

DBT skill training for autistic adults with difficulties in emotion regulation; a feasibility study

Protocol: DBT skill training for autistic adults with difficulties in emotion regulation.

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Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition characterized by challenges in social interaction, communication, sensory sensitivities, and restricted, repetitive behaviors and interests (American Psychiatric Association [APA], 2013). ASD presents heterogeneously among individuals and is more prevalent than previously recognized. The Centers for Disease Control and Prevention (CDC) reported a significant rise in ASD prevalence, from 1 in every 2,222 children in 1968 to 1 in 44 children in 2020 (Maenner et al., 2020). This increase is attributed to evolving definitions, greater awareness, and methodological differences in studies (Zeidan et al., 2022). Notably, much of the recent rise in prevalence involves autistic individuals without intellectual disability or with minimal language impairments, often remaining undiagnosed until adulthood (Lord et al., 2022).

Undiagnosed ASD is particularly prevalent in adult clinical populations. For instance, a Swedish study found that 18.9% of psychiatric outpatients had ASD, with another 5-10%

exhibiting subthreshold symptoms (Nyrenius et al., 2022). Psychiatric comorbidity is common in ASD, with over 70% experiencing at least one psychiatric disorder and a prevalence rate well over 50% compared to the general population (Underwood et al., 2019). Common co-occurring conditions include anxiety, depression, ADHD, obsessive-compulsive disorder (OCD), bipolar disorders, and sleep-wake disorders complicating both diagnosis and treatment (Lord et al., 2022). Additionally, autistic individuals frequently engage in suicidal behaviors, non-suicidal self-harm, and aggressive behaviors, significantly impacting daily functioning (Lord et al., 2022).

Autistic women with without intellectual disability are often underdiagnosed because their symptoms can be less overt, and they may be adept at "camouflaging" their difficulties, mimicking socially acceptable behaviors, and suppressing autistic traits, leading to increased internal stress and delayed diagnosis (Bargiela et al., 2016; Livingston et al., 2019).

Misdiagnosis with personality disorder are common, in particularly misdiagnosing autistic women with borderline personality, with traits often observed in this population contributing to this risk (McQuaid et al., 2024).

Despite increasing diagnosis rates, there is a significant gap in evidence-based treatment options for autistic adults, particularly concerning comorbid mental disorders (Maddox et al., 2020). Many mental health clinicians lack adequate training to work with autistic adults and may avoid both assessing and treating them, while ASD specialists often lack expertise in treating co-occurring mental health conditions (Maddox et al., 2020). According to a report from the Norwegian Official Report committee published in 2020, many autistic individuals do not feel their needs for treatment and assistance are met. There are some structured treatment options available for autistic children and adolescence, and for autistic adults with

intellectual disabilities. There is a serious lack of treatment options for autistic adults without intellectual disabilities within the psychiatric hospitals in Norway (Paulsrød et al., 2020).

Emotion regulation difficulties are increasingly recognized as central challenges for many autistic adults. Shared mechanisms contributing to poor emotion regulation across clinical populations include physiological arousal and alterations in brain regions like the amygdala and prefrontal cortex, while unique mechanisms in ASD involve differences in information processing, cognitive rigidity, and disorganized emotion regulation (Cai, 2018; Mazursky et al., 2013). Autistic adults often struggle with alexithymia, exacerbating emotion regulation issues, and sensory sensitivities and social communication challenges can further trigger emotional dysregulation, necessitating targeted therapeutic interventions (Cai et al., 2018).

Emotion regulation difficulties in autistic adults can manifest as an inability to recognize, understand, and manage emotional responses, leading to maladaptive strategies and behaviors such as meltdowns, self-harm, violence, and avoidance. Developing effective emotion regulation strategies can significantly improve quality of life for autistic individuals (Cai et al., 2018).

