Representation of Invisible Disability: Exploring the Lived Experience of Teenagers with ADHD to Inform Game Design

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Representation of disability in games is important to facilitate inclusive experiences. In our work, we address this issue through an exploration of the representation of ADHD in games. First, we engage in interviews with 15 young people with ADHD to understand their lived experience of ADHD and their perspective on its integration in games. Second, we formulate considerations for the design of games that include ADHD in a way that aligns with their experience. Finally, we apply the guidelines to develop three game concepts and evaluate them with the initial group of young people to critically appraise our design considerations. The results show that nuanced representation of ADHD requires careful deliberation, that lived experience should be leveraged with care, and that game design must be mindful of the challenges associated with identifying the fine line between disability simulation and adequate representation.

CCS Concepts: • **Human-centered computing** → **User studies**; • **Software and its engineering** → **Interactive games**;

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1 Introduction

Representation of disability in games is a relevant [40] focus point for game design because it makes disability visible within the space of digital games [16]. This allows disabled players to identify themselves in digital experiences, a process that has always been available to non-disabled players and that improves player experience [5]. Thus, representation of disability contributes to equitable access to digital play and should therefore be considered by researchers and designers in this space. While some advances have been made with respect to the representation of visible disability in games, e.g., the integration of assistive devices such as wheelchairs in avatar creation systems [36], representations of invisible disabilities—those that are not immediately visible to others [29], e.g., deafness, learning disabilities, **Attention Deficit Hyperactivity Disorder (ADHD)**, or autism—remain underexplored. Here, indie games such as An Aspie Life [28] and Depression Quest [46] are examples of individual explorations of the experiences of autism and depression, and there are research efforts that have explored game-based simulation of invisible disability in the hope of fostering empathy [61]; however, there is no structured shift toward including invisible disability in mainstream gaming. One challenge posed to this is that it cannot be approached through adjustment of the visuals of in-game characters, the main avenue currently leveraged for representation of visible disability in games. Instead, alternative strategies such as the design of in-game character traits, game mechanics, and the game world and overarching narrative need to be explored as potential pathways to representation.

In our work, we address this issue through examination of opportunities and challenges when wishing to include representation of ADHD in games. ADHD is a form of neurodivergence, i.e., neurological difference, and a medical diagnosis that refers to persistent patterns of inattention, hyperactivity and/or impulsivity which impacts how individuals perceive and interact with the world [17]. Here, we focus on adolescents, a group particularly relevant in the context of ADHD, because the condition is typically diagnosed in childhood [45] and strongly affects how adolescents experience family life, school, and leisure [47]. A key challenge for our work is to disentangle the often deficit-focused clinical picture of ADHD [53, 55], the undesirable drawbacks associated with disability simulation (e.g., evoking pity and reinforcing negative stereotypes [37, 42]), and the actual lived experience of young people, in the hope of avoiding stigmatizing representation.

Through our work, we seek to answer the following two **research questions (RQs)**:

RQ1: What are the lived experiences of teenagers with ADHD and how can they be translated into a game (i.e., player characters, non-player characters, and the game world)?

RQ2: What are the challenges and opportunities when creating a game that includes ADHD regarding respectful and accurate representation of ADHD?

We engaged in a qualitative research process to address these RQs. In the first step of our work, we invited 15 teenagers with ADHD to participate in focus groups to examine their perspectives on living with ADHD and potential avenues for representation of ADHD in games. Through Thematic Analysis [9], we show that living with ADHD is challenging for young people particularly because of environmental factors (e.g., due to requirements of maintaining focus or managing unrest being difficult particularly in the context of school), that coping strategies and a life that does not revolve around ADHD are important, and that negative societal perspectives on ADHD strongly impact young people and how they perceive themselves and the implications of ADHD for their lives. In terms of representation of ADHD, participants saw potential in the design of in-game characters that had traits of it and viewed it as an opportunity to normalize ADHD and share knowledge about it. On the basis of these results, we compiled considerations for the representation of ADHD in games, *(1) ADHD is experienced as energy-consuming impairment, but symptom strength differs,*

(2) Coping strategies exist, but there are strings attached, (3) The negative experience of ADHD is amplified by the (social) environment, and (4) ADHD is not all the person is. Building upon them, we devised three game ideas, each addressing a different game genre and taking a different approach toward representation of ADHD. In a final focus group, these ideas were reviewed by the initial group of young people with ADHD in an effort to refine the considerations for design.

