



# Experiences of Neurodivergent People When Playing an Educational Video Game About Their Own Diagnosis

**RESEARCH** 

LISANNE MEINEN (D



### **ABSTRACT**

This paper discusses how participants with diagnoses of autism, psychosis, or OCD (obsessive-compulsive disorder) experienced playing an educational video game about that same diagnosis. Rather than having participants make a specific assessment of the video game they played, the gameplay was used as a creative task to trigger reflection on their experiences with neurodivergent perceptions and knowledge. Central was the phenomenological question of what it means for someone to play a video game intended to communicate to outsiders a vision of neurodiversity that also represents (parts of) their lived experience. The study is based on in-depth semi-structured interviews with 10 adult participants. Using interpretative phenomenological analysis, three main themes were formulated: (1) working with and around the diagnostic label, (2) the paradox of understanding, and (3) the serious nature of play. Then, several theoretical implications concerning the performative effects of a psychiatric diagnosis, cross-neurotype communication, and inclusive definitions of play are formulated. The paper concludes that playing video games during the interviews formed a good conversation starter for sharing neurodiversity-related experiences, which also demonstrates their meaningful complementarity to traditional interview-based qualitative research.

# CORRESPONDING AUTHOR:

### Lisanne Meinen

University of Antwerp, BE Lisanne.Meinen@uantwerpen. be

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# **INTRODUCTION**

Although the amount of video games available is still limited, the existing corpus of video games about lived experiences of neurodiversity is growing. These games range from the self-expressions of neurodivergent designers (Fiadotau, 2022) to applied games developed and further analyzed in an academic context (Whitby & Kowert, 2022). They are often designed as a psychoeducational interventions, to educate friends, relatives, and a wider interested public on daily life with a specific expression of neurodiversity. In the case of applied games, the voices of those who are the subject of these games are increasingly involved in the developing process through user experience research. Most often, neurodivergent participants assess the final products as part of a testing group (Spiel & Gerling, 2020). In rare cases, participants are already involved in the development of the video game from an earlier stage in the design process. Still, the goal of this type of participatory research is often not to extensively engage with the meaning of individual experiences of the neurodivergent participants.

However, besides collecting opinions on applied games about neurodiversity, there is great value in gaining insight into the experience that playing such a game offers. When the diverse and dynamic social experiences of neurodivergent people are consistently overlooked, video games intended to explain to players 'what it is like' to experience a specific expression of psychiatric vulnerability may in practice not resonate with lived experiences. Additionally, these games may stigmatize by accident, which is the opposite of the purpose with which they have been designed. As such, knowledge about experiences of marginalization is essential for improving our complete understanding of the potential meanings of these games. Structured qualitative research that focuses on player experiences is already quite common in games research (Lankoski & Bjork, 2015). There is also a slowly increasing attention to the phenomenology of gaming as a creative and relational process (Crick, 2011; Culiq et al., 2019), and interpretative phenomenological analysis (IPA) has been applied to generate detailed analyses of participant's playing experiences and meaning-making processes (Jørgensen, 2016; Moran, 2023; Redhead Ahm, 2021). IPA is most prevalently used in health research (Smith & Shinebourne, 2012), and can be of great use to better understand the meanings of lived experiences related to neurodiversity.

In this interview study, I explore the phenomenological question of what it means for someone to play an educational video game which is intended to communicate to outsiders a vision of neurodiversity that also represents (parts of) their lived experience. The goal of this study was not to test the efficacy of these specific video games by having the participants make a specific assessment of the video game. Neither was the intention to argue that these video games are perfectly capable of capturing 'what it is like' to be neurodivergent (even though the way these games are marketed might sometimes suggest this). Rather, I wanted to explore how my neurodivergent participants experienced these games. As such, the gameplay was used as a creative task to trigger reflection on their experiences with neurodivergent perceptions, experiences, and knowledge. First, more practical aim of the study is to provide an entry point for those developing an educational video game or interactive psycho-educational tool about neurodiversity, to make the video games better match the needs and perspectives of neurodivergent people. Second, more open aim, is to explore the possibilities of starting a conversation about topics related to the lived experience of neurodiversity through the creative intervention of the video game. What kind of critical and philosophical questions did the playing experiences of the participants generate?