Dialectical Behavior Therapy (DBT) posits that emotion regulation deficits are central to complex symptom presentations. Originally developed for patients with BPD who engaged in self-harm and suicidal behaviors, DBT teaches skills to recognize, modulate, and tolerate emotions effectively (Linehan, 1993). Full standard DBT has shown effectiveness in reducing self-harm and suicidal behaviors among autistic adults (Huntjens et al., 2024). While DBT does not, and should not, aim to cure autism, it can help autistic individuals develop skills to navigate their emotions, relationships, and crises, enhancing their ability to reach their personal goals and build a life worth living.

A feasibility and acceptability study of DBT skills training was conducted among autistic adults without intellectual impairment and suicidal ideation in community clinics in North Carolina, USA (Ritschel et al., 2022). However, similar studies have not been conducted in the Nordic countries for patients in outpatient psychiatric hospital settings. This study aims to evaluate the feasibility and acceptability of DBT skills training among autistic adults in Norway seeking treatment at a psychiatric hospital, incorporating adjustments from the previous USA study to suit the learning styles of autistic adults without intellectual impairment.

Primary objectives

1. If the DBT-skills training is relevant - The severity of difficulties in emotion regulation for the population, and the presences of destructive behaviour such as self-harm and suicide behaviour.
2. If DBT-skills training is accepted by tracking the dropout rate from DBT skills training, as well as the percentage of DBT-SUD skills sessions participated in, and the percentage completed homework.
3. Acceptability and Feasibility post treatment by evaluating participants' experiences with the treatment, and use of unhelpful and helpful strategies with self-rapport instruments.

Secondary objectives

1. Tracking the change in two target behaviours and four target emotions and use of skills in the treatment period with a diary card.

2. Assessing goals, hindrances, and resources at the start and completion of the DBT skills training, with a qualitative interview.

Study Design

This study is a mixed-method feasibility study without a control group. With measurements pre and post treatment intervention

To determine if implementing the intervention is feasible and acceptable, and to gauge potential benefits for future randomized controlled trials (RCTs), a traffic light system will be employed. "Green" will indicate that the progression criteria are met, warranting a full trial; "amber" will indicate that criteria are partially met, necessitating revisions before a full trial; and "red" will indicate that the intervention is not feasible, accepted, or safe, or that potential benefits do not justify proceeding to a full trial (see table 1).

Recruitment of participants:

Data collection

A convenience sample of 10 – 15 patients in the out-patient clinic in More and Romsdal hospital trust, Molde in Norway, that fit the inclusion criteria will be invited to participate in the project. We will collect data at the start of the treatment and in the follow up session in the 1-2 weeks after completion of skills training.

Inclusion criteria for the study:

- 1) Fit general inclusion criteria for the out-patient treatment at the clinic.
- 2) Have diagnosed autism, and pervasive difficulties in emotion regulation.

- 3) Speak Scandinavian (Norwegian, Danish and/or Swedish).
- 4) Manage to commit to participating in the DBT- skills training.
- 5) Be willing to sign the written informed consent.

General exclusion criteria for the study:

- 1) Have a clinically significant low linguistic functioning that hinders the patient in understanding and answering the questions on the self-report instruments.
- 2) Being actively psychotic.
- 3) Have a Body Mass Index (BMI) under 17.
- 4) Cognitive disability IQ <85

The intervention

The intervention period will be from April 2025 – October 2026.

DBT- skills is a group skills training component of Dialectical Behaviour therapy a comprehensive treatment focused on extensive difficulties in emotion regulation (Linehan, 1993). In this project, we will use the standard DBT skill-training model by Linehan (Linehan, 2014) with an addition of Autism specific interventions and adjustments (Ritchel et. al 2022). Every patient participating in the DBT skills training is assigned a DBT-trained therapist, for orientation, half-way evaluation and summary (3-5 sessions). While in skills training the participants will continue their standard out- patients treatment with their regular therapist (individual therapy, medication management).