Our work makes the following three main contributions: (1) We provide a first exploration of representation of invisible disability in games from the perspective of game design, showing how elements beyond game visuals can be leveraged to represent disability. (2) We provide design considerations for the representation of ADHD in games that center the experiences of young people with ADHD, thereby supporting the work of researchers and designers wishing to represent ADHD in their games. (3) We discuss challenges in representing ADHD in games and reflect on the tension between representation, disability simulation, and the challenge of accurately representing individual experience while avoiding stereotypical or stigmatizing representation of ADHD.

Representation of neurodivergence in games is an important step toward more inclusive experiences that reflect the diversity of our societies. Through our work, we hope to take a first step toward the representation of invisible disability in games, offering starting points for design as well as insights into potential pitfalls that need to be avoided. Likewise, our work offers insights into the lived experience of ADHD. We hope that it will encourage conversation within our research community about how it can inform the design of technology more broadly, contributing to the body of literature that seeks to prompt reflection on how we understand ADHD, and how researchers and designers approach it.

2 Related Work

This section covers two areas of relevance to our work: First, we provide an introduction to ADHD. Second, this section gives an overview of related work on representation of disability in games.

2.1 An Introduction to ADHD

There are different views of ADHD, as well as a range of expressions of the condition. From a clinical perspective, it is a diagnostic classification of the **Diagnostic and Statistical Manual of Mental Disorders (DSM-5**; [2]**)**. ADHD is characterized by the DSM-5 as having persistent patterns of inattention, hyperactivity, and/or impulsivity symptoms [2]. This pattern of inattentive, hyperactive, and/or impulsive symptoms is inconsistent with the developmental level of the individual and interferes with functioning or development. In contrast, the lens of neurodiversity allows us to view instances of neurodivergence such as ADHD or autism without broadly pathologizing individual traits, instead leaving room to understand both opportunities and challenges that are associated with neurological difference both on a personal and societal level [6]. This shift in perspective allows us to appreciate the heterogeneity of neurodivergent individuals and opens up a space to adjust perspectives and challenge the notion of disorder and medical labels [3]. Applying the currently available diagnostic criteria, ADHD is one of the most prevalent diagnostic classifications in childhood and adolescence, with estimated prevalence rates of around 5% [45]. Prevalence of diagnoses and medication rates are higher among boys (see [62]), prompting discussion regarding diagnostic criteria and perspectives on the condition that result in gender differences. This is closely associated with the domains (inattention hyperactivity-impulsivity) and associated subtypes of the condition, i.e., people who present predominantly as inattentive type, the hyperactive-impulsive type, and combined types [64]. Here, girls may present with a set of symptoms uniquely distinct from that of boys [18].

Overall, ADHD is associated with significant differences in academic and social functioning that are often experienced as increasingly challenging throughout adolescence [33, 34]. For example, inattention symptoms, difficulties with organization, elevated levels of activity, and impulsivity make it difficult to meet societal norms and standards of academic success in secondary education in particular (e.g., sitting still and paying attention in class, planning and making homework, waiting before answering questions of teachers; [33]). Furthermore, ADHD symptoms can interfere with social functioning and acceptance among (typically neurotypical) peers, which is increasingly important in adolescence (e.g., forgetting appointments with friends, impulsive responding or interrupting others in social interactions [65]) and has negative implications for well-being.

Here, we want to point out that medical research routinely adopts a perspective that focuses on what is seen as an individual deficit, failing to challenge societal norms and structures that contribute to challenges that people with ADHD experience (e.g., the way that educational systems are structured [26]). To some extent, this issue is addressed through qualitative work. An integrative synthesis of 16 qualitative studies of adolescent's experience of ADHD carried out by clinical researchers reveals four relevant categories [48]. The first category is experiences related to one's body and psychological abilities, such as a lack of control of their behavior, experiencing difficulties with the consequences of having ADHD symptoms, and the biological determination of ADHD [48]. The second category is the ambivalent experience of the need to adapt oneself to demands of their environment but also the need to be accepted as who they are. The third is ambivalence in the social domain; demands and expectations of parents and teachers are difficult, they experience a lack of belonging and stigma, but also express the need for help from significant others. The fourth is related to the challenges in the formation of a personal identity, with negative views of themselves, and ambivalent self-conceptions in relation to their ADHD symptoms. In our work, we adopt a perspective that primarily views ADHD as neurological difference (rather than a disorder as such), and we engage with the existing knowledge and clinical perspectives on ADHD as well as previous studies of lived experience to support our analysis of adolescent's lived experience of ADHD in the context of game design, both as a way of reflecting on their symptoms and to delineate where clinical perspectives on ADHD are insufficient to capture how young people experience their own lives in interaction with their environment.