### THEORETICAL FRAMEWORK

This interview study was conducted and analyzed through a neurodiversity lens, which deliberately tries to extend thinking about psychological vulnerability beyond the individual and biomedical model (Goodley, 2016). The neurodiversity *movement* refers to concrete individuals who share a collective affinity based on a divergence from norms that presents itself in specific social, sensory, and cognitive phenomena (Kafer, 2013; Stenning & Rosqvist, 2021). However, neurodiversity is also applied beyond this focus on political identity, as an analytical lens that can help to critically engage with neuronormativity, most prominently in academic research (Arnaud & Gagné-Julien, 2023). The inclusion of neurodivergent voices in research processes in order to counter epistemic injustice is a crucial aspect of this neurodiversity *research* 

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paradigm (Chapman & Carel, 2022; Harris et al., 2022). Doing research within this paradigm calls for a methodology capable of paying attention and doing justice to the nature of lived experiences. IPA, with its attention to individual meaning-making processes built into the methodology, is very well suited for this. By centralizing neurodiversity, my intention is not to argue that neurodivergent people by definition experience everything differently from so-called 'neurotypicals', but rather to explicitly dedicate attention to nonnormative experiences and the ways these are expressed.<sup>1</sup>

The critical mode of the neurodiversity research paradigm overlaps with the field of Critical Disability Studies (CDS) in some elements relevant to this study. Most notable is the shared commitment to questioning (knowledge-making) practices which produce and reinforce ab/normal binaries (Goodley et al., 2019). While some neurodivergent individuals may not see their specific expression of neurodiversity as a *disability*, they will undoubtedly in their lifetime experience some form of *disablement* (Walker, 2021). The core principles of CDS are indeed useful for all of those with atypical bodyminds. Neurodiversity is often framed solely as a vulnerability, and a significant body of empirical work links particular cognitive traits related to autism or ADHD with problematic gaming practices (Craig et al., 2021; Dullur et al., 2021). On the other hand, neurodiversity is sometimes presented solely as a positive 'asset', such as with the glorification of hyperfocus as a tool for productivity (Broderick & Roscigno, 2021). In both instances, CDS offers a useful critical lens through its critique of the dominance of a medical model of disability in which disability is conceptualized as an individual deficit that calls for treatment or compensation (Goodley, 2016).

Spiel and Gerling (2020) observe that despite an increasing interest in video games and marginalization, more clinically oriented studies of neurodiversity and games dominate. Design-based approaches use video games to treat a specific condition or for a diagnostic assessment (Lau et al., 2017). Additionally, the field of psychology sees an increasing interest in the therapeutic uses of specific video games (Dewhirst et al., 2022). Importantly, Spiel and Gerling (2020) point out that these approaches to disability reflect a perspective on technology and video games as a quick fix for neurodiversity-related difficulties. Besides the potential therapeutic use of games, interest in their possibilities to facilitate psychoeducation is also growing (Ceranoglu, 2010; Rice, 2022). Specifically, games are praised for their possibilities for perspective-taking (Bennett & Rosner, 2019; Schrier & Farber, 2021). Since representations of neurodiversity in video games always reflect certain ideas and norms about neuro(a)typicality, it is crucial to (re)think critically together with and guided by neurodivergent people: what these games (should) look like? and what their implied goals should be?

# **METHODOLOGY**

### PARTICIPANTS AND INTERVIEW CONTEXT

I conducted 10 interviews with participants with experiences of autism (5), psychosis (2), and obsessive-compulsive disorder (OCD) (3). Participants were recruited through an open call shared within Dutch and Flemish peer networks for specific diagnoses, on social media such as Facebook and Twitter, and through my personal and professional network. I aimed to select adults of any age and with a balance in gender identities. Some participants responded because of their affinity with video games, while others did not have (extensive) gaming experience, a variable that I welcomed. Participants chose the interview location and while some preferred the safety of their own home, others did not want or could not let someone else enter the safe space of their home and preferred to be interviewed in my office. My position as a neurodivergent scholar working within the field of critical disability studies influenced the interviews fundamentally since I was able to relate closely to many of the participants' experiences. My lived awareness of the impact of stigma and misunderstanding made me want

<sup>1</sup> Since OCD is often experienced as something external to oneself (egodystonic) rather than a fundamental part of oneself (egosyntonic), as is the case with, for example, autism or psychosis, it is perhaps more difficult to relate it to neurodiversity as a political identity. Rather, with this paper I want to demonstrate how neurodiversity can function as an emancipatory framework, with methodological implications that can also be beneficial for engaging with OCD.

<sup>2</sup> The interviews were conducted, transcribed, and analyzed in Dutch. For the purposes of publication, relevant fragments were translated into English.

to conduct the interviews as non-hierarchically as possible, and I went into these interviews with the intention of consciously paying attention to this (Table 1).

