

Preventatives and Future Research Regarding Suicidality Among Emerging Autistic Adults

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Current trends in research on suicidal ideations (SI) among autistic emerging adults' will be reviewed regarding the risk factors and prevalence of SI in this population of individuals. What is the correlation between suicidal ideation among emerging adults with autism spectrum disorder? When the early diagnosis of autism is identified, this becomes a key component to the relationship of SI and this group of emerging adults. It also helps to bring about effective strategies of prevention and intervention to meet the needs of those in ASD category. Six scholarly quantitative research articles were reviewed relative to this correlation. The researcher will also conduct further investigation into preventative measures and future recommendations in the connection of SI and autistic adults.

In reviewing two of the scholarly articles, Zahid and Upthegrove (2017) as well as Moxon-Emre et al. (2022) furnished literary research, connecting the prevalence of suicidal thinking to co-morbidity with autism diagnosis while also bringing to light the biological markers that are associated. The third article, Cassidy et al. (2020) asserted that the SBQ-R and the interpersonal theory of suicide questionnaire must be adjusted specifically for the autism community. In doing so, the autism community will be able to provide a more accurate depiction of the risk factors as it relates to SI. The researchers of the fourth article Kirby, et al. (2019), took on a longitudinal study within the state of Utah, while researching control groups of ASD and non-ASD emerging adults over a five-year interval (2019). Their recent discovery was that ASD females had a higher propensity of committing suicide because of differences in gender characteristics. The last two articles, Cassidy, et al. (2021) and Burghardt and Bodansky, (2021), examined why theory-driven research should be utilized and specifically for the future of more

effective research in the connection of suicide and the thoughts of suicide among these special needs' young adults. They also expressed how the SBQ-ASC assessment tool (2021) is one in which future researchers should consider.

Characteristics of Autism Spectrum Disorder

Analysis of the characteristics of this neurological disorder should be observed to better inform the literature review. The criteria of autism in a young adult includes repetitive or challenging behaviors according to Cassidy, as well as social communication deficits such as lack of social skills and interests as stated by Zahid and Upthegrove (Cassidy, et al., 2020, p. 3447; Zahid and Upthegrove, 2017, p. 237). Nonetheless, the Diagnostic and Statistical Manual of Mental Disorders, Edition 5 (DSM-V) more clearly defines features of autism as “Deficits in developing, maintaining, and understanding relationships...total lack of facial expressions, nonverbal communications...reduced sharing of interests, emotions or affect” (2017, p. 50). Social deficits are most prevalent among the autism community including alexithymia and rumination. Emotional connectedness is very difficult in this regard and many autistics are not able to convey their personal emotions and specifically in social situations, hence the term alexithymia. Additionally, these individuals repeat thoughts regarding feelings of failure in their minds especially when confronted with a social situation that is overwhelming for them. This character trait of rumination would be an example of an autistic person who internalizes their failure of fitting into a social gathering with a persistent feeling and thought such as, “Why am I such a failure?” Overall, the constant pressures and high levels of stress in social situations create a whirlwind of hopelessness in which SI/S takes center stage.

Biological indicators

Regarding prevalence, the biochemistry of the brain was indicated as the researchers assessed the sample studies of both autistic and non-autistic control groups. The biological interactions in the brain of an ASD person apparently are indicative of chemical disruptions or disturbances as proposed by (Moxon-emre, et al., 2022, p. 2) and was found to be a significant indicator of SI and suicidality in their study. This significance stems from an imbalance involving Glutamate (Glu) excitatory neurotransmission and metabolism as well as N-acetylaspartate (NAA) which can be converted into glutamate and in which both NAA and GLU converge (Moxon-Emre et al., p. 2, 2022). They hypothesized that this neuronal exchange affects ASD young adults with suicidal thinking (SI) more so than those who did not have these thoughts. The researchers who conducted their study selected a small sample group of thirteen participants with suicidal ideation (SI) and fifteen participants who did not have SI. Interestingly, they looked within the dorsolateral prefrontal cortex (2022) and measured activity between NAA and GLU. Their results concurred with their hypothesis that this biological exchange is indeed a factor to consider since those who did not have SI did not have a higher NAA/Glu indicator as their counterpart. "Participants in the SI group had higher NAA/GLU ratio than participants in the SI-group" (Moxon-Emre et al., 2022, p. 3).