2.2 Representation of Disability in Games and Implications for Game Accessibility

Discussions around representation of disability in the media [6] have a long history within the academic community, exploring current practice (e.g., see [25] and [41]) as well as challenges and opportunities associated with it. In the context of games, Hawreliak and Lemieux [27] highlight that adequate representation of disability is a matter of justice and is necessary to diversify gaming culture, making gaming a welcoming activity for everyone. Thus, a growing body of work in game studies focuses on the theoretical analysis of how disability is represented in digital games, with case studies predominantly addressing mainstream science-fiction shooters, e.g., Dead Space [13], Borderlands [39], or Cyberpunk 2077 [20]. What unites these pieces of work is their critical perspective on representation of disability in games, highlighting how games that emphasize agency of disabled characters can contribute to more positive perspectives on disability (e.g., see [15]). However, because of the analytical focus, no tangible recommendations for design are derived. Taking a more practical approach, Thompson explores representation of disability in games, highlighting both the powerful potential of accurate representation, while also noting the many ways in which games continue to employ disability as a trope (e.g., that of the disabled villain) [59]. Likewise, Gibbons [24] explores two playful experiences that seek to convey the lived experience of autism. In her work, she effectively outlines the challenges when representing disability in games (e.g., ensuring the playful experience is representative), touches upon pitfalls (e.g., invoking

stereotypes or ableism, such as one of the games framing autism as a *nightmare*, thereby rendering it undesirable), and considerations throughout the design process (e.g., the need to directly involve disabled people in game design). Examining the current state of representation of disability in mainstream games, more recent empirical work by Shell [50] that leverages a combination of game trailer analysis and survey responses shows that disabled characters are still underrepresented and that little guidance for game designers on how to create appropriate disabled game characters is available. This is echoed by industry outlets ([43]), outlining that non-stereotypical representation of disability in games remains challenging and suggesting that designers require better guidance as well as more disability representation within the workforce. Finally, a recent analytical exploration of the role of neurodiversity (i.e., representation of neurological diversity) in games by Meinen [38] highlights that there is potential for games to focus on attunement. In particular, the author argues that enabling players to engage with lived experiences of neurodivergence without postulating empathy or care as a goal for players to achieve [38]. This opens up a new design space, focusing on the *exchange* of experiences of neurodiversity instead. This is in direct disagreement with recent research that leverages games as simulation of invisible disability [61]. In their work, the authors focus on negative experiences of invisible disability without engaging with cautious perspectives on disability simulation (e.g., see [37, 42], and—perhaps predictably—create artifacts that lead to reinforcement of stereotypes and pity among non-disabled players. Previous research has also explored representation of disability as a means of reducing the perception of game characters as "idealized human heroes" [14], but do so without critically appraising how their design approach might impact player attitudes toward disabled persons. This reflects a wider issue within the **Human–Computer Interaction (HCI)** research community that continues to approach disability as a deficit, with harmful consequences for researched communities (including people with ADHD [56]), and unnecessarily narrow perspectives on the potential of technology for these groups [54]. In more recent work, there has been a trend to prioritize the perspective of disabled people (e.g., research examining how to holistically design for children with ADHD in a way that also emphasizes preferences and strengths [57]). Likewise, previous work on children living with ADHD has emphasized the importance of acknowledging lived experience in technology design and evaluation [51], a perspective that we also adopt in our work.

However, relatively little work in the HCI and game research community has addressed representation of disability in games from a designerly perspective, where game accessibility is predominantly approached from the perspective of making game interfaces accessible for disabled players (e.g., see [11]), rather than reflecting on the relevance of in-game content for the experiential accessibility of games. Gerling et al. [22, 23] have provided anecdotal evidence for the relevance of representation of disability in the context of movement-based play and Virtual Reality, concluding that it opens up the opportunity for disabled players to feel more included in play, but also comes with unique design challenges with respect to disabled player avatars. This is also reflected in the literature on serious games for disabled people, which has previously discussed the benefits of personalization and customization of player avatars in the context of physical disability (e.g., see [60]). However, there remains a gap in research that specifically examines representation of invisible disability in games with the goal of providing actionable guidance for researchers and game designers.