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PSEUDONYM	AGE	DIAGNOSIS AS DESCRIBED BY PARTICIPANTS	EXPERIENCE WITH VIDEO GAMES <sup>3</sup>	DISCLOSED COOCCURRING CONDITIONS <sup>4</sup>	
Axel	30	Autism	Avid player	Intellectual disability	
Bernard	45	OCD	Avid player		
Lieke	26	Psychosis sensitivity	Avid player	Autism	
Lydia	24	Early-onset autism	Occasional player	ADHD	
Menno	40s	Psychosis sensitivity	Occasional player		
Moniek	29	Classic autism	Casual player	Intellectual disability	
Nelleke	33	OCD	Occasional player		
Roel	35	Autism (Asperger's)	Casual player		
Silke	25	Compulsions	None	Depression and psychotic mood disorder	
Simone	44	High-functioning autism	Occasional player (mostly with her son)		

**Table 1** Participant demographics by pseudonym.

# **INTERVIEWING THROUGH VIDEO GAMES**

During the interview (average 90 min long), the participants first played a preselected video game. I made some field notes about the interview setting and asked questions about the sound, visuals, and gameplay to stimulate the participants' reflection on their playing experience.

The educational video games, *Prism* (autism), *Split Mind* (psychosis), and *OCGame* (OCD), each thematized a specific diagnosis. *Prism* is designed in an academic context, intended to be an applied game for children around the age of 8. *Split Mind* is created with the intention of battling stigma, by a woman with experiences of psychosis and her husband, and *OCGame* is an autobiographical game released on the designer's personal profile on indie game platform *Itch.io*. All games were still in the early stages of development. For pragmatic reasons, I only selected free-to-play single-player video games that could be completed within 30 min. More important than genres was that the selected games treated mental health themes with sensitivity and care, and explicitly focused on (education about) psychiatric diagnoses. I began with an interest in certain psychiatric conditions that are often discussed within the neurodiversity movement. However, when no suitable games were available (which was, e.g., the case with ADHD and Tourette), I chose to switch to OCD, which was explicitly and carefully represented in *OCGame*.

The participants were informed in advance that the games were intended to explain to outsiders what it is like to have a particular psychiatric diagnosis. However, I only explained the context of the specific game we played afterward. Participants were not required to play the game until completion, and some used this option to quit early. Playing the game happened together behind my laptop in the case of *Prism* and *Split Mind*, and next to each other looking at my phone in the case of *OCGame*. Although I offered participants the opportunity to play on their own devices, all of them preferred to play on mine. Only Lieke chose to use her headphones when *Split Mind* suggested to put on headphones to increase the immersive experience. The participants were free to play the game according to their preferences and received no explicit instructions, but most of them naturally followed a think-aloud protocol (Knoll, 2018). This

<sup>3</sup> When getting acquainted with the participants through e-mail, I asked them whether they had played videogames before. These four categories are based on their answers: avid players who played (almost) daily, casual players who would play once per week or so, occasional players who would mostly play in a social context or had played but did not do so anymore, and those who had never played a game before.

<sup>4</sup> I did not ask the participants to disclose any cooccurring conditions, but they were invited to share any details about their diagnosis that they found important.

meant they commented on their experiences and described the in-game events to me as they played (Table 2).

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VIDEO GAME	DESCRIPTION	PLAYED WITH
Prism	Third-person game where the player controls a fox who, being a night animal, experiences difficulties adapting to daytime and sunlight, which serves as a metaphor for autism-related sensory sensitivity.	<ul><li>Roel</li><li>Simone</li><li>Axel</li><li>Moniek</li><li>Lydia</li></ul>
Split Mind	The only game from a first-person perspective, where the player steps into the mind of the female protagonist experiencing paranoid schizophrenia and plays as if they were her.	<ul><li>Lieke</li><li>Menno</li></ul>
OCGame	The most abstract of the three games, designed like a retro platformer game where the player controls the female protagonist and looks at the events happening from a distance. Cut scenes with text boxes explaining her anxious thoughts and compulsions allow the player to relate to her experiences.	

**Table 2** Video games with descriptions.

### DATA COLLECTION AND ANALYSIS

Interviews took place in three different phases spread out over a year: November–December 2021 (autistic participants), February 2022 (participants with experience of psychosis), and November 2022 (participants with OCD diagnosis). After the participants played the selected video game, I would let the conversation flow semi-freely. The questions asked were mainly intended to provoke reflection, rather than to exhaustively discuss them. More general questions concerned how the game related to other playing experiences and media consumption, and what the participants thought the application of such a game could be. Additional questions encouraged participants to discuss their emotional and embodied experiences, and were intended to trigger reflection on themes such as their feelings and thoughts while playing the game, possible identification with the in-game representation, or their opinions on the very existence of the game.