Risk factors

Equally important, the researchers asserted other risk factors contributing to high risk of SI among this population. Zahid & Upthegrove (2017) found that comorbidity, agitation, depression, and history of suicide attempts were among the markers of risk. In their sampling study, 94% of their 2,651 participants had at least one psychiatric comorbidity disorder (2017) but all participants presented with depression. However, in the study of Cassidy, Thwarted Belonging and Perceived Burdensomeness were measured with the Interpersonal Theory of

Suicide (ITS) model, and their results confer that emerging ASD adults attempt to hide their awkwardness in social situations; therefore, experiencing an increase in thwarted belongingness and suicidality (Cassidy, et al., 2020, p. 3447). To put it simply, ASD young adults perceive themselves to be a burden and fall to the pressures of blending into the “normal,” social expectations. Interestingly, the researchers of the longitudinal study in the state of Utah focused on suicide *death* during a twenty-year span and five-year intervals (Kirby, et al., 2019, p. 663). What they found was an increase of suicide death among females between the years 2013-2017 (2019, p. 661). These researchers share their opinion that “...females may feel the need and can ...cover-up their autism symptoms [which]... are significantly associated with suicidality in ASD” (Kirby, et al., 2019, p. 663). Their discovery proved to coincide with the previous research of Cassidy, et al. that individuals with ASD tend to “camouflage these in order to fit in social situations, which is associated with increased feelings of thwarted belongingness and suicidality” (Cassidy et al., 2020, p. 3447). Because ASD young adults grapple so much with areas of hopelessness when struggling with social pressures and the biochemical exchanges spoken of previously, suicidality/suicide becomes a very real tragic possibility for them.

While the researchers in this literature review expanded on the relationship of suicide and ASD in their findings, there is room for growth for future research regarding prevention strategies. Firstly, there should be an increase towards longitudinal studies in this community of individuals which will help to bring about information that is more accurate and reliable as opposed to short term research with a smaller sample study. For example, Kirby, et al., (2019), conducted their twenty-year study in the state of Utah. It spanned between 1998–2017 and what they found was that there was a gradual increase of suicide ideation and suicide, specifically among females who succumbed to suicide between 2013-2017. Thus, the other literature articles

opted to study through pilot, convenience and community samples which are of a smaller population and brief. Moxon-emre, et al., (2022) confirms their research was limited stating, “the convenience sample reported on here was small (n=28), thus we did not evaluate the potential role of key demographic and clinical characteristics...on our NAA/Glu finding.” (Moxon-emre, et al., 2022, p. 5). Secondly, while the quantitative study was rich in information and research with its questionnaires and surveys, there could have been more theory-driven research overall. One can see the effort on Cassidy, et al., (2020) as they researched through the model of Interpersonal theory of suicide (ITS) which is a theoretical model, however they themselves remarked that current trends of research are limited, stating, “...research exploring self-harm, suicidal thoughts and behaviors in autism has tended not to be theoretically driven” (Cassidy, et al., 2020, p. 3447). Thirdly, there are no specifically tailored assessment tools to assess SI/Suicide more accurately among autistic young adults. For instance, Cassidy, et. al., (2020) stated that “autistic adults ...reported difficulties interpreting and responding to the SBQ-R (Suicide Behaviors Questionnaire -Revised) items, due to difficulties with abstract questions, complex language and response options, and lack of items relevant to autistic people’s unique experience of suicidality” (Cassidy, et al., 2020, p. 3446).

Methods

It is because of these factors that the researcher would like to conduct a further study on preventative strategies that were not readily researched from the previous readings. The key component in this endeavor is to provide prevention strategies that are specifically tailored to this population. Part of the issue is when there is a delay in diagnosis. According to Cassidy, et al., autistic people who have experienced delay in autism diagnosis until adulthood show the highest estimates of lifetime suicidal thoughts (66%), and suicide attempt (s) (35-36%) (2021). This is

alarming and a call to aggressive early intervention is required. A preventative could be stronger support systems put into place within pre-school and kindergartens where an early diagnosis can be detected. Nonetheless, future research would entail a greater focus on theory-driven research which is more precise in its method of research. Current and future research as it refers to the topic, can yield results that are marred in nonspecific, vague, and disingenuous results that can hurt the public because of practices that are more novel and explorative as opposed to theory driven. Researchers Burghardt and Bodansky (2021) asserted that "...we must drop the innovation requirement for theory-driven and instead require the strongest methods which are marked by high internal and external validity" (Burgardt and Bodansky, 2021, p.1). The writer would be sure to research the past theoretical underpinnings of the said topic through scientific methods so that there will be greater accuracy in the information found and in which other researchers will be able to replicate.

