

Findings Summary for Dissertation by Alicia Danforth, Ph.D.

Courage, Connection, and Clarity: A Mixed-Methods Collective-Case Study of MDMA (Ecstasy) Experiences of Autistic Adults

I. Overview

The purpose of this mixed-methods study was to explore how autistic adults experience the subjective effects of the drug 3,4-methylenedioxymethamphetamine (MDMA), which is also known as the street drug ecstasy, in nonclinical settings. The twofold goal was to document a comprehensive analysis of emergent themes from interviews and to highlight themes of clinical relevance to potential future pilot studies of MDMA-assisted therapy with autistic adults. Participants were asked to describe in detail what taking ecstasy was like for them. They were also asked about any changes they noticed after the experience. Was MDMA/ecstasy helpful? Was it problematic? Did taking MDMA/ecstasy result in long-term changes in attitudes or behaviors? Findings were presented as a collective-case study, in which multiple cases provided various perspectives for the purpose of increasing understanding of what MDMA/ecstasy use is like for autistic adults.

A score of 32 or higher on the Autism-Spectrum Quotient (AQ) was required as a screening measure for enrollment. Demographic data were collected through a secure, globally available website, and three self-report assessments of social orientation were administered (the Empathy Quotient, the Interpersonal Reactivity Index, and the Cambridge Friendship Questionnaire). Participants from 13 countries submitted data, including 100 MDMA/ecstasy-experienced individuals (76% males; 24% females) and a 50-participant MDMA/ecstasy-naïve comparison group (54% males; 46% females). Participants' ages ranged from 21 to 74 years.

In typically developing populations, MDMA has well-documented acute effects that promote prosocial attitudes such as caring, trust, and concern for the well-being of others. Findings from this study suggested that MDMA-assisted therapy may be an effective catalyst for intra- and interpersonal change in the broad domains of courage, communication, connection, communion, and clarity (mental and emotional). In addition, the majority of participants reported accounts of lasting transformation and healing after MDMA/ecstasy from conditions such as trauma and social anxiety that are common in autistic populations. No participants reported long-term adverse outcomes as a result of using MDMA/ecstasy. Qualitative findings supported a case for future randomized, double-blinded, placebo controlled pilot studies of MDMA-assisted therapy with autistic adults who present with social adaptability challenges.

II. Background

A growing body of research literature and testimonial accounts from autistic individuals, their family members, and allies assert that popular assumptions about affective experiences and an absence of empathy related to autism are inaccurate or invalid. The common perception that individuals on the autism spectrum do not experience empathy is incorrect. A more accurate assessment would be that their emotional and empathic experiences and processing are

qualitatively different from those of the neurotypical, or typically developing, majority. As a result, they often struggle with social relationships in ways that are distressing and which can become a source of ongoing struggle and isolation.

Research on the risks and benefits of MDMA has been controversial. Some studies indicate that excessive MDMA use or polydrug use including MDMA/ecstasy may result in *neurotoxicity* and cognitive impairments. However, MDMA/ecstasy experiences are also reported to amplify and enhance a sense of connection to others and to promote prosocial affect and behaviors. In 2010, researchers reported no evidence of adverse effects or outcomes from a clinical study of MDMA-assisted therapy for otherwise healthy participants with refractory post-traumatic stress disorder (PTSD). In addition, some studies suggest that other factors, such as sleep disruption, might contribute to temporary subacute effects such as lowered mood. The clinically important toxic effects of MDMA use have not been ruled in or ruled out. Therefore, a reasonable hypothesis to investigate in future studies would be whether or not limited MDMA-assisted therapy provided in a safe and structured setting could help some autistic adults increase social adaptability.

III. Methods Summary

Participants submitted quantitative data via online surveys and assessments after completing an online consent form. Individuals who self-reported that they were autistic and received a score of 32 or higher on the Autism-Spectrum Quotient were invited to complete a general research and demographic survey and three assessments: The Empathy Quotient, the Interpersonal Reactivity Index, and the Cambridge Friendship. Two groups of respondents were identified: 100 autistic individuals who had taken MDMA/ecstasy and a comparison group of 50 autistic individuals who had not.