The interviews were conducted and analyzed within the framework of IPA (Smith et al., 2022; Vagle, 2018). Drawing on the philosophical approach of phenomenology, IPA aims to understand experiences as experience, to find out how particular groups of people make sense of certain phenomena. As such, IPA is 'exploratory rather than explanatory' (Larkin & Thompson, 2011), intended for broad and open investigations that can produce new insights into the phenomena under investigation, rather than testing hypotheses, producing explanations or confirming pre-existing theories (Smith et al., 2022). IPA involves not only looking for sameness but also capturing individual variations. The inductive coding process, starting from the data, was carried out both by hand, on the printed transcripts, and in Word, by using the comment function. In the process of coding these interpretations, I preferred to work as manually as possible to engage as closely as possible with the individual stories. I compiled a document where I ordered codes and relevant data excerpts, identified patterns, and formulated preliminary subthemes. I reviewed and reordered these themes by printing and cutting them out and ordering them manually. This allowed me to split, combine, and discard themes in order to refine them. The hermeneutic analysis, where I repeatedly moved from the raw research materials to the analysis and back again, while simultaneously acknowledging my own frame of reference, happened continually throughout this year. More intense periods shortly after conducting the interviews alternated with more relaxed reflections in between these periods. I first wrote up a plot reading of the themes in August 2022, after which I incorporated the final interviews and refined the themes. The final analysis focused on themes that returned in conversations with all participants, but the individual contexts and idiosyncrasies of their experiences were always taken into consideration as well.

# **FINDINGS**

This study explored what it meant for the participants to play a video game intended to communicate to outsiders a vision of neurodiversity that also represents (parts of) their lived

experience. In general, their experience was characterized by attempts to find a balance between optimism about seeing themselves represented in a video game, and criticism about the specificities of those representations. Additionally, participants were emotionally invested in how the video game they played was used and received in practice. Analysis of the data using IPA led to the formulation of three main themes: (1) working with and around the diagnostic label, (2) the paradox of understanding, and (3) the serious nature of video games. These themes will now be discussed in greater detail.

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### **WORKING WITH AND AROUND THE DIAGNOSTIC LABEL**

A diagnostic label such as autism spectrum disorder, OCD, or psychosis sensitivity influences self-understanding, as well as someone's perspective on and interpretation of the world around them (O'Connor et al., 2018). Many participants interpreted the video game we played together based on their lived experience. Vice versa, they referred to aspects of the video game to better explain their experiences with a specific diagnosis. Nevertheless, they were all triggered by different aspects of the games, and related to the games differently.

# Lived experience as a guiding principle for game comprehension

While playing, the participants often empathized with the perspective of the game's protagonist, who had a specific psychiatric diagnosis that the player could get to know better by playing. For example, Moniek interpreted the game she played based on her personal experiences of autism, making her lived experience a guiding principle for understanding the game. While playing Prism, she notes that the little fox she controls walks slowly and at a consistent pace. Although the fox did not recognizably move slower than the other game characters, Moniek believes this is intended as a metaphor for the slower information processing that some autistic people experience. Later, when asked if Prism also represents parts of her experiences, Moniek refers back to the details of information processing:

The game is slower than normal. Because normally you're stimulated to go faster and faster. And at some point you just get overexcited because you have to act and think and do things so fast. For example, if you have to do too many things at the same time and then at a certain moment your head, especially in people with autism I think, says 'you just figure it out yourself. I'm going standby'. [Moniek]

Moniek describes how an information overload can sometimes make it difficult to think clearly at all, with her brain 'going standby'. She gives an interpretation of the meaning of a game element based on an aspect she herself deals with in her daily life, reinforcing the connection between herself and the game character.

However, not only their interpretations, but also the participants' in-game actions are influenced by their experiences. Roel plays Prism (a game from a third-person perspective) and mostly looks at the scene from a distance to offer advice as an outsider. When he is tasked with convincing different animals to help build a bridge over the river, he runs into a little deer. The deer's attention is completely captured by some fireflies and does not respond at first when Roel-as-the-fox starts a conversation. Based on his first-hand knowledge, Roel tries to empathize with the character and thus determine which decision to make in the game:

If I answer '2' ... then he's probably going to start a whole dialogue. Then I am feeding his interest. If I press '1' then that can either trigger an alarm or panic response, or he's effectively going to listen to me. [Roel]

Roel selects option '2' and decides to adapt his communication style to get on the level of the deer and asks some specific questions about the fireflies. In summary, all participants made sense of the game based on their own experiences, but this happened at different levels. Moniek adopted a meta-perspective, thinking from the intention of the game designers, while Roel tried to think along with the character's perspective. Additionally, not all participants made personal interpretations of the game like Moniek did. Some participants felt most comfortable with keeping a critical distance from the themes of the game, and based their in-game decisions largely on knowledge of the symptoms attributed to a specific diagnosis.