Secondly, the future researcher will include both cross-sectional and longitudinal studies that will target 18 – 29-year-old ASD adults/general population along with families of toddlers in longitudinal quantitative research. Cross-sectional integration will include non-abstract questions and visuals that the autism community can understand, helping them to answer more accurately. The benefits of this are that cross-sectional data will be less costly and yield immediate results. Longitudinal studies will also assist in preventing underdiagnosis of autism and the high prevalence of suicide among this population. Although longitudinal studies are more expensive and long term, grant money will be focused on and will include fundraisers, donations and partnerships with stakeholders who have common interests and who would invest in furthering research. As an example, OPWDD has offered to match the donations of the public up to 50,000 in the upcoming fundraiser Autism walk event here in New York City in the month of June 2023.

Lastly, proposed future research will include assessment tools that bring clarity and language that the autism community will readily understand and be comfortable in answering. Cassidy, et al., (2021) confirms this by stating that a key issue in suicidality in autism research is the lack of measurement tools available to assess and compare suicidality and associated risk markers between different groups. These assessment tools will include further refinement of the current SBQ-ASC as well as surveys such as visual components, a larger selection of choices that are simplified and items that will be more relevant relative to the ASD communities' experiences of suicidality.

Research Proposal

Hypothesis

Through this research proposal, the hypothesis that will be addressed is that an increase of preventative strategies will bring a decrease of SI/S among emerging autistic adults. It is vital that future research in support of preventative measures be expounded on regarding the high risk of SI/S among this population or we run the risk of our children and our special needs community dying silently and not being able to express their covert behaviors leading to their death. When the preventatives that are spoken of are put into place, professionals for the special needs community will be better equipped to confront and stabilize individuals on the spectrum through early intervention, tailored social supports and assessment tools. Additionally, this research takes into consideration the ethical principles that must encompass sound, reliable and accurate study of volunteer participants. The researcher must ensure that the cultural environment of each participant is understood and incorporated in the studies proposed. This will be done by acknowledging the beliefs, values and concerns of the autism community and their families.

Variables

Preventative strategies will be the independent variable, and suicidality will be the dependent variable. Preventative strategies will be measured according to the tools that will be used to collect data. These strategies, as spoken previously, will further investigation into the *why* of SI/S in this population. There will mostly be a focus on early intervention research among the younger group of children because of past research into the high risk of SI/S among undiagnosed ASD individuals.

Participants

Participants in this research design proposal are autistic emerging adults/non-autistic adults between the ages of 18 – 29 years old. In addition, and because of further longitudinal research, research will begin through early intervention and research of autistic toddlers starting from the age of two. Autistic tendencies among individuals can be observed as different branches connected to a tree and in keeping this point in mind, the proposed studies will consider the different personalities/characteristics of each ASD individual as well as demographics. They are of a variety of nationalities within the New York State region and will be pooled from day habilitation programs and residential settings. The pool of participants will consist of 800 male and female individuals. Four hundred of these individuals are diagnosed with Autism while the other 400 are non-autistic. The researcher will also study 20 longitudinal study participants over a period of eighteen years. The researcher is working in conjunction with the New York State Office for People with Developmental Disabilities (OPWDD). OPWDD will show their support by assisting with the contact information for the autistic individuals receiving services including email addresses. Non-autistic adults will be chosen through public arenas such as college campuses and local mall settings in verbal interactions. Through voluntary willingness to

participate, both autistic and non-autistic consent forms will be delivered via email. Our computer program then divides both groups into two.

