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Brief Report

Opinions on Youth Suicide Risk Screening from Individuals with Neurodevelopmental Disabilities and Their Therapists: A Pilot Study

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Abstract: Background: Individuals with neurodevelopmental disorders (NDD) are at increased risk for suicide, yet little work has been done to address the specific needs for this population. Specifically, there are no validated suicide risk screening instruments and processes for individuals with NDD; this study aimed to assess the opinions of individuals with NDD and their therapists on suicide risk screening in order to inform best practices for screening. Method: A pilot study was launched to qualitatively evaluate processes and instruments that may be used in future studies on suicide screening risk in NDDs. Participants and their therapists were surveyed after filling out suicide risk screening instruments and provided qualitative feedback on their opinions of screening for suicide risk. Results: Most participants (9/15) reported positive experiences of being screened for suicide risk. Additionally, almost all therapists (14/15) were in support of suicide risk screening. Several themes, such as interpersonal benefits, emerged as reasons for supporting screening. Conclusions: The findings from this pilot study provide initial qualitative evidence that many individuals with NDD and their therapists would be comfortable with and are in support of suicide risk screening for this population. Screening tools to guide clinicians on how to ask about suicide risk are needed and appear to be desired by clinicians on the frontlines of mental health treatment for people with NDD.

Keywords: suicide risk screening; neurodevelopmental disorders

1. Introduction

Over 60% of individuals with neurodevelopmental disorders (NDD) have at least one comorbid mental health disorder [1], including a high rate of mood disorders [2]. Relatedly, individuals with NDD are an often-overlooked group at high-risk for suicide [3]. Progress has been made in validating brief suicide risk screening tools for the general population, however, individuals with NDD are routinely and systematically excluded from instrument development and validation studies [4], creating a gap in research on suicide risk detection among NDD populations.

Due to the presence of common symptoms of NDD (e.g., perseverative thinking) or the presence of intellectual impairments (e.g., difficulty with abstract thinking) suicide risk screening for this population may require specific wording and methods of screening delivery. Additionally, many clinicians have concerns about the iatrogenic risk of asking

about suicide, a myth that has been disproved in typically developing cohorts [5]. However, iatrogenic risk remains a concern for neurodevelopmentally challenged populations due to perseveration as a common symptom of NDD [6].

Given the unknown challenges associated with screening for suicide risk among individuals with NDD, there is a need to determine how screening is viewed among both individuals with NDD and their therapists. Recent research on clinician beliefs towards suicide risk screening with individuals with NDD revealed that clinicians felt less confident in their ability to screen their clients with autism for suicide risk, which may be in part due to a lack of screening tools that are validated for this population [7].

Prior to efforts to implement suicide risk screening on a large scale for this population, we sought to investigate the perspective of individuals with NDD, as well as their therapists, on screening. A pilot study in a specialized mental health clinic was initiated with the aim of obtaining preliminary qualitative data on individuals with NDD and therapist opinions of suicide risk screening.

2. Materials and Methods

2.1. Participants and Procedures

The current study collected qualitative pilot data as a pilot study for a larger instrument development study to test the Ask Suicide-Screening Questions [8] (ASQ) and additional candidate items in a sample of individuals with NDD. The sample included youth and adults receiving services at Surrey Place, a community mental health center for individuals with NDD, from February 2013 to August 2016. Eligibility criteria included that potential participants be engaged in individual counseling and attended at least three therapy appointments at Surrey Place, fall in the range of mild intellectual disability (with an IQ score between 55 and 75), speak English, and have an English-speaking legal guardian to provide informed consent if under the age of 18. Subjects who were non-verbal or did not meet the other inclusion criteria were excluded from the study.

Therapists provided research assistants with a list of potential participants based on the above criteria and used clinical judgment to exclude potential participants who were actively experiencing acute psychiatric symptoms. Master's level research assistants obtained informed consent and/or informed assent from participants who agreed to volunteer to enroll in the study. The same research assistants also administered all assessments. Participants who screened positive for suicide risk received a follow-up suicide risk assessment and safety was managed as per standard of care. The participant's therapist was on-call during the administration of the measures in case the participant experienced distress. This study was approved by the National Institutes of Health Institutional Review Board and was approved by a Surrey Place ethics board.

