Suicidality in Autistic People: A Brief Review and Recommendations for Prevention

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Details

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Background

Many people have some thoughts of suicide known as suicide ideation during their lifetime, which is when someone thinks about, considers, or plans for suicide. Autistic people are however at increased risk of suicidality. There were 11-66% of autistic people who had thought about suicide and 35% had planned or attempted suicide during their lifetime (Hedley & Uljarević, 2018). More importantly, a leading cause of premature death in autistic people is suicide (Hirvikoski et al., 2015). Therefore, there is a strong and urgent need to develop effective prevention strategies for autistic people. To do this, we work with The Department of Health and Social Care, supporting them in developing a new, long-term suicide prevention strategy that has a priority on autism. In this briefing, we view the risk factors and warning signs of suicide in autistic people. By integrating what we know about autistic people and suicide prevention in non-autistic people, we make recommendations on potential prevention strategies that are tailored for autistic people.

Recommendations

1. **Improving public understanding and perceptions of autism, particularly for professionals supporting autistic people**
2. **Including autistic people in the design and delivery of training and public campaigns**
3. **Reviewing current assessment and support processes for timely autism diagnosis and clear referral pathway across primary, secondary and specialist care**
4. **Suicide awareness and prevention training should be given to all individuals who provide support, in its broadest sense, to autistic people**

Understanding Autism and its increased risk of suicidality

Autism is clinically characterised by difficulties in social interaction and communication as well as repetitive patterns of behaviours and thinking (American Psychiatric Association, 2013). In other words, autistic people communicate, behave and think differently compared to non-autistic people. However, they are a group of heterogenous persons presenting different strengths and challenges. They may make use of their strengths to compensate for their challenges and mask/camouflage their autistic characteristics to fit in the predominately non-autistic world (Hull et al., 2017; Lai et al., 2011, 2017). They are more prone to traumatic experiences compared to the general population (e.g., maltreatment and bullying; Mandell et al., 2005; Sterzing et al., 2012). They also experience challenges relating to getting an autism diagnosis and accessing relevant support (Crane et al., 2018). All of these autism-specific factors contribute to increased risk of suicidality in autistic people. Each factor and its relation to suicidality are reviewed below. Social interaction and communication are challenging for autistic people. They tend to have poor social relationships and support (e.g., Mazurek, 2014)

and are more likely to feel lonely or a burden compared to non-autistic people (Pelton et al., 2020). According to the Interpersonal Theory of Suicide developed with non-autistic people (van Orden et al., 2010), the simultaneous presence of "thwarted belongingness" and "perceived burdensomeness" are associated with suicidal ideation (e.g., Campos & Holden, 2016; Chu et al., 2017). However, autistic people may not know how to ask for help and communicate thoughts and feelings about suicide (Cassidy et al., 2021). For those who reported stronger feelings of "thwarted belongingness" and "perceived burdensomeness" in the autistic sample of Pelton et al. (2020), they were more likely to report suicide attempt rather than ideation. It is likely that autistic people may transit to suicide attempt more quickly than non-autistic people (Kato et al., 2013).

Repetitive patterns of behaviours and thinking were also associated with suicidality in autistic people (McDonnell et al., 2019). Repetitive behaviours may include self-harm (e.g., hitting, scratching and biting oneself). There is a higher prevalence of self-harm in autistic people (50-65%) compared to non-autistic people (17-23%; Cassidy et al., 2018; Maddox et al., 2016) and self-harm is associated with increased risk of suicidality in both autistic and non-autistic populations (Cassidy et al., 2018; Ribeiro et al., 2016). Repetitive and sometimes rigid patterns of thinking may include rumination on negative events, affecting autistic people's ability to cope with negative feelings and contributing to the onset and maintenance of depressive symptoms (e.g., depressed mood, hopelessness; Gotham et al., 2014). These depressive symptoms are strongly associated with suicidality in both autistic and non-autistic populations (e.g., Cassidy et al., 2014; Windfuhr et al., 2008).