Concurrent with survey and assessment data collection, 24 autistic adults who had the ability to communicate verbally in English and 2 third-party observers (a girlfriend and a best friend) participated in semi-structured interviews about their experiences with MDMA/ecstasy. Interviews were recorded and transcribed, and a technique known as *applied thematic analysis* was completed manually and with the aid of an online qualitative data analysis application (<http://www.dedoose.com>). Meaning units from the transcript text were cataloged in a codebook. Two independent, MDMA-neutral intercoders blind coded 17% of the transcripts without prior review of the researcher's draft codebook, and the codebook was revised as needed to reflect reviewer agreement.

The lists of the emergent metathemes, themes, and subthemes were finalized after the researcher completed three in-depth analyses of all transcripts over 11 months. Upon completing the interviews, statistical analysis was performed to compare the quantitative data from the two groups in order to determine whether or not there were potential correlations between MDMA/ecstasy experiences and scores on the quantitative assessments. All interviewees were invited to participate in a member-checking review of the qualitative findings chapter for accuracy, level of researcher respect, and appropriateness of the presentation. The six participants who returned feedback confirmed that the findings were presented in an accurate manner that reflected their experiences to their satisfaction.

IV. Key Findings

A. Quantitative Findings Summary

One disappointing outcome of this study was a lack of statistically significant findings from the four assessment measures. As a result, the integration of quantitative and qualitative data was not as robust as anticipated. This was the first study of its kind. Therefore, the researcher and the dissertation committee considered the administration of standard assessment measures which had been validated for an autistic population as a necessary component of the study design in the event that the outcomes showed significant differences between the two groups.

The only statistically significant difference between assessment scores of the MDMA/ecstasy-experienced group ($N = 100$) and the MDMA/ecstasy-naïve comparison group ($N = 50$) across all four measures was observed when an independent samples t-test was applied to scores for the AS. Mean scores for the MDMA/ecstasy-experienced participants were lower than those of the MDMA-naïve group, $t(148) = 2.61, p = .01$. This finding should not be interpreted to indicate that individuals were somehow "less autistic" after MDMA/ecstasy. Autism is a broad term to describe heterogeneous and pervasive neurocognitive differences. No data support the case that exposure to MDMA/ecstasy would change an individual's autism expression even if its use can support change in social domains. Many factors could have contributed to the difference between the two groups. Even though the data show a statistically significant difference, the correlation could be due to multiple factors other than exposure to MDMA/ecstasy. For example, were individuals with lower AS scores at baseline better able to make the social connections required to obtain MDMA/ecstasy? Without baseline data, trends toward lower AS scores after MDMA/ecstasy could not be measured or demonstrated.

Few options for assessment measures that had been validated for an autistic adult population were available to the researcher during the design phase of the study. After an extensive literature review, the four measures were confirmed as suboptimal for measuring MDMA/ecstasy-related change, but also as the best options for measures which had been validated for an adult autistic population available at the time. During data gathering, the researcher received frequent feedback from participants that was critical of the choice of measures. In hindsight, the researcher would choose measures more related to mood, anxiety, and quality of life as opposed to autistic traits.

One indication that trends toward increased social adaptability might be observed in a controlled study with MDMA-naïve participants who provided baseline data came from the scores of one participant who provided both pre- and post-MDMA data. He submitted his first data set when he had never taken MDMA/ecstasy, and then he submitted a second data set 14 days later after having a positive experience using MDMA/ecstasy in a recreational setting. The most notable change was observed in his IRI score, which increased from 51 to 67, indicating trends toward increased prosocial aptitudes in all four interpersonal skills domains measured. Interestingly, the IRI was the only instrument used in the study that was not developed specifically for populations on the autism spectrum.

