, I. (2023). Psychosocial Factors Associated with Camouflaging and Its Relationship with Mental Health and Well-being in Autistic and Non-autistic People: A Mixed Methods Systematic Review.