2.2. Measures

Participants completed three study evaluation questions to provide qualitative feedback regarding their experience answering suicide risk screening questions. The items were created based on previous studies assessing participant opinions on suicide risks screening [9]. The first item asked, "Has anyone ever asked you about suicide before?" The next question asked: "What was it like to be asked these questions today?" The final item queried for any additional comments. Participants answered these questions verbally directly after answering the suicide risk screening questions. When available, direct quotations from participants were recorded manually in writing. In other instances, the data collector's summary of the participant's response is reported. The therapists of each participant also completed items which asked whether they thought that individuals with NDD should be screened for suicidality at therapy appointments. Additional qualitative feedback was also collected.

2.3. Data Analysis

Descriptive statistics are reported to characterize the sample. An exploratory content analysis approach was used to analyze the qualitative data. The analytic approach did not depend on a set of pre-determined coding themes. All data was coded independently by two coders who met throughout the coding process for consensus meetings to define and redefine thematic categories, discuss each response to the open-ended questions, review any discrepancies, and arrive at a consensus. The independent coders had a 78% agreement rate.

3. Results

Thirty-one eligible potential participants were referred and approached for participation in this pilot study, of which 17 participants consented and enrolled (55% enrollment rate). The sample was predominantly male (12/17) and White (13/17). The majority of the participants (14/17) were youth ages 12–24, with a youth mean age of 15.0 years (SD = 3.0). Participant IQs were all within the range of 55–75 and all participants had a diagnosis of a specific NDD. Six participants (6/17) had a diagnosis of ASD, in addition to an intellectual disability (ID) or developmental delay (DD). Table 1 contains sample demographic characteristics. Fifteen of the 17 NDD participants (15/17) and 15/17 of therapists participating completed the study feedback questions. NDD participant and clinician qualitative responses are reported in Table 2.

Table 1. Participant Demographics.

Participant Demographics	**N (%)**
Gender	
Female	5/17 (29.4%)
Male	12/17 (70.6%)
Race/ethnicity	
White	13/17 (76.5%)
African American	3/17 (17.6%)
Unknown	1/17 (5.9%)
Mean Age (SD)	
12–24 years	14/17 (82.4%)
Youth mean age (SD)	15.0 years (3.0)
24 + years	3/17 (17.6%)
Adult mean age (SD)	53.0 years (5.7)
IQ score	Range = 55–75
Neurodevelopmental disorder diagnoses (some participants have multiple)	
Autism spectrum disorder	6/17 (35.3%)
Attention deficit hyperactive disorder	3/17 (17.6%)
Alcohol-related neurodevelopmental disorder	1/17 (5.9%)
Down's syndrome	1/17 (5.9%)
Intellectual disability	17/17 (100%)
Klinefelter's syndrome	1/17 (5.9%)

Table 2. Participant and Therapist Opinions of Suicide Risk Screening.

Participant Number	"Has Anyone Ever Asked You about Suicide Before? If Yes, Who Asked You?"	Participant Opinions: "What Was It Like to Be Asked These Questions Today?" "Additional Comments/Notes?"	Therapist Opinions: "Do You Think That Therapy Clients with ID/DD Should Be Screened for Suicidality? Please Explain."
1	No	"It felt good."	Yes: "The screening may provide them with an opportunity to express the depth of their struggles and to have these feelings acknowledged by significant others."
2	No	"Not too bad, feeling okay."	Yes: "This is an important topic that needs to be addressed-current tools wholly inadequate for clients with DD/ID."
3	No	Data collector reported: It made the participant feel happy and that the questions were easy to answer.	Yes: "I think all clients who have any indication of depression or serious social difficulties that bother them should be screened, especially teenagers."
4	No	Data collector reported: Participant was a bit worried there might be questions they didn't know how to answer or didn't understand. The patient feels better after completing the questions and feels good now and wouldn't mind doing it again.	Yes: "One way to acknowledge the depth of their struggles (clients'). One way to raise awareness for the parents the extent of their children's emotional pain."
5	Yes, Parents	Data collector reported: Participant feels overwhelmed, upset, embarrassed, ashamed, heartbroken but feeling much happier now that he has talked about it. Further stated that they "can't believe" they think this way but sometimes does and that it was good to be able to talk about it. It didn't make them feel uncomfortable. They sometimes have these thoughts because of their disability.	Yes: "The screener was helpful as a tool for discussion of suicidal ideation in a non-threatening way."
6	No	Data collector reported: Made the participant feel okay.	
7	No	Data collector reported: Made the participant feel a little better.	Yes: "I feel it was important that this screening was done. It allowed [Participant 6] to say something important about how she felt. This in turn may have allowed her mother to treat her daughters' thoughts with more respect."
8	No	Upsetting	Yes: "I believe that all therapy clients should be screened for suicidality, regardless of whether they have an ID/DD."
9	No	Data collector reported: participant expressed being happy but worried, and would not do it again	