In our work, we address this issue specifically with respect to ADHD. We engage in a two-phase research process in which we first examine the perspectives of young people who have ADHD and their thoughts on representation of ADHD in games, and we then devise initial design considerations that we further assess through development of game concepts and in conversation with young people with ADHD.

3 Phase 1: Understanding the Lived Experience of Young People with ADHD and Opportunities for Representation of ADHD in Games

In this first phase of our study, we conducted online focus groups with young people with an ADHD diagnosis (N = 15, four groups) to gain insights in their personal experience of living with ADHD and to understand how they would integrate their experience of ADHD into games. In this phase, we sought to address our *first RQ (RQ1)*: What is the lived experience of teenagers living with ADHD, and how can it be translated into a game?

3.1 Method

Our work employs focus groups that entail exploration of the research topic through conversation and guided ideation around the representation of ADHD in games. In total, we conducted three sessions: (1) a session to allow participants to get to know each other, share their hobbies and interests, and to discuss their lived experience of ADHD, (2) a session to generate initial ideas around the representation of ADHD in games in an open-ended way, and (3) a session to refine and appraise outcomes of the previous one while giving room for structured reflection. For each session, we developed a set of slides that were used to provide structure for participants, including an overview of each session, and information on progression throughout.

3.1.1 Session 1: Exploring the Lived Experience of ADHD. In the first session, participants were introduced to each other and were invited to share their hobbies and interests. Topics for introduction included talking about their favorite games. The topic for discussion that followed addressed their lived experience of ADHD; questions in this part of the focus groups were informed by our review of existing work on ADHD (see Section 2.1), but designed in an open-ended way as to allow participants to recollect their own experiences, rather than limiting them by sets of symptoms that emerged from clinical work. We explored the participants' lived experience using prompts such as: "What does a day in your life look like?" "What parts of your day do you like?" "What parts of your day do you dislike?" "Who do you meet/interact with during the day, and what is it like?" and "Where does ADHD play a role in your day?" Hence, what ADHD meant for the participants could be communicated in the context of their daily lives, i.e., structured around activities and interactions with others. We ended the first session with the question of "How would you explain having ADHD to someone who does not have ADHD?" as a segue into the following session, which would focus on ways of representing of ADHD in games.

3.1.2 Session 2: Initial Idea Generation to Support Representation of ADHD in Games. The second session focused on generating game ideas that would include representation of ADHD. This session was organized in two parts: First, participants were invited to take part in half an hour of free ideation to give them space to express their personal ideas. For this purpose, the participants were given a blank digital post-it board to come up with as many ideas as possible. At the beginning of the activity, participants were given an overview of different approaches toward the representation of ADHD (i.e., through game characters or game mechanics). The second part of this session existed of adapting existing games to include representation of ADHD. The idea behind this approach was to give the participants the opportunity to think of alternative genres, game mechanics, and styles which they might have overlooked during the free ideation approach. For this purpose, we used a series of five of the highest ranking mobile games on the Google Play Store at the time of conducting our study (November 2020): *Minecraft* (a popular sandbox/adventure game), *Among Us* (an online multiplayer social deduction game), *Candy Crush* (a switch-and-match puzzle game), *Toca Life: Hospital* (sandbox game in a hospital setting), and *Chat Master!* (chat scenarios puzzle game). We opted for these games because we assumed that all participants would have experience

playing mobile games due to the widespread popularity of the platform [19], allowing them to relate to the gaming platform, and because we wanted to ensure that we covered a breadth of game genres. To end the session, we asked participants to choose a final, individual game and reflect on the integration of ADHD, e.g., a game they really enjoyed, a game they played recently, or a game they thought would be challenging to adapt to include representation of ADHD.

3.1.3 Session 3: Appraisal and Refinement of Design Ideas. The third and final session did not introduce any new topics but was instead leveraged to jointly review the outcomes of the previous sessions, which were summarized by the research team. This session was intended to give participants opportunity to further elaborate on their perspectives in previous sessions, to make space for ideas that participants may have had after the end of the previous session, and to allow everyone to re-engage with their group's contributions in reflection. Likewise, it enabled the research team to ask clarification questions about participants' comments and design suggestions, allowing us to further refine outcomes together with the participants.

