

Growing up with Autism: Qualitative Studies of Occupational Identity Formation and the Role of Interventions and Social Media

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Overview of the Studies

- Compilation of two studies: one focused on Occupational Identity and the use of Social Media and the other on Occupational Identity and OT interventions.
- Occupational Identity is defined theoretically using the Model of Human Occupation
- Total of 15 Participants across the two studies. Recruited through social media, personal contacts and snowball sampling. One study include artifact elicitation.
- Method: Semi-structured interviews
- Analysis: Thematic analysis with multiple rounds of coding
- Analyzed separately, this is more a comparison of results. Considering re-analyzing all together for publication.

Common Themes Across the Studies

Theme 1: Social Relationships are identified as very important, but there are many barriers. These include bullying, rejection, dismissal in spaces dominated by non-autistics, but also when requesting accommodations for school or work. Eventually low confidence and desire to avoid rejection.

“a lot of times they're really negative and it kind of presumes that the way that we act and the way that we think is inferior to the way that allistic people do and that there's something wrong with our communication and our needs” Study 2

“It means a lot to have friends now. Because like I was telling you earlier, I didn't have any friends for a long time. And most of my friends are people that I met online and have known for a while my best friend now I met her, gosh, eight years ago. And so she's been very important to me. I'm glad to have that connection.” Study 1

“I think that a lot of my relationships with other autistic people...we are able to get along really well in a way that I don't really get along with people who aren't autistic” Study 2

Theme 2: Self-acceptance is complex and a journey impacted by many social factors. Diagnosis and treatment can provide some understanding, but also come with constant messages of not being okay. Intervention often led to feelings of self-doubt and incapacity. Intervention was rarely aligned with the goals of the person, and any concerns and desires were dismissed. Two people expressed positive feelings toward interventions, expressing the desire to be normal.

“So I like to get more trust with myself, because like, I'm not always wrong now. But even still, like going into even like writing an email, like I second, third and four times, like doubt myself in like, is this what I'm supposed to say? Or do? Is my face doing the right thing? You know, so many, so many different things that like come up, and like, I'm not actually gonna get like penalized in any way. But like, it's still like to have more like, trust in myself before I do stuff.” Study 2

Theme 2 (cont.) Many stated their journey to acceptance started with them doing their own research on autism (not from those identified as helpers). Only after learning about the autistic community, did they start to see themselves as worthy and capable.

“when I was first researching it, I was like, Oh, these are new ways where like, I'm realizing like, things that I do that are wrong and different and that I can learn to change. Um, That was like kind of a really short period of time. And then I was like, Oh, what if I just kind of try to accommodate myself. And I feel like that has improved my self confidence a lot, and my relationship to being autistic.” Study 2

“I felt like part of learning to unmask has been trying to reconnect with who I was before I learned like the right and wrong way to be and just like, who I kind of naturally was and how I acted...I look to like, be really comfortable with who I was. And I wasn't as like concerned with the way that I was being perceived...Like I wasn't trying to, like look good or like normal or anything. I was just like having fun.” Study 2

And when I got into college, and I was when I was studying Child Development in Community College, then it was interesting to see how other people perceived autism. And I was more confident in being able to say, Well, I'm autistic, and this is how it feels from the inside. Study 1

Theme 3: Social Media provides opportunity to connect with like-minded peers. Participants felt their interactions with other autistics were positive and they sought that out. This allowed for social relationships in which participants felt more confident and accepted for who they are. Participants did recognize the potential for bullying in social media platforms.

Yeah, I would also like to add that I really like using social media because you don't have to share anything about who you are in real life. You could just talk about your interests, and there's people there that will listen to you, and they won't like shame you for what you like, especially if it's something childish say, I know, one of my friend's special interest is SpongeBob. And they just don't like to talk about it in real life. But online, they can talk about it freely without any shame from anybody really, or something like that.” Study 1.

“the things that generally feel more meaningful to me are usually interacting with people and with like politics, but I think that those things kind of like go together for me.” Study 2

Table 1
Demographic Information for both studies combined

Variable	Characteristics	Frequency (n=15)
Age	18-34 years	11
	35-44 years	4
Gender	Male	6
	Female	7
	Bigender	1
	Prefer not to identify	1
Ethnicity	White/Caucasian	10
	African American	4
	Asian Pacific Islander	1
Educational Status	High School Diploma	3
	Some college	4
	Associate's degree, occupational, technical, or vocational program	4
	Bachelor's degree	3
	Doctorate	1

Takeaways

- Social relationships with family and coworkers, and the ability to find, make and keep friends was probably the most important issue for participants though there was wide variety in how that happens. Healthy social media use, as well as tier one approaches to bullying and inclusivity should be a focus for OT.
- OT Intervention must be strengths based and practitioners must learn about neurodiverse approaches to intervention. We must move away from deficit focused skill building to person directed performance interventions that consider barriers in the environment as much, if not more than in the person.
- Practitioners need to familiarize themselves with the work of the Autistic community, even including people who identify as autistic as integral aspects of our intervention processes. We also need to welcome autistic students into OT programs.

Listen to what we need from you. Listen to what has hurt us. I have encountered practitioners who are overjoyed to see autistics behaving more like their neurotypical peers. Is that truly something to celebrate? Is our goal to teach autistics to mask? Because autistics will always be autistic. Each time I am praised for not being autistic, I learn that people like me . . . when I am not me. (L. M. Elezy, personal communication, February 22, 2022, in Patton, 2022).

Contributors to the Research Projects

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Resources

- Autistic Self-Advocacy Network (ASAN) <https://autisticadvocacy.org/>
- ASAN You Tube Channel - <https://www.youtube.com/user/autselfadvocacyntwk>
- Neurodiverse Connection – Check out the language guide. <https://ndconnection.co.uk/>
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