Participants in the MDMA/ecstasy-experienced group were asked to indicate which items from a list of commonly reported acute subjective and physiological MDMA effects, if any, they recalled experiencing when they took MDMA/ecstasy. The acute effects selected were consistent with known effects for MDMA, and responses were consistent with the high level of confidence that participants reported that the substance they consumed contained MDMA. Two notable findings from the survey questions about drug effects were that **91% of respondents reported that they experienced “Increased Feelings of Empathy/Connectedness,”** and **86% indicated “Ease of Communication” as an effect of their MDMA/ecstasy use.**

Table 14 shows data about the intensity of reported effects on a 0-6 Likert-type scale. Positive effects (e.g., joy, openness, enjoying being touched) were reported as more strongly experienced in all examples; whereas, no participants reported strongly experiencing anxiety. Some of the more interesting data are found in the “0 = Did Not Experience column.” For example, only 2% of participants reported that they did not experience “feeling more emotions than usual, and only 2% indicated that finding it “easier than usual to talk with others” was not a feature of their MDMA/ecstasy experience.

As shown in Table 15, some participants reported sustained benefits from MDMA/ecstasy use in recreational settings. A notable finding was that **72% of MDMA/ecstasy-experienced participants reported “more comfort in social settings,”** and 12% indicated that the effect lasted for two or more years. Another positive outcome reported was that **78% of the MDMA/ecstasy-experienced group reported “feeling at ease in my own body”** as an effect, and 15% indicated that the effect lasted two years or longer.

A finding that might have particular relevance to establishing rapport with therapists in clinical settings was that **77% of the MDMA/ecstasy-experienced group reported that they found it “easier than usual to talk to others”** as an effect of taking MDMA/ecstasy, and 18% indicated that the effect lasted up to one year or longer. A final finding about the duration of effects that could have implications for psychotherapy for autistic adults was that 22% of the MDMA/ecstasy-experienced group reported “increased insight into own thought processes” that persisted for two or more years.

Despite the researcher’s multifold efforts to encourage participants to disclose negative outcomes and to provide balanced accounts of their experiences, the final dataset revealed an absence of reported moderate or serious, long-term adverse outcomes. The types of undesired effects and outcomes reported are listed in the subthemes column in Table 16.

Table 14

Intensity of Effects Autistic Adults Reported Experiencing During MDMA/Ecstasy

Effect	0--Did not experience %	1 %	2 %	3 %	4 %	5 %	6--Strongly experienced %
Increased insight into own thought processes	10	4	6	10	17	16	37
Joy	3	1	1	4	14	14	63
Feeling more emotions than usual	2	2	4	4	14	22	52
Getting a sense of how others feel	8	6	6	7	23	20	30
Anxiousness	39	21	20	12	4	4	0
Understanding why others feel the way they do	16	7	4	18	17	16	22
Openness	3	2	2	0	12	22	59
Feeling at ease in my own body	6	1	0	4	10	19	60
Enjoying being touched	8	3	2	6	9	18	54
Disappointment	63	16	5	4	5	2	5
Increased sense of humor	13	5	4	26	20	18	14
Easier than usual to talk with others	2	2	4	5	8	23	56
More comfort in social settings	3	3	3	6	11	18	56
Better able to discuss emotions	10	0	2	9	14	17	48
Easier to express affection	3	0	5	5	8	21	58
Pleasant body sensations	2	3	1	5	5	20	64
Unpleasant body sensations	41	33	14	6	4	0	2