The DBT-SUD Skills intervention consists of:

- 2-3 sessions with a DBT therapist focusing on treatment orientation – mapping the patients' goals, obstacles, and resources, DBT- hierarchy, and commitment.
- Skills training – 28, two-hour sessions – once a week. The skills consist of:
 - o Mindfulness 3 x 2
 - o Distress Tolerance x 7
 - o Interpersonal Effectiveness x 6

- Emotion regulation x 7
- One status and evaluation session half-way through the skills training.
- One summary session with a focus on goals reached and troubleshooting.

Two DBT therapists lead the group, and each group consists of approx. 4-6 participants.

Measurement

Demographics. Basic demographic information from the participants is registered. This includes age, gender, nationality, level of education, employment/support status, living situation, marital status, children, co-occurring psychiatric diagnosis, and medical status.

Cognitive disability.

Wechsler Abbreviated Scale of Intelligence (WASI) is a brief measure of general intelligence designed for use with children and adults between the ages of 6 and 89 years. The WASI requires approximately 30 min to administer the full test and 15 min to administer the abbreviated test. The full test consists of four subtests; Vocabulary (V) and Similarities (S) subtests combine to measure VIQ (verbal– crystallized abilities), and Block Design (BD) and Matrix Reasoning (MR) combine to measure PIQ (nonverbal–fluid abilities). The abbreviated test consists of two subtests, Vocabulary and Matrix Reasoning, which combine to assess general intelligence. WASI subtests are scaled in T score units ($M = 50$, $SD = 10$), and the IQ scores are scaled in traditional IQ– standard score units ($M = 100$, $SD = 15$). Four IQ scores are provided for the WASI and include the Full-Scale IQ–Four Subtest (FSIQ-4), Full-Scale IQ–Two Subtest (FSIQ-2), Verbal IQ (VIQ), and Performance IQ (PIQ) (Psychological Corporation, 1999).

Emotion regulation.

Difficulties in Emotion Regulation Scale 8 items (DERS-8) is a shortened self-report instrument, developed from the original DERS-36 meant to measure difficulties in emotion regulation (Gratz & Roemer, 2004). The DERS-8 consistist of 8 items prefaced with the phrase “When I’m upset,” to provide respondents with a uniform context that elicits thinking about situations requiring regulation of negative emotion; answers to items likely to represent

affect, thought, and actions in response to such situations. The scale offers a brief unidimensional measure of difficulties in emotion regulation for adolescents and adults. Items are scored on a 5-point Likert-type scale (1 = almost never (0–10%), 2 = sometimes (11–35%), 3 = about half the time (36–65%), 4 = most of the time (66–90%), and 5 = almost always (91–100%)). Scores (8 – 40) are summed to yield a total score. Higher scores indicate greater levels of difficulties in emotion regulation (Penner et al., 2022).

Aversive behaviours: Self-harm, Suicide behaviour.

Inventory of Statements About Self-Injury (ISAS) consists of two sections ISAS 1 that assesses lifetime frequency of 12 Self-harm behaviors performed “intentionally (i.e., on purpose) and without suicidal intent. Five additional questions assess descriptive and contextual factors (Klonsky & Glenn, 2009). Those endorsing one or more self-harm behaviour are instructed to complete the second section of the ISAS. The second section assesses 13 potential functions of the self-harm through 39 different statements: affect- regulation, anti-dissociation, anti-suicide, autonomy, interpersonal boundaries, interpersonal influence, marking distress, peer-bonding, self-care, self-punishment, revenge, sensation seeking, and toughness. Each function is assessed by three items Likert scale: “0-not relevant,” “1- somewhat relevant,” or “2-very relevant”. Thus, the scores for each of the 13 ISAS functions can range from 0-6 (Klonsky & Glenn, 2009). The functions of self-harm measured with ISAS show a robust 2 factor structure (Klonsky & Glenn, 2009). The instrument has been used in research among autistic adults (Newell et. al., 2024) and has been assessed for Norwegian population and found to have sound psychometric properties (Vigfusdottir, et. al, 2020).