### Video games as a reference point for sharing experiences

On both the levels of gameplay, narrative, and design elements, participants would recognize an aspect of their own experience, or a personal preference, and discuss it by referring to it. Even when their experience did not match the game, participants would still acknowledge it:

It's funny, though. I didn't brush my teeth for a long time either but that wasn't 'I hate myself,' it was because it just didn't occur to me to brush my teeth. So it was just not a thought that I had room for or something. [Menno]

Referring to *Split Mind*, Menno's comment indicates that there can be different underlying reasons for the same behavior. In the game, the reason for not wanting to brush one's teeth is formulated quite strongly. However, as Menno stresses, for him the underlying thoughts were not so explicitly negative, it simply did not occur to him to do so. Pointing out that contrast helps to put into words what for him was the exact reasoning behind his actions.

Besides the narrative component, the affective and embodied aspect of the game means that what only takes place 'on the inside', in one's head, can now be made tangible and thus discussable. Lieke is playing Split Mind, where the player character moves around in their apartment completing everyday tasks while experiencing hallucinations of increasing intensity. In the video game, these hallucinations are represented as pixelated black speckles showing up for a few seconds at a time. Lieke recognizes the metaphor and relates it to her own experiences:

You see black spots from the corner of your eye and when you look at it it's gone, which is really not nice. I kind of recognize that. ... Then I think I see someone sitting like that. But it is very brief. And when I look at it, of course it's gone [Lieke]

The black spot metaphor evokes a tense and unsettling feeling in the player, to which Lieke refers. The experiences of hallucination that she describes may be hard to imagine for someone who has not experienced it themselves, precisely because it is something so elusive. However, by referring to specific effects, it is still possible to have a conversation about the hallucinations together, without all the work of finding the right wording coming down to Lieke alone.

Finally, even explicitly positive aspects of the video games can trigger negative effects. Silke played *OCGame*, where the player has to move a box a certain amount of time in order to relieve their anxious thoughts. Looking at the in-game events from a distance, Silke felt the acknowledgment and recognition of her experiences, but also unease related to her self-image. *OCGame* ends with a hopeful and nuanced message, where the player character is supported by friends to go to a psychiatrist. Although the OCD-related symptoms will never really disappear, the main character learns to live with them as well as possible. For Silke, *OCGame's* portrayal of OCD feels not as one of many experiences, but as the correct and only experience. In the past, she has received extensive psychological and psychiatric care but has not found satisfactory support yet. The realization, induced by the video game, that this is different from others is confrontational and reinforces her self-image as 'abnormal and crazy':

I also realized while playing, that in that case I am really abnormal. ... they say 'I found help at a psychiatrist' ... and then I think, oh yes, but that's not the case with me. And that makes me really, really abnormal and crazy. [Silke]

*OCGame's* hopeful ending does not match Silke's experiences, confirming her fear that she is one of the exceptionally 'bad' cases. As such, the positive closing message has an exclusionary effect on those who do not recognize themselves in it.

### THE PARADOX OF UNDERSTANDING

The participants' beliefs on whether it was possible for others to understand their own perspective through a video game also influenced the nature and emotional intensity of their playing experience. If at the start of the interview, participants were optimistic about the possibility of a video game to represent their own perspectives, they generally also had a more positive experience while playing the game. The reverse was also true: a more critical perspective led to a more frustrating playing experience. Additionally, participants questioned how these video games attempt to induce understanding from outsiders, and expressed several reservations about (gamified) perspective-taking exercises.

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# Do we need to understand to be understanding?

Most of the participants were enthusiastic about the theoretical potential of simulation games to show not only what a psychiatric condition looks like from the outside, but also what's going on in someone else's mind. When discussing the behavior of the different animals in *Prism*, Simone describes that even though her expression of sensory sensitivities might differ from other autistic people, the underlying thought processes are still quite similar:

I see the underlying processes and I recognize them, then I think yes, I do understand where it is coming from. ... And it's that underlying part that the explanation should be about. Not how it presents itself. [Simone]

The perspective-taking that the video games enable to better understand what it means to experience a certain expression of neurodiversity. However, participants frequently objected that since neurodivergent experiences are so heterogenous, it would be impossible to include all of them in a single game. So while most participants agreed that video games can support the process of another person's understanding, they did question whether it is ultimately possible to make a game that really makes another person fully understand their experiences.