Table 2. *Cont.*

Participant Number	"Has Anyone Ever Asked You about Suicide Before? If Yes, Who Asked You?"	Participant Opinions: "What Was It Like to Be Asked These Questions Today?" "Additional Comments/Notes?"	Therapist Opinions: "Do You Think That Therapy Clients with ID/DD Should Be Screened for Suicidality? Please Explain."
10	No	Data collector reported: the patient was okay and happy.	Yes: "It should be part of routine screening-simply inquiring about this could create an opportunity to not only assess risk but to speak about painful experiences and strong feelings. Screening would provide an opportunity for advanced plannning to ensure client safety and improve the efficiency with which services are delivered during a crisis."
11	No	"It was simple to answer the questions. I don't know why people would kill themselves. I'm not an idiot who thinks like that"	Yes: "I believe that any client should be screened for suicidality regardless of their level of cognitive and adaptive functioning."
12	No	"It was intense. It's an emotional subject. It's hard to say what I was feeling."	Yes: "If they are presenting with those issues and concern (e.g., depression, feeling down on life, etc."
13	No	Data collector reported: the participant did not report feeling distressed, upset, or worried.	Yes
14	No	"I know I would never do it, like kill or take alcohol. I felt a bit weird because I got up early."	Yes: "At intake/part of initial assessment for often as needed."
15	No	"It's okay. I don't mind."	Yes: "All therapists should receive training with screening for suicidality in clients with ID/DD. Especially if there are risk factors present in the client's history or if there are risk factors currently present, therapists need to be vigilant and screen if needed. it could possibly be included as part of therapy assessment with clients, where therapists could go through a developmentally appropriate screening measure with clients once they have established a rapport with them."
16			No
17			Yes: "If the issues come up in therapy then more detailed questions need to be asked."

3.1. Participant Opinions

NDD participant opinions on being screened for suicide risk varied, with three themes emerging: (1) comfort with screening, (2) ambivalence towards screening, and (3) negative experiences with screening. Fifteen participants (15/17) completed the qualitative feedback portion of the study. Fourteen participants (14/15) reported they had never previously been asked about suicide, and one participant reported they had been asked about suicide in the past (1/15) by their parent.

Nine participants (9/15) reported a comfortable experience when being asked questions about suicide risk, including reports of feeling happy due to being able to answer the study questions and feeling better from it as a result of discussing their feelings.

Four participants (4/15) expressed neutral or mixed (ambivalent) feelings towards answering questions about suicide. While two participants reported feeling "okay" with the process, one participant reported feeling overwhelmed and ashamed, but also noted it made him feel happier. Another participant stated: "It was intense. It's an emotional subject. It's hard to say what I was feeling". Two participants (2/15) reported discomfort with the process; of note, these participants were two of the 14 participants that reported they had never previously been asked about suicide. One participant expressed worry during completion of the questionnaires due to the amount of study questions asked. The other participant found the process upsetting and did not finish the study. Both participants debriefed with their therapists and caregivers after the study.

3.2. Therapist Opinions

Almost all (14/15) of the participating providers were in favor of all individuals with NDD being screened for suicide risk at therapy appointments. Four themes emerged among the therapists who were in support of screening: (1) screening as a therapeutic tool, (2) interpersonal benefits of screening, (3) importance of universal screening, and (4) the need for improved suicide risk detection. Some responses overlapped between multiple themes.