3.2 Participants and Procedure

Participants were recruited from existing pools of young people who had previously registered interest in research about ADHD at our home institution and were located in the Flemish part of Belgium. Additionally, the study was advertised online and through social media channels (e.g., Facebook, X (formerly known as Twitter)), and participants were recruited via word of mouth. A total of 15 young people with an ADHD diagnosis agreed to take part in the online focus groups (mean age = 14.3, SD = 0.7, 4 girls, 11 boys). We deemed this number of participants sufficient as we gained the impression that the body of data was rich enough to allow us to explore in depth participants' lived experiences, with some conversational topics consistently reoccurring [10]. Participants reported different presentations of ADHD, including the inattentive type, hyperactive/impulsive, and a combination thereof. Most participants reported medical management of symptoms; only three participants were not taking medication. All participants were in school, which took up the majority of their time. In terms of gaming habits, most participants played video games regularly (i.e., for at least an hour a day) and across a variety of platforms, with mobile games being most common, followed by modern consoles and PC gaming. Favorite games included construction games such as Minecraft and various action games, e.g., Fortnite, Rocket League, or the Call of Duty and GTA series. Additionally, many participants reported enjoying playing Among Us. Beyond games, participants reported a range of hobbies and interests. Many of them engaged in high-intensity activities, e.g., boxing, cycling, gymnastics, skateboarding, snowboarding, and surfing. Additionally, participants reported a broad range of creative hobbies, e.g., drawing, digital content creation, upcycling and making, playing musical instruments, or being part of drama clubs. Likewise, participants reported activities that they sought out for relaxation, e.g., completing puzzles, building with Lego bricks, watching TV/Netflix, or "hanging out with friends," which was the preferred activity for almost everyone.

At the beginning of the research, participants filled in a screening survey via Qualtrics. Inclusion criteria for participation were an official ADHD diagnosis, age range 13–16, and fluency in the local language. Exclusion criterion was a secondary diagnosis (e.g., ASD). This criterion was introduced as we already expected the group of young people with a diagnosis of ADHD to be quite heterogeneous and because including other groups of young people (e.g., with a diagnosis of autism) would have required a different approach in terms of research methods (e.g., not only offering a group-based option, and also including non-verbal forms of participation). Completing the online screening survey required the candidate participant to download, read, and sign the informed consent form, as well as sign a form of digital discretion, which declared that they agreed

not to take video or audio-recordings of the sessions, agreed that no one would be able to overhear the sessions, and to not spread any information shared during the online focus group sessions. When the adolescent was younger than 16, an additional informed consent form was asked to be read and signed by their parent or guardian. Because of the COVID-19 pandemic, all focus group sessions were organized online using MS Teams, and moderated by the main researcher. We limited the number of participants per focus group to four to facilitate discussion over video call. As such, three groups of four and one group of three participants were created based on participant availability. The members of each group remained the same for all three sessions. At the beginning of each session, participants were welcomed and given space to ask questions that would need to be clarified. Afterward, the main researcher introduced the specific topic of the session (see Section 3.1) and engaged participants in discussion. Here, particular attention was paid to the involvement of all participants, ensuring that everyone would have the chance to contribute their perspective. At the end of each session, participants were given another opportunity to ask questions and thanked for their time. Overall, the session layout and methodological approach enabled all participants to contribute to the focus groups without further support. Each session lasted about an hour and was recorded using the respective functionality in MS Teams. Participants were compensated for their time with a total 50 EUR worth of vouchers, or with 50 EUR transferred directly to a preferred bank account. The research protocol, the method of recruitment, and reimbursement were approved by the KU Leuven Social and Societal Ethics Committee (G-2020-2089).

3.3 Positionality of the Research Team

Because of the qualitative research approach and interpretative, reflexive nature of our chosen analytical approach, Thematic Analysis according to Braun and Clarke [8], it is important to view our findings in the light of the individual backgrounds of the research team.