Autistic people often engage in masking/camouflaging to fit in the predominately non-autistic world. For example, pretending to make eye contact during conversation by looking at partner's nose and using cognitive strategies to recall and follow social conventions. These strategies may however contribute to delayed diagnosis and support (e.g., Begeer et al., 2013; Cage et al., 2018) and multiple mental health issues including experiences of stress, anxiety, burnout, lost sense of self-identity, loneliness, depression and suicidality (e.g., Beck et al., 2020; Cassidy et al., 2014; Hull et al., 2021). It was found that autistic females may camouflage across more situations and more frequently than autistic males (Cassidy et al., 2018; Lai et al., 2017). This may partially explain why autistic females are underdiagnosed and more likely to be misdiagnosed or diagnosed later in life (Lai et al., 2015; Ratto et al., 2018). Given that undiagnosed possible autism and delayed diagnosis are associated with increased risk of suicidality (Richard et al., 2019; South et al., 2019), autistic or possibly autistic females are at a higher risk of suicidality. However, it is also important to note that there are higher rates of gender diversity in the autistic population and gender diversity is associated with increased risk of suicidality in both autistic and non-autistic population (e.g., Corbett et al., 2023; Dewinter et al., 2017; Stuart-Maver et al., 2023).

Undiagnosed possible autism and delayed diagnosis are also due to the fact that health professionals tend not to understand the behaviours of autism and overlook symptoms. There is a delay of 3 to 4 years from first-time approaching health professionals to the confirmation of an autism diagnosis (e.g., Crane et al., 2016; Jones et al., 2014). There is also a shortage of professionals trained to support

autistic people who present with self-harm and suicidality (Camm-Crosbie et al., 2018; Raja, 2014) . Existing services are perceived to be unsuitable and inaccessible by autistic people and their families (Brede et al., 2022; Camm-Crosbie et al., 2018; Crane et al., 2019). Health professionals may also be unwilling to tailor their support for autistic people (Adams & Young, 2021; Brede et al., 2022). Negative experiences with services may further prevent autistic people from help-seeking and may even cause additional harm such as feeling hopeless and isolated (Brede et al., 2022; Coleman-Fountain et al., 2020). Such feelings and experiences can be traumatic and increase risk of suicidality in autistic people.

Autistic people are more prone to traumatic experiences including physical, psychological and sexual maltreatment, bullying, abuse and neglect compared to the general population (e.g., Mandell et al., 2005; Sterzing et al., 2012). Autistic people can also find different kinds of events traumatic, e.g., social events and changes to routine (Haruvi-Lamdan et al., 2020; Kerns et al., 2022). Moreover, they have a more difficult time processing, understanding and coping with traumatic events and experiences (Bleil Walters et al., 2013; Rieffe et al., 2012). It was found that autistic youth who were teased were three times more likely than non-teased autistic youth to report suicidality (Mayes et al., 2013) and those with post-traumatic stress disorder (PTSD) showed increased propensity for suicidal thoughts over those without (Storch et la., 2013). Given that seeking help from services is a social event which can be traumatic and increase risk of suicidality in autistic people, there is a strong and urgent need for health professionals and service providers to increase their understanding of autism. It is essential to be aware of warning signs, indicating an immediate risk of suicide, and provide prompt support. However, intervening without fully understanding what the person, regardless of autistic status, is experiencing can be traumatic and have devastating consequences.

Warning signs

Warning signs of suicide may indicate an immediate risk of suicide. They include changes in presentation (e.g., weight, mood, concentration) and behaviours (e.g., sleep habits, substance use, recklessness) which differ from how one typically present or behave. Out of the ordinary, one may talk about death/suicide/ hurting oneself and/or look for ways to kill oneself. These may, however, not be communicated directly or explicitly. When assessing autistic people, the following warning signs warrant additional considerations according to expert consensus and research findings (Morgan et al., 2021; Morgan & Maddox, 2020).

1. **Differences in communicating distress compared to non-autistic people**
2. **No reason for living or no sense of purpose or no hope in life**
3. **Withdrawal from friends, family and society**
4. **Worsening symptoms of depression and/or anxiety**
5. **Increase in rate and/or severity of self-harm**
6. **Current traumatic event**
7. **Fixated and perseverative suicidal thoughts and ruminations**
8. **Seeking means or making plans for suicide**

1. Differences in communicating distress compared to non-autistic people

Autistic people may not know how to communicate distress and their suicide attempts so they may not tell anyone (Cassidy et al., 2021). Or they may not show the same degree of distress as non-autistic people when reporting suicidal thoughts and/or behaviours so they were not believed or taken seriously (Camm-Crosbie et al., 2018; Cassidy, 2020). Others' reactions may affect whether they would make another attempt to express distress. Therefore, taking time and exploring ways of communication that would work with an autistic person even they may not know how to communicate and/or show appropriate emotions are fundamental. For example, nonverbal ways of communication such as gesturing, drawing, card sorting, picture pointing can be helpful. However, it is very important to note that what works for one may not work for all.