Additionally, participants were divided on the necessity of perspective-taking exercises—where players are put into the shoes of a neurodivergent person—to increase understanding. They were especially skeptical about the potential to convey through gameplay what it is like to experience something on an affective level:

I think people are indeed going to be a little frustrated, but they are not going to feel the panic and overwhelming feeling that we are experiencing. [Nelleke]

Nelleke is reflecting on the exercise in *OCGame* where the player physically has to move the game character with the key arrows and move a box a certain amount of times to make them experience some of the OCD-related obsessive behavior. She is skeptical whether the feeling of frustration the player will experience when they lose track of their counting will really convey what OCD is like.

Here, Nelleke also refers to the different aspects that are involved in understanding another person's experience. Besides having knowledge about certain characteristics or the social implications of a diagnosis, much also happens at an affective level. Performing the same compulsive actions can evoke different effects in people, so they still do not literally experience the same thing. Therefore, the promise of simulation games to really show players 'what it is like' can never really be fulfilled.

# Fear of misunderstanding

Participants frequently addressed aspects of their personal experiences that were missing in the game, such as the impact on their daily lives, or traumatizing events such as forced hospitalization. Even though none of the participants found the representations of their respective diagnoses to be completely in line with their own experiences, there were always some aspects that they did recognize. Additionally, even though they did not always like the specific representation, most participants were sympathetic to the core intention of educational games. However, ambivalent feeling of being grateful for the attention to one's perspective, but simultaneously fearing stereotyping and misunderstanding, was frequently addressed. Menno, for example, was skeptical about the representation of psychosis as something strictly negative:

If you only have something negative like this [game], then I'm afraid people are going to kind of feel sorry for you more than say ... 'how you see the world has value too. I don't get it, but we can stay in conversation about that'. [Menno]

Menno stresses how the portrayal of psychosis as something strictly negative can also cause further dialogical misunderstanding. If players do not properly understand the multi-faceted meaning of experiencing psychosis, this will interfere with the opportunity to communicate about it as well.

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Disability Research DOI: 10.16993/sjdr.1037 Fearing stigmatization, most of the participants did not necessarily want outsiders to attempt and see situations from their perspective. Rather, they believed improving communication to be something that neurodivergent people could benefit from more. Simone found it important for people to adapt their communication to the preferred style of the neurodivergent person, instead of expecting them to meet their own communicative expectations:

And that's a message I might really want to put into such a game. Why should we have to adapt to you all the time when there is little or no flexibility from your side. [Simone]

She believes that a video game-like *Prism*, which demonstrates the interaction between different kinds of animals and makes players adapt to their needs in order to make progress in the game, would be able to convey this message quite well. Many participants similarly expressed that the purpose of video games like the one we played should be to make players reflect on their own role in the interaction with neurodivergent people. This shows a preference for not primarily receiving understanding or care, but for an equitable approach, even if others do not exactly understand their lived experiences.

### THE SERIOUS NATURE OF PLAY

Since the video games also offered difficult and emotionally intense experiences, most participants did not find them entertaining, but they did find their playing experiences meaningful. Due to the seriousness of the themes they dealt with, for most participants the entertainment value of the video games we played was no priority. However, Moniek negated the opposition between serious games and entertainment games. To an outsider, *Prism* might be a boring game, since the game is quite slow and not very challenging, but it was meaningful to Moniek:

Because [the game] shows exactly what autism does to you. And therefore it is not boring but educational. [Moniek]

For Moniek, education is the opposite of boring because the theme matters to her on a personal level. As such, her reaction negates the common opposition between serious games as boring and entertainment games as engaging; it is not boring, exactly because the game is educational.

Although the participants were unmistakably playing, 'play' started to mean more than merely entertainment. The video games we played during the interviews are designed to evoke a feeling of what it is like to experience paranoia, sensory overload, or compulsive thoughts. Those participants whose own sensitivities were triggered through the game simulations often struggled to get through it. Bernard, for example, asked to quit playing before completing the game because he started to feel anxious due to the repetitive tasks that *OCGame* makes its players perform. Furthermore, Simone complained about the effect in *Prism* where the screen became increasingly brightly lit and pixelated, while the soundtrack also became increasingly shrill. Only after pressing the 'F' key, the wolf-like player-character would howl in order to release pressure, and the effect would briefly disappear. This visualization was intended to simulate sensory overload but triggered Simone's sensory sensitivities as well.