We have been working in the fields of HCI and clinical psychology for many years and have previously carried out research with young people with ADHD. The HCI researchers involved in this project have backgrounds ranging from Media Studies to Cognitive Science and Computer Science, and they have previously worked on projects that explored games in the context of disability. This includes research into the experiences that games offer for neurodivergent people and examinations of gaming technology from the perspective of disability studies. The Psychology researchers involved in this project are rooted in clinical psychology and have worked with young people in different settings. The main researcher who directly engaged in the focus groups has extensive experience in working with young people in the context of his own involvement in youth movements such as the scouts. There was only a small age gap between the main researcher and the participants, and he is a gamer, so could relate with the participants through shared experiences. The other co-authors have a background in clinical psychology. One is specialized in intervention research for children and adolescents with ADHD and their families and works as a therapist. Another co-author likewise is a clinical psychologist and therapist who was introduced to ADHD during his first internship as a Master student. Here, he became intrigued about the prominent role of the environment (parents, teachers, peers), viewing ADHD through a social lens on disability. Finally, a game developer was involved in this project. Aside from game development, he teaches computer science subjects at university level and has been involved in research into serious games with a particular focus on health, accessibility, and inclusion. There are neurodivergent persons among the research team (including lived experience of ADHD) who identified with the experiences reported by the participants; at times, this made engaging with the data difficult. Likewise, some members of the research team have experience with ADHD in their personal environments, sensitizing their perspective on the importance of accounting for the lived experience of ADHD.

Within the research team, the nature of the research has prompted reflection on different perspectives on ADHD in different research disciplines; everyone within the team expressed the desire to put the needs and perspectives of adolescents with ADHD first and viewed ADHD as something that requires wider societal adjustment and accommodation rather than intervention that solely targets people with ADHD.

3.4 Data Analysis

All video recordings of sessions were transcribed using Word, and transcripts were imported into NVivo 12 (https://lumivero.com/products/nvivo/) for further processing. Data were analyzed using inductive Thematic Analysis, following the reflexive approach put forward by Braun and Clarke [8]. This is an appropriate method of analysis for seeking to understand experiences, thoughts, or behaviors across a qualitative dataset [32]; working inductively allows for exploration of data without *a priori* focus points, thereby prioritizing interpretation of participant perspectives and allowing for bottom-up crafting of themes. Transcription, familiarization with the data through thorough reading the transcripts several times, and initial coding were done by the first author, who also developed the initial themes. These were then discussed and refined within the research team. Throughout the process, we reflected upon our own positionality in an effort to make biases explicit. Initial coding resulted in 390 codes, which were further refined into 31 codes, from which three main themes were crafted.

3.5 Results

Here, we present the results of our qualitative analysis, broken up into the three main themes of *Living with ADHD is Challenging for Young People*, *Identifying Coping Strategies and Maintaining a Life Beyond ADHD*, and *The Impact of a Lack of Knowledge and Empathy in Others*. Within each theme, we highlight how participants thought that characteristics or specific experiences of ADHD could be reflected in games.

3.5.1 Theme 1: Living with ADHD Is Challenging for Young People. Our results show that the participants found living with ADHD challenging and were acutely aware of issues and barriers that they experienced in many areas of their lives. A large majority of the participants' comments emerged around their experience of school, i.e., a structured environment over which they have little control, and in which tasks, expectations, and (in)acceptable behaviors are typically defined by other parties. Here, we organize our findings around the subthemes of *The Struggle to Focus on the Right Thing*, *Managing Inhibition and Unrest*, *Efforts to Maintain Structure and Overview*, and *Navigating Relationships With Others*.

The Struggle to Focus on the Right Thing. This subtheme describes how the majority of participants experienced difficulties with concentration, i.e., focusing on the task at hand and not getting distracted. For example, one participant described the experience of distraction as a situation in which "Stimuli come through a strainer…and for normal people, the most important go through, and the unimportant ones get caught…they then don't go to your thoughts…you don't really hear or see those. But for us, the holes [in the strainer] are way bigger and a lot more reaches us, so we get distracted by so many more things." Here, we highlight that participants did not only acknowledge their efforts to focus but also efficiently pointed out the role that (un)suitable environments play in this process. Furthermore, this subtheme incorporates the added challenge of investing the energy to stay motivated to spend time and energy on tasks such as homework, while already having to make additional efforts to remain focused. For example, one participant commented that "[…] then I am just staring at my book and then I'm like, well, f*ck this. And then I grab my phone and waste my time until five minutes before the end of the study session, and then I panic because I still have

to study. And then I put off studying until 10:00 PM, and then my concentration is even worse, then it's all gone."