Six therapists (6/14) viewed suicide risk screening as a therapeutic tool, including for use as a developmentally appropriate screening tool that would offer the opportunity for safety planning.

Four therapists (4/14) noted "interpersonal benefits" for the participants in connecting with family and friends as a result of suicide risk screening. Two therapists discussed the potential of screening to allow individuals to have their suicidal thoughts acknowledged by significant people in their lives. One therapist stated that screening "allowed [participant] to say something important about how she felt. This in turn may have allowed her mother to treat her daughter's thoughts with more respect".

Four therapists (4/14) emphasized the importance of universal suicide risk screening and routine screening of therapy clients, with one therapist stating: "I believe that all therapy clients should be screened for suicidality, regardless of whether they have an ID/DD". An additional therapist expressed a similar viewpoint in support of universal screening, advocating for suicide risk screening for all therapy clients, "regardless of their level of cognitive and adaptive functioning".

Three therapists (3/14) highlighted a need for improved detection of suicide risk among individuals with NDD. One therapist commented on the need for therapists to receive more training on how to screen individuals with NDD for suicide risk while another therapist described the current tools that exist for this purpose as "wholly inadequate" for individuals with NDD.

4. Discussion

The findings from this pilot study provide initial qualitative evidence that many individuals with NDD and their therapists would be comfortable with and support suicide risk screening for this population. Screening tools to guide clinicians on how to ask about suicide risk are needed and appear to be desired by clinicians who provide mental health treatment for people with NDD [7].

While participant opinions varied, over half of participants expressed positive views about being asked questions about suicide. Two participants reported discomfort, however, this was the first time they reported being asked about suicide risk. This may suggest that their feelings of discomfort were due to struggles discussing the abstract concepts of suicide and death, or due to stigma surrounding suicidal thoughts. Additionally, their discomfort may have been exacerbated by the study measures, as one participant commented specifically on the amount of study questions asked, suggesting that screening tools for individuals with NDD should be brief. Tools such as the ASQ [8] and the Patient Safety Screener-3 [10] (PSS-3) may be particularly apt for this population due to their brevity.

The majority of therapists in this study supported suicide risk screening among individuals with NDD in therapy and a portion highlighted screening as an important therapeutic tool. Therapists need tools to facilitate the process of detecting suicide risk among their clients to make screening more approachable and lessen discomfort for both the patient and therapist. Since training was suggested by therapists in this study, and discomfort (in the form of limited self-efficacy) was noted in another recent study [7], implementing training to directly address clinician confidence in suicide risk screening is essential.

Several therapists discussed concerns regarding accurate detection of suicide risk in NDD populations. This included improved training for therapists to intervene and assess suicide risk and better tools to screen for suicide risk, given the insufficiency of the existing tools for this population [6,11]. Results highlighted the need for a suicide risk screening tool that is developed specifically for use among individuals with NDD, meaning that future studies should seek to not just investigate the validity of existing brief screening tools, but further investigate whether adaptation is needed for individuals with NDD.

There are several limitations to note. First, this was a small convenience sample and, to maximize participant safety and comfort, this pilot utilized participants who were already in mental health treatment. Second, the study enrollment rate for the pilot was lower than optimal since several potential participants declined enrollment. Lastly, therapists served as gatekeepers for participant enrollment, potentially introducing selection bias to the results and limiting generalizability.

This study found preliminary qualitative evidence that individuals with NDD and their therapists are comfortable with and support suicide risk screening. As a result of investigating the opinions of individuals with NDD and their therapists, several important lessons were learned that will be relevant in developing a screening instrument, including the need for a brief tool. Future research should expand on the findings of this pilot study by studying the process of validating tools and widescale implementation of suicide risk screening for this understudied population at risk.

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Informed Consent Statement: All participants ages 18 years old and older provided written informed consent. All participants under the age of 18 years old provided written informed assent and parental permission/consent was obtained for these participants.

Data Availability Statement: Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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Conflicts of Interest: The authors declare no conflict of interest.

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