2. No reason for living or no sense of purpose or no hope in life

Autistic people may feel different and not being accepted for their entire life. They may also feel thwarted belonging and have to mask/camouflage to fit in the predominately non-autistic world (e.g., Lai et al., 2017; Pelton et al., 2020). Statements such as "I don't belong to this world," "I've never fit into this world," "I wish I were anywhere but here," "I wish I could leave here and be in a place I belong, and it's not on this earth," and "I feel hopeless" may indicate suicidality.

3. Withdrawal from friends, family and society

Autistic people may need to withdraw socially to stay regulated and recover from social events in which they may have been masking/camouflaging. However, social withdrawal can also be a warning sign (Cassidy et al., 2021). The key to identify whether it is a warning sign of suicide at a particular time point is to find out whether it is new/sudden or typical (in terms of quality and quantity) and the reasons behind it.

4. Worsening symptoms of depression and/or anxiety

Depression and anxiety in autistic people are common (e.g., Croen et al., 2015; Skokauskas & Gallagher, 2010). However, they can be missed and misattributed to characteristics of autism (Au-Yeung et al., 2019). Moreover, autistic people may not be able to describe feelings in relation to depression and anxiety . One way to detect changes in depression and anxiety in autistic people is to detect changes in behaviours related to depression and anxiety (e.g., sleep difficulties, social withdrawal, loss of interests, intolerance of uncertainty). There are tools developed with and for autistic people to better identify changes in depression and anxiety (e.g., the Anxiety Scale for Autism; Rodgers et al., 2020).

5. Increase in rate and/or severity of self-harm

Autistic people may repetitively engage in self-harm which may serve as a coping response for distress (e.g., Maddox et al., 2016). An increase in rate and/or severity of these behaviours may thus indicate an increase of intolerable distress. Careful consideration of the reasons behind these behaviours and their increase in rate and/or severity is essential. No matter whether there are suicidal thoughts or intent to end life, self-harm increases risk of fatal injury (Cassidy, 2020). Supporting autistic people to explore and optimise strategies for self- and/or co-regulation could be beneficial.

6. Current traumatic event

Autistic people may be impacted by events that may not be considered as traumatic to non-

autistic people (Haruvi-Lamdan et al., 2020; Kerns et al., 2022). They may have a difficult time processing and coping with these events as well as events that are commonly considered as traumatic (e.g., abuse; Bleil Walters et al., 2013; Rieffe et al., 2012). It is again important to notice and understand changes in behaviours which may indicate a current traumatic event/experience that may pose a risk of suicidality.

7. Fixated and perseverative suicidal thoughts and ruminations

Autistic people may become fixated on death-related topics and focus on suicidal talk and thoughts. They may experience an episode of suicidal thoughts and ruminations that lasts 8 hours or more (Cassidy et al., 2021). This is a much longer period than those reported by non-autistic people. Mentally switching away from suicidal thoughts and consider other options could be extremely difficult for autistic people (Cassidy, 2020).

8. Seeking means or making plans for suicide

Autistic people may do extensive research and detailed investigation on ways to end life. They may make detailed plans including stockpiling medications, giving away possessions or seeking long-term care for pets, especially possessions and pets that are precious or emotionally connected to them. One may mention being unavailable after a certain date. There may also be a sudden increase in energy or lift of mood (e.g., appear calmer) as plans are made.

Recommendations

This briefing makes the following recommendations which are further expanded on below for consideration:

1. **Improving public understanding and perceptions of autism, particularly for professionals supporting autistic people**
2. **Including autistic people in the design and delivery of training and public campaigns**
3. **Reviewing current assessment and support processes for timely autism diagnosis and clear referral pathway across primary, secondary and specialist care**
4. **Suicide awareness and prevention training should be given to all individuals who provide support, in its broadest sense, to autistic people**

Improving understanding of autism

Previous sections of this briefing have highlighted how autistic people may be different from non-autistic people and may feel misinterpreted, dismissed, lonely and not being accepted for most of their lives. Many of them have to constantly mask/camouflage to fit in this predominately non-autistic world and some may feel that suicide is the only way to resolve their distress. To better support autistic people and reduce their risk of suicide, it is crucial to understand how autistic people may be different from (and similar to) non-autistic people, and how making adjustments may make a significant difference. For example, some autistic people may need more time to find words to express themselves just as a non-autistic non-native speaker would. These adjustments could result in autistic people not feeling the need to mask or camouflage as much but feeling more comfortable to seek help.

