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A Participatory and Creative Exploration of how Autistic Young People Experience Loneliness and Connection

A research report by
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 **OAR**
ORGANIZATION FOR
AUTISM RESEARCH

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What is this research about?

We wanted to know more about the experiences of loneliness and connection for autistic young people.

How was the topic investigated?

We started the project by asking autistic people about suitable methods for data collection. We followed their recommendation to offer autistic young people choice in how they wanted to contribute. Autistic young people (12-24 years old) were invited to take part in an interview, produce a piece of art which would be used as a conversation starter, or add anonymous posts to a virtual wall of thoughts about their experiences of loneliness. They could choose to take part in more than one way.

How did we get to our results?

We analysed the results using Reflexive Thematic Analysis and participatory data analysis. This means that we took our views back to participants, who helped us make sense of the data in every step of the process.



What did we find out?

Loneliness is commonly understood as a negative feeling that comes when we recognise that our social needs are not being met. We know that **social loneliness** is defined as the perception of having an inadequate social network and **emotional loneliness** is defined as feeling dissatisfied with the quality of social connections. Autistic young people's descriptions of loneliness extended this understanding by going beyond the social and emotional domains and by adding more nuanced views of what being lonely or not lonely means for them. We showed that their descriptions could be understood as **existential loneliness**, **experiential loneliness** and **positive loneliness**. By revising existing loneliness scales, we also identified **global loneliness** as another dimension to be explored.

Why is this research important?

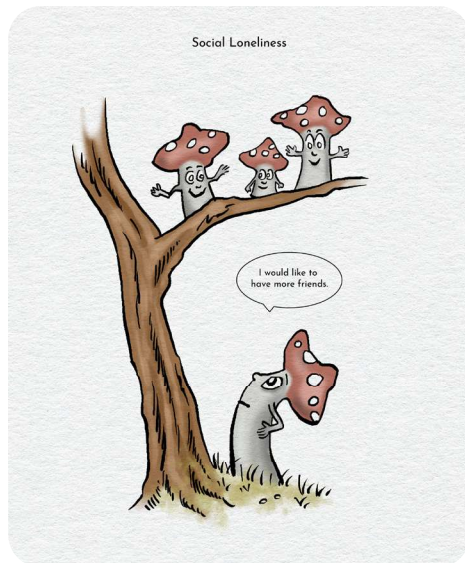
By asking autistic young people about their experiences of loneliness, we are adding autistic voice to research rather than assuming that we know how loneliness feels based on neurotypical experiences.

What we hope this can do?

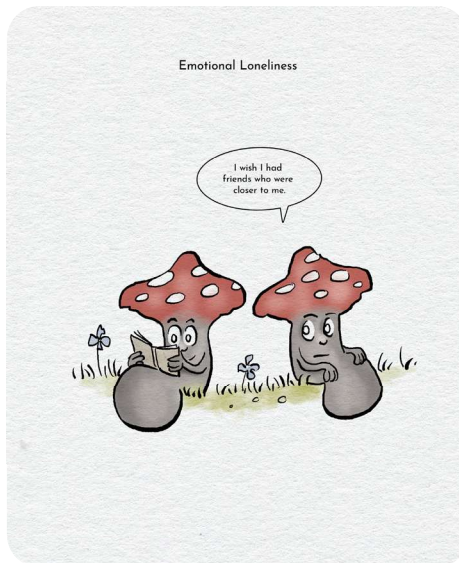
We hope that these findings will improve the understanding of how autistic young people experience loneliness. The images and descriptions presented here could be used as a conversation starter to explore feelings of loneliness and to inform parents, teachers and clinicians on how to better support autistic young people who are feeling lonely.

How do autistic young people experience loneliness?