For others, the setting in which they played the game also influenced their gameplay experience:

I always find that stressful. ... when someone is just sitting there looking at you ... Then I always think oh, if only I'm doing the right thing. Don't forget what the buttons mean, ..., I do find that stressful. [Lydia]

Lydia describes that she was often afraid of doing something wrong and was looking for the 'right' way to play the game. She felt hyper-aware of her gaming behavior and started to experience it differently: it became a chore that she continued doing out of a sense of duty whereas in her home environment, she might have quit the game earlier out of boredom or frustration. However, for Axel, who was already an experienced gamer, the openness of the gameworld offered freedom to engage creatively with the limits of *Prism*. When a game bug appeared that allowed for an infinite amount of apples to be generated, Axel starts to explore:

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Disability Research DOI: 10.16993/sjdr.1037 I'm stacking. I'm very curious as to how far I can stack the fruit. Seeing how much fruit I can drag along. ... Well, now that I see what it looks like I believe that's not the intention [of the game]. It's crooked. [Axel]

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Axel tests all sorts of possibilities and clearly enjoyed creating strange and unexpected situations, effectively subverting the research context as well by bringing his personal creativity and play preferences both to the game and to the interview context.

# THEORETICAL IMPLICATIONS

Although this study was conducted and analyzed through a neurodiversity lens, the participants' thought process during the interview was primarily guided by an (internalized) medical perspective on their respective diagnoses (Sims et al., 2021). A diagnostic label guides self-understanding, as well as someone's perspective on and interpretation of the world around them. Additionally, being aware of one's own diagnostic label can also make someone feel responsible to be representative of that particular diagnosis, and adopt the role of expert by experience (Voronka, 2019). For most participants, the playing process was characterized by constantly relating the video game to their own experiences with their psychiatric diagnosis. However, it differed per person and situation if they made sense of the video game based on lived experience and self-understanding or based on general knowledge about their own diagnosis. While playing, some participants would base their in-game decisions and interpretations on knowledge of the symptoms attributed to a specific diagnosis.

Remi Yergeau (2018), writing about the rhetorical and performative dimensions of autism, describes this common (even customary) process where cultural expressions of autism are interpreted by linking visual and textual features to specific symptoms of disability and illness. Yergeau is critical of this 'symptomatic' or 'diagnostic' reading mode since it limits the meaning of disability to a purely clinical classification, 'a mere check box on a patient intake form' (Yergeau, 2018: 13).<sup>5</sup> However, if done by neurodivergent people themselves, as was the case in these interviews, the symptomatic interpretations gain additional significance. Discussing these topics from a third-person perspective or based on knowledge about symptoms creates a safe distance, while relating directly to oneself and one's own experiences is much more confrontational. In principle, many of the games made it possible to do both of these things, simultaneously or alternately, but not all participants took advantage of this.

Others, who had not yet created easily narratable stories based on their experiences, were more likely to use the video games as an aid in reliving and making sense of these experiences from a safe distance in order to discuss them. Sandra Danilovic (2019), in her study on the self-healing resources of autobiographical game design, describes the process of sociopoiesis. This collective meaning-making process allowed the game designers who participated in her study to embody different epistemological perspectives at the same time. Working on a game about their own experiences allowed them to immerse themselves and distance themselves at the same time, due to cognitive shifts among the subjective, second-person relational, and observer perspectives. The same process was visible during the interviews in this study, where the participants were able to retell and reflect on their own experiences by playing something similar in a video game.

All participants were hesitant or at least ambivalent about the possibility of educational video games to fully teach their players what it is like to be autistic, have OCD, or experience psychosis. As an alternative to perspective-taking, some participants proposed promoting non-hierarchical communication as a possible purpose of the video game they played. This approach is also reflected in Damian Milton's double empathy hypothesis. Milton (2012) observes that autistic and non-autistic individuals have differences in their sociality that lead to frequent misunderstandings during interaction. However, he maintains, that these communication difficulties are bi-directional and not caused by a cognitive deficit in the autistic communication

Besides Yergeau, others have written about the reductive nature of making only diagnostic interpretations of disability and illness narratives, and have proposed alternatives (Bérubé, 2016; Rodas, 2018; Savarese, 2018). The main criticisms are that such a reading mode leaves no space for all the different ways in which we can relate to language, expression, and subjectivity, and also overlooks what these narratives can do or generate (Van Goidsenhoven, Forthcoming). These critiques can also be viewed as responses in Cultural Studies to the common criticism within CDS of the limitations of a strictly (bio)medical approach to disability.