Including autistic people in the design and delivery of training and public campaigns

In the United Kingdom, autism awareness has been promoted through the strategic action plans of the Department of Health since 2015. However, campaigns and training programmes that aim to increase knowledge of autism may not significantly increased positive attitudes towards autistic people (e.g., Mac Cárthaigh & López, 2020; White et al., 2016). Some campaigns and training programmes pathologise difference rather than embrace neurodiversity (McGuire, 2012), highlighting the importance for these public programmes being designed with and delivered by autistic people to ensure appropriate language and content are used. In 2022, the Oliver McGowen Mandatory Training on Learning Disability and Autism was launched as a sector wide awareness training for health and social care staff. Autistic people were included in the design and delivery of this training however, details relating to the content of this are not publicly available. A call for an evaluation of the training was announced in May 2023 by National Institute for Health and Care Research so we do not yet know how effective this training is, however, this will inform future development of training for and delivered by autistic people.

Another vital component of these campaigns and training programmes is to demonstrate that each autistic person is unique with different strengths and challenges. Promoting neurodiverse experience rather than forcing autistic people to fit in the predominately non-autistic world can help reduce discrimination, stigma, mental health issues, and risk of suicidality.

It is also essential for campaigns and training to go beyond factual knowledge and be part of a package of support for the intended audience (Mac Cárthaigh & López, 2020). Unigwe et al. (2017) suggested that GPs may have good knowledge of autism but they lack confidence in their ability to support autistic people. Support for professionals and service providers should include applied help in cultivating communication skills with autistic people, e.g., scenarios demonstrating concrete, unambiguous explanation of procedures for autistic people in relevant settings such as health and social care. Continual monitoring and evaluation of such support and training as well as its impact on practice are also needed.

Reviewing current assessment and support processes

There is an urgent need for a review of the current assessment process for autism diagnosis and offer a clear referral pathway across primary, secondary and specialist care. The aim of these is to minimise barriers to assessment and support, reducing the time required for receiving an autism diagnosis and accessing appropriate support. As there are many individuals and specialisms involved in the diagnosis of autism, a clear referral pathway would support both a person seeking diagnosis and the professionals who will contribute to this.

In addition to this, more than half of clinicians in Wigham et al. (2023) reported not providing preventive intervention to support the well-being of autistic people who are not in crisis within 12 months after they receive an autism diagnosis . However, continuity of support and care from the same professional could support autistic people who find change difficult (Mason et al., 2021). This also helps tailoring the support and care to the autistic person's individual needs. These would require resources for professionals to increase their capacity to support autistic people, but also to involve autistic people to develop (and evaluate) 'step -on, step-off' services so that any person with a known diagnosis would not need a new referral to access the same service again (Wigham et al., 2023). Tailored follow-up support helps rapport building, making early identification and assessment of autistic people who are at a high risk of suicide more possible.

Suicide awareness and prevention training

Given the heightened risk of suicidality in autistic people, suicide awareness and prevention training should be provided to people who are in contact with and provide support to autistic people. This training should help them develop alertness to potential risk factors and warning signs, and promptly detect and appropriately respond to suicidal thoughts and behaviours in autistic people. The Suicide Response Project (https://www.suicideresponseproject.com/ launched by La Trobe University in Australia) was co-designed with autistic and LGBTIQA+ people with lived experience of suicide ideation as well as their families and people with lived experience of being bereaved by suicide or having supported someone after a suicide attempt. It provides lay advice on how to detect and respond to suicidal thoughts and behaviours in autistic people. It has a clear objective and content aligns with the objective. It uses clear language with multiple message formats to communicate simple messages accessibly and outline a course of action for those who are at risk. However, to our knowledge, it has not been empirically tested for efficacy to ensure the intended outcomes are achieved.

It is suggested that an open conversation around suicide and the risk of suicidality among autistic people should be encouraged, counteracting the myth that speaking about suicide may increase suicide risk, normalising the topic and increasing help-seeking. However, appropriate language should be used as negative language can reinforce stigma (e.g., do not use phrases such as "commit suicide", "successful/failed suicide" or other phrases that make death by suicide seem like a positive outcome). A deeper investigation with direct questions and intentional communication is however needed

when assessing autistic people for suicide (Morgan & Maddox, 2020). Some autistic people may interpret questions literally (e.g., Mitchell et al., 1997). For example, "Have you ever attempted suicide?" is likely to be answered with a "Yes" by an autistic person whereas "Have you ever attempted suicide since losing your job?" probes the specific circumstances that may be more helpful for an assessment. Although it may be challenging to communicate with an autistic person and detect changes in depression and anxiety in them, there are ways to communicate non-verbally (e.g., gesturing and drawing) and detect changes in behaviours related to depression and anxiety (e.g., social withdrawal and sleep difficulties). There are also tools developed with and for autistic people to better assess suicidality and identify changes in depression and anxiety in autism. These tools are freely available online (e.g., the Suicidal Behaviours Questionnaire-Autism Spectrum Conditions; Cassidy et al., 2021). However, they are recently developed for research use, to estimate the level of risk on a larger scale, rather than on individual level.