Table 15

Duration of Effects Autistic Adults Reported After Taking MDMA/Ecstasy

Effect	Did not experience %	≤ 1 hr %	≤ 6 hrs %	≤ 1 day %	≤ 1 wk %	≤ 1 mo %	≤ 6 mos %	≤ 1 yr %	> 2 yrs %	Missing <i>n</i>
Increased insight into own thought processes	10.6	2.1	9.6	11.7	21.3	4.3	11.7	6.4	22.3	6
Joy	14.1	5.4	13	31.5	17.4	3.3	5.4	2.2	7.6	8
Feeling more emotions than usual	14.3	6.6	11	15.4	22	9.9	4.4	3.3	13.2	0
Getting a sense of how others feel	31.5	2.2	8.7	19.6	8.7	4.3	5.4	6.5	13.0	0
Anxiousness	35.2	11.0	11.0	12.1	17.6	3.3	4.4	0	5.5	0
Understanding why others feel the way they do	34.1	3.4	6.8	17.0	9.1	5.7	4.5	5.7	13.6	0
Openness	15.2	1.1	15.2	15.2	16.3	4.3	7.6	7.6	17.4	0
Feeling at ease in my own body	22.0	0.0	12.1	16.5	15.4	4.4	8.8	5.5	15.4	0
Enjoying being touched	31.1	4.4	25.6	10.0	5.6	3.3	5.6	3.3	11.1	0
Disappointment	55.1	3.4	2.2	12.4	11.2	3.4	3.4	1.1	7.9	0
Increased sense of humor	43.2	3.4	17.0	11.4	10.2	2.3	3.4	2.3	6.8	0
Easier than usual to talk with others	23.0	2.3	10.3	17.2	19.5	5.7	3.4	10.3	8.0	0
More comfort in social settings	27.8	0	14.4	17.8	11.1	6.7	4.4	5.6	12.2	0
Better able to discuss emotions	22.5	0	10.1	16.9	14.6	2.2	7.9	5.6	20.2	0
Easier to express affection	26.4	1.1	15.4	14.3	13.2	4.4	5.5	4.4	15.4	0
Pleasant body sensations	33.7	4.5	28.1	12.4	11.2	1.1	2.2	2.2	4.5	0
Unpleasant body sensations	51.1	4.5	11.4	14.8	11.4	1.1	1.1	1.1	3.4	0

III. Qualitative Findings Summary

The data sources for the qualitative findings included 24 interviews with participants presumed to be on the autism spectrum (aged 21-49), based on self-report and by meeting a threshold score on a screening measure. In addition, two supplemental interviews by third-party observers (a girlfriend and a best friend) were analyzed. The 90 free-response written accounts of MDMA/ecstasy use that were collected from survey participants were used for background purposes and were analyzed separately to minimize variability in the current data analysis. The goal was to provide an accurate and rich description of the entire data set, as opposed to identifying a few key themes in support of a predetermined theory or hypothesis. The researcher included extensive quoted content in the dissertation in an effort to keep the analysis as data-driven and as true to the participants’ voices as possible. There was no need for the researcher to “speak for” or “on behalf of” the participant coresearchers, who shared their accounts in detail and with apparent candor. A small sampling of quotes is included in this summary to provide a sense of how interview content was presented.

Table 16

Inductively Developed General Themes on MDMA/Ecstasy Use by Autistic Adults

Theme	Subtheme
Response Spectrum	Minimal Responders Moderate Responders Optimal Responders
Baseline vs. Normalcy	(no subthemes)
How Experiences are Described	Ineffable Figurative Novel Sudden Unexpected Serendipitous
Undesirable Experiences	Disappointment Difficulties/Distress Come Down Overwhelm Over disclosure

Qualitative findings were organized in two main categories. In the first category, themes related to the notable features of *how* participants described their experiences were examined. Examples of these features included degrees of response to drug effects, distinct and repetitive word choices, and patterns that occurred across multiple interviews. Inductively developed themes and their subthemes related to MDMA/ecstasy use that were not specific to clinical

considerations but provided insight into the qualities and relevance of the experiences are listed in Table 16. Review of this content was essential to the reader's fuller comprehension of the experience descriptions in the second category, which included analysis of three metathemes of particular clinical relevance: Change, Transformation, and Healing. Table 17 shows the three qualitative metathemes of clinical relevance along with their corresponding themes and subthemes.