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partner. Milton's hypothesis focuses on autism, but its open formulation makes it arguably also applicable to communication difficulties that arise related to different expressions of neurodiversity (Milton et al., 2022). While it is a joint responsibility of the conversation partners to attend to miscommunications that arise as a natural feature of cross-neurotype communication, the differences in communication style themselves should be accepted rather than overcome.<sup>6</sup> In this light, it becomes possible to better understand why the participants stressed the importance of valuing other people's perspectives, even if we do not completely understand them.

Since the topic is not something they can take a break from, playing a video game closely related to their own psychiatric diagnosis was a very intense and serious experience for many participants. However, the negative effects they experienced while playing also demand some reflection on the nature of play. The inclusion of neurodivergent experiences in thinking about play means also attending to the difficult feelings that play can generate. Aaron Trammell (2023) discusses how many canonical definitions of play, such as those from Huizinga, Caillois, and Piaget, exclude black experiences of playfulness. Trammell discusses the wide range of effects that play can produce—from pain to amusement and everything in between—and questions who has access to which feelings and why. Similarly, Bo Ruberg's (2019) notion of queer forms of play beyond 'fun' stresses the potential playfulness and subversiveness of experiencing more difficult and negative emotions through gameplay. Both Ruberg and Trammel propose a reparative definition of play that opens up the concept to negative experiences related to play as well. Taking neurodivergent play seriously, in turn, means attending to all complex feelings that playing a game can evoke and interpreting them as play, rather than only interpreting them as a symptom or side-effect of a specific diagnosis.

### **LIMITATIONS**

Although the interview process opened up space for the exploration of neurodivergent lived experiences, it also generated many tensions that can be attended to in further work. In the selection of participants, potential intersecting identity markers were considered. However, since the recruitment primarily happened through informal networks and peer network associations in which white, middle-class people are overrepresented, this was most likely also the case for the participant group I ended up interviewing. Importantly, this overrepresentation also influenced the topics that were (not) discussed: I was only able to reach participants who had access to an official psychiatric diagnosis (although not always one they felt content or comfortable with), which is also dependent on socioeconomic status (Delgadillo et al., 2018; Niemeyer & Knaevelsrud, 2022). Consequently, we did not discuss themes such as the benefits of applied video games for those who do not have access to psychological care, for example, recognition and validation, self-diagnosis, and support.

# **CONCLUSION**

This article explored what it means for someone to play a video game which is intended to communicate to outsiders a vision of neurodiversity that also represents (parts of) their lived experience. The experiences of the participants were all widely varied, which demonstrates the plurality of meanings that being confronted with a representation of one's own psychiatric diagnosis can have. Some participants saw the video game as a validation that their experiences should be taken seriously and are worthwhile to look at. Others were especially critical and uncomfortable with the idea that outsiders would engage effectively with a part of their lived experience. All participants made their own interpretation of the video game based on their lived experience, which also emphasizes the impossibility of video games to mirror a singular neurodivergent mind. Participants were emotionally invested in how the video game they played was used and received in practice. In particular, their concerns about

<sup>6</sup> A customary assumption is that communication differences that lead to miscommunication need to be eliminated, for example, when autistic people are offered Social Skills Training (SST) by authority figures such as psychiatrists (who thereby reinforce the idea that their communication style is something that should be fixed). Seen from the other side, perspective-taking videogames through which 'outsiders' can increase their understanding of a specific expression of neurodiversity, could also be viewed as an attempt to fix communication differences.

stereotypes show how prevalent these still are in media representations of specific expressions of neurodiversity. In contrast, the video games did offer participants a way to reflect on themselves. Playing video games during the interviews formed a good conversation starter for sharing neurodiversity-related experiences, which also demonstrates their meaningful complementarity to traditional interview-based qualitative research. My hope is that this study triggers some critical discussions about the development and application of educational games, stimulating further research into the way that video games can support the self-identified needs of neurodivergent people besides provoking understanding from outsiders. However, my aim is not to be critical of the video game medium as such. I believe there could be an important role for video games about neurodiversity-related themes for neurodivergent people as well: to provide in a playful and creative manner recognition, self-understanding, and the language to explain their own experiences to others.

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# **ETHICS AND CONSENT**

For this study, I obtained permission from the University of Antwerp Ethics Committee for the Social Sciences and Humanities (study number SHW\_21\_116). Participants signed an informed consent form and a pseudonym was used in the reporting of the interviews.

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# **COMPETING INTERESTS**

The author has no competing interests to declare.

### **AUTHOR AFFILIATIONS**

**Lisanne Meinen** orcid.org/0000-0002-3771-1362 University of Antwerp, BE

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