Support and intervention options

To our knowledge, there has not been any empirical evidence available to suggest that an intervention for reducing suicide risk in autistic people is effective. Some of the available support options and interventions are:

1. **Self-help resources and phone apps**
2. **Crisis helplines**
3. **Support from friends and family**
4. **Support groups**
5. **Referral to GP**
6. **Safety planning**
7. **Means restriction**

Self-help resources and phone apps

Online self-help resources and apps may reduce suicidal thoughts and boost well-being and support coping, generally and in crisis. These are used more by females. Self-help information specific to autistic people can be found on websites such as the National Autistic Society (https://www.autism.org.uk/advice-and-guidance/topics/mental-health/suicide).

Crisis helplines

These operate via telephone call, online chat, or text service. Only highly reputable services should be recommended as lack of responsiveness and unavailability may have negative effects on autistic people. Availability and potential constraints to accessing services should be noted alongside the contact details to provide a better understanding of support options to those affected. Even though there is no specific helpline designated for autistic people, general resources (offered by e.g., Samaritans - https://www.samaritans.org/how-we-can-help/if-youre-having-difficult-time/i-want-kill-myself/,

Mind—https://www.mind.org.uk/need-urgent-help/using-this-tool/ or NHS - https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/behaviours/help-for-suicidal-thoughts/) may be helpful.

Support from friends and family

People are most likely to talk to a family member or friend about suicide or self-harm. Social support can decrease the likelihood of a suicide attempt. However, some autistic people may be socially isolated and may not have someone to talk to.

Support groups

The sharing of common experience and mutual understanding has been found to be beneficial in aiding recovery and supporting well-being. For example, National Autistic Society offers AutAngel Support Programme and Groups, designed to offer peer support to autistic people (https://www.autangel.org.uk/community/#ourgroups).

Referral to GP

Seeing a GP is widely proposed as the first step when someone may be at increased risk of suicide or self-harm. However, as discussed earlier, GPs may lack confidence in their ability to support autistic people so training and support for professionals who provide support for autistic people is critical.

Safety planning

Although safety planning is predominately a self-help approach, it is most effective when undertaken within a programme of support or intervention. When supporting an autistic person, concrete instructions (i.e., no metaphors) should be used at all stages of safety planning. Structured checklist and safety plan sheet that allows non-verbal/pictorial expression could be helpful. To identify coping strategies, one may consider strategies such as engagement in a circumscribed interest if that is safe to do so. A generic safety plan for autistic people is the Autism adapted Safety Plan which is currently under pilot evaluation (Rogers et al., 2023). Additionally, there are population-specific safety plans, such as the Probation Service Safety Plan, which have been adapted to enhance accessibility for autistic people (HMPPS, 2023)

Means restriction

Implementing measures to restrict access to potentially lethal methods of suicide, e.g., access to medications, is an effective strategy for suicide prevention (e.g., Yip et al., 2012). Autistic people, compared to non-autistic people, are found to use more aggressive and lethal methods of suicide that lead to prolonged hospital stays and more severe physical and mental health outcomes afterwards (e.g., Kato et al., 2013; Stark et al., 2022). Kato et al. (2013) reported that the most commonly used methods are drug overdose (34.9%), cutting/stabbing (20.9%), carbon monoxide intoxication (20.9%) and jumping from height (14%). Moreover, 37.2% of autistic people experienced a precipitating event in 24 hours prior to a suicide attempt, compared to 53.7% of non-autistic people. As such, restricting access to drugs at times of crisis regardless of whether there is a precipitating event in the last 24 hours could be helpful.

Conclusion

In this briefing, we viewed the risk factors and warning signs of suicide in autistic people. We highlighted the need to enhance public understanding of autism and suicide prevention for autistic people. We also identified service

gaps. More importantly, we integrated what we know about autistic people and suicide prevention and provided recommendations on potential suicide prevention strategies that are tailored for autistic people. It is however essential to co-design and co-develop these strategies with autistic people. Since autism isa complex condition and no two autistic people are the same, support and intervention should also be personalised and tailored to the individual to improve outcomes for the individual and people who care for them.

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