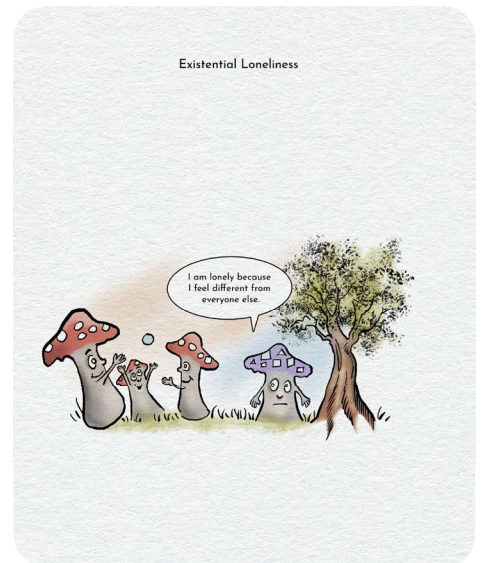
Autistic young people described loneliness as a complex and varying feeling. We identified six different domains of loneliness.



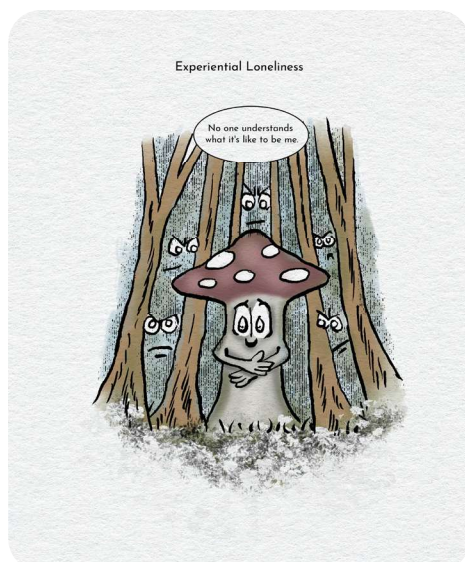
Social loneliness is when you feel you do not have enough friends.



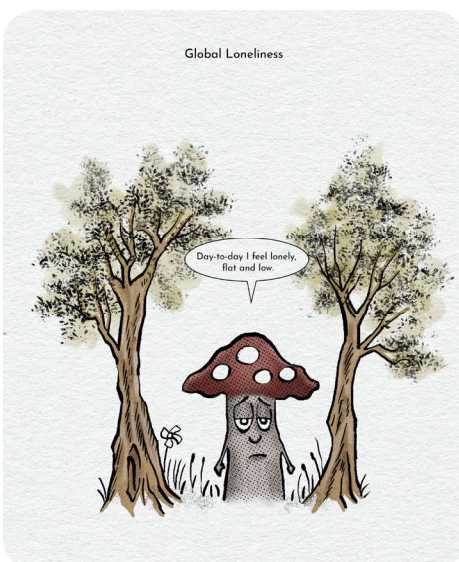
Emotional loneliness is when you miss having close relationships.



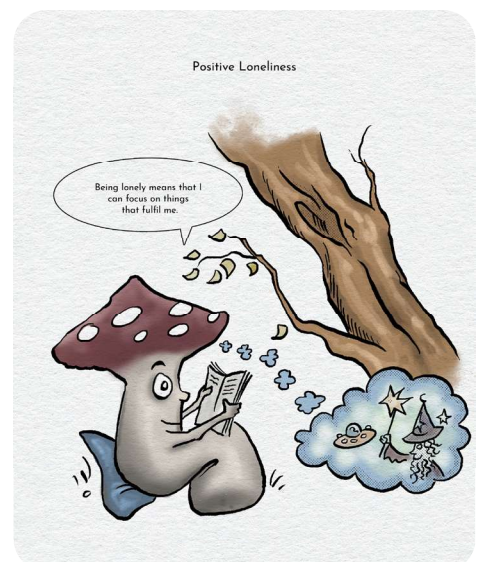
Existential loneliness is when you feel you are different from everyone else. You feel like an outlier, odd or irregular, as if you are not part of this world.



Experiential loneliness is when you feel that no one understands the way you experience the world. No one understands what it is like to be you in the world.



Global loneliness is a general feeling of loneliness that might include several of these domains. It is just a feeling that makes you feel down or flat.



Positive loneliness is when you feel that in the absence of others you can focus on things that are important for you and that make you feel fulfilled. It can be a challenging feeling, but it is meaningful and wanted.

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