Columbia-suicide severity rating scale (C-SSRS) is a suicidal ideation and behaviour-rating interview created to evaluate suicide risk. The interview consists of 10 categories with binary responses (yes/no) to indicate a presence or absence of the behaviour. The outcome of the C-SSRS is a numerical score obtained from the categories (Posner et.al. 2011).

Dropout from treatment:

Dropout is registered, and dichotomous variables are created (yes/no). In case of dropout, number of skills sessions is registered and the reason given for dropout.

Feasibility and acceptability

To measure acceptability, we register proportion of DBT-skills training sessions they participated in, the completion of assignments completed and frequency of use of skills registered on a diary card.

Participants Satisfaction Questionnaire is a self-rapport questionnaire developed to measure the satisfaction of autistic adults participating in DBT skills training (Ritschel et.al, 2022). The satisfaction is measured by answering 30 questions about: General satisfaction, satisfaction with the procedures, and Outcomes on different areas (social, emotional, Cognitive, self, behaviour, quality of life). The questions are answered on a 5 Likert scale with 1 = not at all, 3 = neutral, and 5 = very much. The scale was developed and used in research for evaluation of the feasibility for autistic adults (Rischel et. al, 2022).

Dialectical Behavior Therapy- Ways of Coping Checklist (DBT-WCCL) is a 59 item self-rapport questionnaire that Assesses both positive and negative methods of coping with stressful situations including problem-focus, seeking social support, blaming self, blaming others, wishful thinking, and avoidance as well as DBT skills use on 4-point likert scale: 0 = Never Used, 1= Rarely Used, 2= Sometimes Used, 3 = Regularly Used. The questionnaire is divided into 2 subscales: 1) DBT skills subscale that consists of Nine items represent emotion regulation skills, seven represent interpersonal effectiveness skills, five depict mindfulness skills, 19 represent crisis survival skills, two depict reality acceptance skills (0-114). and 2) Dysfunctional Coping Subscale that consist of 17 items referring to dysfunctional behavior in general along with items referring more specifically to blaming others (0-63). (Neacsu et al., 2010)

Qualitative interview guide – DBT skills training ASD (see attached Interview guide), focusing on the participants goals, hindrances and resources, and how they experienced the treatment interventions in relation to achieving these goals.

Adherence

Statistical analysis

To assess if adding DBT skills to standard treatment is relevant, feasible, accepted and potential benefits descriptive statistics will be provided. Descriptive statistics for demographic and psychological factors measured on a continuous scale will be reported in terms of mean or median value with appropriate measure of spread (standard deviation or quartiles) whereas the distribution of categorical factors will be reported in terms of proportions and percentages.

Ethics

Attending study is voluntary and requires an informed consent. Refusing participation in the study will not affect patient's access to other treatment. The participation is time consuming and demanding for the patient. There are number of potential benefits for participants in this project such as access to treatment that can lead to symptom reduction, less suffering, and greater quality of life. Benefits from participation are supposed to outweigh potential discomfort.

Data Protection: All data will be stored according to established protocols on data protection of More & Romsdal Health Trust. The data will be stored 5 years after the end of the project. The information will be stored in a de-identified manner. The scoring key will be stored separately in a locked cabinet at the outpatient at the DBT clinic ROBUST in Molde and only the authors (JV, RH and IG) will have access to it. All statistical analysis and use of data collected in this project will be done on a group level.

Strength and limitations

Strength: This is a feasibility study in naturalistic treatment, making the results generalizable.

The result of the study gives relevant information in a population that is often excluded from studies because of ASD diagnosis.

Limitations: With a lack of a randomized control group, one cannot measure the direct effect of the intervention.

Future research: If the intervention fits the progression criteria and proves to be relevant, feasible, acceptable, and of potential benefit for the patients, the future aim is to conduct a Randomized Control Trial (RCT) on the effect of DBT skills training for autistic adults with difficulties in emotion regulation.

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