[Note: Pseudonyms are used to identify all of the quoted participants in the following sections.]

MDMA/ecstasy as change catalyst. One of the three, foundational open-ended questions in the interviews was a prompt to reflect upon any changes that participants observed as a result of taking MDMA/ecstasy in nonclinical settings. A perennial question that is debated in psychology and psychiatry is which interventions promote true and lasting change. Thirteen percent of participants denied notable transient or persisting changes, in addition to the usual acute effects that they attributed to MDMA/ecstasy use. However, 87% of participants did report notable and lasting changes.

All interview participants were asked, "Describe what, if anything changed for you after your experience(s) with MDMA/ecstasy." Therefore, the high frequency of discussions about change and change-related topics was to be expected. Some of the responses were about non-specific change. For example, Begrimed responded, "I can tell it changed me in some way." Sylvan, age 24, indicated that his change was of significant magnitude, "I was so changed by that experience." George, also age 24, suggested that his MDMA/ecstasy-related changes were significant when he reported, "I've tried a lot of different other drugs and they affect you in different ways, but this was like sort of total fundamental change."

Meri, another 24-year-old, offered a figurative, before-and-after perspective on his change when he explained, "I considered myself a machine in terms of emotions. I tried very hard not to succumb to any emotions. I felt that it was a stupid, a foolish human trait that I was above. And MDMA changed that." He valued the expansion of his affective capacities: "It feels nice to be able to change as a person. It was not something that I was expecting very much. Again, for most of my life, I did not change."

MDMA/ecstasy as transformation catalyst. Transformation is the second of the three metathemes. For the purposes of this analysis, *transformation* was defined as a marked and lasting change for the better. To further distinguish transformative change from the other types of change discussed, an assumption was made that the change had a quality that suggested that the experiencer's life was altered in a meaningful and valuable way that was more or less permanent and pervasive.

One transformation-related theme was then-and-now comparisons that suggested a sort of metamorphosis into an evolved version of the old self or identity. Bi0drinx, age 33, reported that the "person I went with noticed the old me is definitely way gone and much more confident and happy." Sylvan, age 24, said, "I'm actually a totally different person since, well... I would say, yeah, since I did it." David, age 39, observed, "Comparing how I was and what I am now, there is a big difference."

The accounts of transformation were positive. No participants reported lasting harm or regression to a lesser state or deteriorated condition as a result of MDMA/ecstasy use. However, this trend may have been due to self-selection bias in favor of positive testimonials and outcomes. By staying close to the data collected, multiple examples of positive transformation were apparent. For example, Jules, age 32, asserted, “It's definitely helpful. It's definitely, my life would be very different if I had not had this experience.” Meri compared his former state of affective repression to his freer, transformed self: “For most of my life, I was very consistently depressed, and very much a hateful person. And I'm fairly certain that MDMA made me a very loving person.”

MDMA/ecstasy as healing catalyst. Healing was the third qualitative metatheme examined. MDMA-assisted change is not about curing or treating autism. The model of a spectrum can be helpful to conceptualize MDMA's potential as a healing agent in autistic populations. On one end, as the findings from data in this analysis suggested, MDMA has been shown to have the potential to support improvement of some clinical indications, such as enhancing therapeutic rapport, increasing affect regulation and coping skills, reducing defenses, increasing self-esteem, improving interpersonal skills, enhancing psycho-social well-being, and minimizing resistances to psychotherapeutic processes. On the other end of the clinical spectrum, MDMA-assisted interventions may be effective as adjunctive treatment for specific indications, including several *DSM* Axis I diagnoses, such as trauma and anxiety.