Instruments Used

As the cross-sectional/longitudinal studies are under way in this proposal, scales and questionnaires will also be utilized. Both aspects will engender early intervention preventative strategies along with social and family supports that are aggressive and consistent. In this interim, scales and questionnaires will be used for the other participants between the ages of 18 – 29 years old. In comparing stress levels, the autistic/non-autistic emerging adult population will be evaluated using the Stress and Adversity Inventory for Adults (STRAIN). Several classifications of stressors will be studied such as work, life, marriage, family, etc. There is a recognition that this inventory considers levels of stress between the two populations which contributes to SI in ASD adults and that the ASD community will [have] greater stressor exposure and severity than do non-autistic adults (Mosely, et al. 2021). The key factor in suicide prevention is to be able to have the ASD individual convey their covert behaviors that contribute to SI/S, hence, the UCLA Scale. The UCLA Loneliness Scale will be used for both populations in which participants will rate 20 statements such as, “I feel withdrawn and separate from other people.” (Mosely, et al. 2021, p. 559). This scale will help to assess in what way prevention can be tailored. It has also considered the social isolation and loneliness that autistic individuals struggle with. Additionally, there will be a Social Behavior Questionnaire given to the non-verbal Autistic community that will further pinpoint social deficits. This questionnaire consists of 40 yes or no questions that are simple to understand and in which visuals are provided.

Procedures

Data collection will be over a two-month time frame in which participants have completed the questionnaires and scales. As indicated earlier, participants will be contacted via email and the questionnaires and scales will be conducted through a link that will be provided for them via email. Consequently, it will be expressed to each participant and caregivers, that their names will be kept anonymous, and their information will not be distributed to third party solicitors.

Limitations

There are a few limitations that one can consider regarding this research. Firstly, the researcher understands the expenses incurred through a longitudinal study. This study will be over a span of eighteen years in which cost will be a factor apart from OPWDD matching donations. Secondly, since cost would be a factor, the sample study of just 20 participants is understandably small. Future research should entail a sample study of a larger group to ensure the accuracy of data collected. Thirdly, this will be the researchers first time in experiencing scientific data collection and therefore the process of the methods that will be used may be flawed in some way. Lastly, the participant pool is in the New York City area and is strictly delegated to this region and because of this narrowing of location, results may be limited in scope.

Implications/Contributions to the Field

The research to be conducted sheds some light on preventative tailored strategies as possible considerations regarding SI/S and ASD emerging adults. Past research has indicated a high risk of SI/S among the Autistic population – those diagnosed and those not diagnosed until adulthood. The questionnaires, surveys and inventories used all show results of high potential however, preventative measures were not researched further, hence this proposal. Further

research in support of prevention will bring strategies to help families who are going through the emotional upheavals and social deficits of this neurological disorder. The assessments conducted through the longitudinal studies are pivotal in understanding the covert behaviors through the different developmental stages that an Autistic individual progresses through in age.

Another consideration is that the long-term study will prevent an individual from being undiagnosed later in adulthood and succumbing to suicide. On the other hand, in the five-year interval of a twenty-year study, Kirby, et. al, found that individuals with ASD succumbed to suicide with an increase over the twenty-year period (2019) in which 49 of them died. In either factor, an increase in these long-term studies is necessary.

Direction for Future Research

Further testing into this population of autistic and undiagnosed individuals with SI should be considered because of the generalizability of this research regarding preventative strategies that were mentioned. The researcher would suggest expanding research into both quantitative/ and qualitative research. Exploring both aspects of the research design will bring specific and accurate data collection that take into consideration not just a broad picture of the relationships between the two variables but also the phenomenology of participants, case studies and interviews that will help put language to the data collected. Additionally, the bias that can alter surveys and questionnaires through participants, can be focused on by future researchers as they go out into the field to conduct participant interviews. Lastly, theoretically driven research, as a sounder research platform, should be considered. Theoretically driven methods will allow for future researcher's confidence to conduct evidence-based research that is sound and accurate.

Conclusion

The research proposal seeks to answer the hypothesis that the increase of preventative strategies will bring a decrease of SI/S among emerging autistic adults. One can consider the findings of the researchers in these articles and understand that ASD young adults have many pressures and biological components which create depression and SI or the unfortunate act of suicide. Most importantly, many individuals have yet to be diagnosed with ASD leading to a late diagnosis in adulthood. By then, these individuals are at greater risk to succumb to the very act of committing suicide and specifically if they are female. This proposal seeks to further test this population with non-autistic individuals through longitudinal studies, scales, surveys, and questionnaires. Future research must further considerations of how best to assess for early diagnosis which will lead to tailored prevention and intervention of the autism community and the decrease of SI/S in future findings.

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