There was strong consensus among the majority of interview participants that MDMA has potential value as a therapeutic agent. The Mole, age 27, expressed his opinion that “there are things outside of, you know, the standard psychiatric catalog of chemicals that can help.” Furthermore,

I think there's a great benefit to be reaped from this chemical. . . I think a lot of people that [*sic*] suffer mentally, you know, with self-image problems, and stuff like that would benefit immensely. Especially people with Asperger's, and you know autism spectrum, and people that [*sic*] have trouble vocalizing. (The Mole)

Doc Star, age 35, acknowledged that MDMA/ecstasy had a novel anxiety-reducing effect for him:

The best I could say it, I think would be it was just a feeling of complete lack of anxiety and just love of everything that was happening, no matter what it was. Not being anxious about anything . . . I'm a fairly anxious person, so to have relief from it was kind of a . . . that was what led to such a powerful experience. So that was one of the reasons why it was so powerful was because it led to that state. I can't really say that there are many other things that have done that ever. (Doc Star)

Vincent, age 24, reflected on the therapeutic value he discovered from MDMA/ecstasy use when he said, “I can say for sure that doing MDMA and the psychedelic drugs have been a really important part in my life. That it really helped me to clear some things up, which I was doubting before.” Due to the healing from PTSD symptoms that she experienced after MDMA/ecstasy use with supportive partners, Isabeau, age 33, advocated for therapeutic use when she said,

It was used in the early 80s in couples counseling. So, I think it does make it a little easier to talk, a little easier to empathize with another person's point of view a little, so I think it can definitely enhance communication if used correctly and safely and not every night.
(Isabeau)

Finally, George, age 24, stated his belief about the potential therapeutic value of MDMA, "I genuinely think that administered at low doses this drug could be of real benefit."

A critical distinction to underscore in this summary was that no participants who contributed data to this study expressed a desire to cure, heal from, or eliminate autism. To the contrary, autism was described in some cases as an intrinsic and valued feature of the self. Some attributes of autism and Asperger's were discussed as disabilities and challenges pertaining to social difficulties. As per the findings summarized under the transformation metatheme, an important subtheme ("Still the Same Person") emerged from participant statements asserting the value of one's unique autistic attributes. Although some participants experienced major changes and underwent transformation, no participants reported no longer being autistic after or as a result of taking MDMA/ecstasy.

IV. Conclusion

The researcher hoped to expand general awareness of the autistic experience of MDMA/ecstasy. Findings from this study may be used to inform future studies with adults on the autism spectrum who may benefit from MDMA-assisted therapy that is integrated into a treatment regimen in support of improving social adaptability and comfort in social situations and in interpersonal relationships.

The researcher is a graduate of the Institute of Transpersonal Psychology (now Sofia University). Transpersonal research acknowledges the importance of honoring the full spectrum of human experience. In transpersonal psychology, individual and collective transformation are reciprocal processes. If individuals on the autism spectrum are excluded from full participation in transformative research, then the collective is diminished. Going forward, research teams will benefit from full inclusion of adults on the spectrum contributing data as participants as well as collaborating as members of research teams to refine and customize study design and methods to best meet the needs of autism communities.

Table 17

Metathemes, Themes, and Subthemes of Clinical Relevance

Metathemes	Themes	Subthemes
MDMA/Ecstasy as Change Catalyst	Courage	Decreased Barriers Reduced Inhibition Self-Acceptance Increased Sociability Increased Openness
	Communication	Talking Listening Eye Contact Body Language
	Connection	Clearer Boundaries Greater Intimacy Friends Family Romantic Relationships Sexuality
	Communion	Sharing General Empathy Understanding Feeling Unity

(continued)

Metathemes	Themes	Subthemes
MDMA/Ecstasy as Transformation Catalyst	Clarity	Metacognition Mental Clarity Insight/Epiphany/Revelation
	Peak Experiences Retention	Effect-related Utilitarian Memory Applied Learning
MDMA/Ecstasy as Healing Catalyst	“Still the same person”	
	MDMA-Assisted Psychotherapy	Couples Therapy Touch Exposure Music/Movement/ Dance Therapy
	Affect and Mood Improvement	Affect Awareness Alexithymia Improved Mood Problem Solving Optimism
	Clinical Indications	Trauma/PTSD Social Anxiety