Design ideas associated with this subtheme reflect this struggle to focus through adaptations of game mechanics and interface elements but were not necessarily tied to a specific game genre. For example, participants suggested the introduction of mechanics that make it difficult for the player to maintain visual focus on relevant in-game events, including random camera shifts away from the main action, or the introduction of distractors that would occlude important elements of gameplay, e.g., overlapping with written information such as dialogues with non-player characters. Likewise, participants saw potential in reflecting a lack of focus through management of virtual items, i.e., rather than neatly presenting players with a tidy overview of elements such as their own inventory or power-ups, they thought that a less organized in-game interface could communicate their experience of ADHD. Finally, one participant suggested to introduce interface elements specifically addressing ADHD, i.e., similar to how games reflect player health using a *health* bar, they thought that a *motivation* bar could reflect their struggle to maintain focus on a given task.

Managing Inhibition and Unrest. This subtheme describes how participants find it difficult to adjust their bodies to the expectations of others, i.e., inhibiting fidgeting and other movement, remaining silent for long periods and the general act of waiting, or more broadly stopping their thoughts from racing in their head. For many participants, this led to feelings of frustration and irritability because the expected behaviors did not come natural to them. For example, one participant highlighted that "I'm always bouncing in my chair and then I get a note from the teacher. I always have to stay still, but I keep bouncing. I just cannot stop it. It's just stressful to have to sit still all day." and another one pointed out that they were worried about stimming and fidgeting (i.e., engaging in repetitive behaviors to self-soothe), e.g., "I'm afraid that I'd be unconsciously picking those tiny pieces of my skin on my hands, or that I'm wobbling with my nose to move my glasses or something." Additionally, inhibition control was associated with the challenge of acting impulsively, and controlling their emotions. For example, one participant highlighted how he struggled to control his own actions, e.g., "[…] when you are being annoying, they tell you to stop, [but you] cannot immediately stop." With respect to their experience of their own emotions, one participant commented that "my emotions go much deeper, if I am angry, then I am really angry, and if I am sad, then it immediately feels as though the world were about to end. But if I am happy, then I'm really pleased and feeling good. Like that…[how I experience my emotions] is really true." This highlights that participants did not only experience a need to manage their own bodies in response to others but were also aware of the effort that they needed to make to put the way they experience the world in perspective.

Design ideas associated with this subtheme address the experience of failed inhibition control and restlessness through game mechanics. With respect to inhibition control, participants suggested the design of game mechanics in which the player is encouraged to act first, only to reveal full consequences of their actions in the next step, giving them the feeling of having acted prematurely. Here, one participant suggested that unintended effects such as "taking all power-ups at once" rather than one at a time would be an accurate representation of their experience of ADHD. Furthermore, there was consensus that restlessness could best be communicated through physically restless player characters, i.e., including visual indications of fidgeting and other movement, also extending into *random bursts of energy*, e.g., a player character moving faster than the player intended, or starting to move around without player input.

Efforts to Maintain Structure and Overview. This subtheme addresses participants' experiences of attempting to keep track of what is important or expected from them in life, and associated efforts that are required to maintain structure in their lives. On a general level, participants reported that they lived full lives that included busying themselves with many tasks at the same time, but that

their engagement with these tasks was impacted by their ADHD. For example, one participant pointed out that handling many tasks at the same time can be overwhelming: "I am always busy, and I am mostly busy with ten things at the same time, out of which nine never get finished," highlighting that closure was difficult to achieve. Likewise, participants commented that it was common for them to completely forget about tasks such as homework, in turn leading to conflicts in other areas of their lives. Likewise, maintaining structure in a tangible way was not straightforward for many participants, with one commenting that "this is the reason why I never put anything into a cabinet, I just wouldn't find anything any more." Additionally, there were many examples that highlighted how time management was challenging, e.g., "I have to get up at 7:00 AM, and at half, I mean at 7:35 AM, I already have to leave for the bus, but I mostly just leave at 7:40 AM and then I have to run, and that's the norm because I cannot estimate time well." This was echoed by another participant, who frequently lost track of time, and for example stayed out with friends, missing bus after bus that would take them home "until my parents would have to come pick me up eventually."

Design ideas associated with this subtheme predominantly focus on the way that the players receive and are enabled to deal with new tasks within games. Here, participants highlighted how overwhelming the player with new tasks that constantly push into the focus of their attention (e.g., through the game interface) could replicate their experience of struggling to maintain overview. Likewise, participants suggested that simulating the experience of forgetting tasks (either by providing too many, or by removing records of tasks) would align with their lived experience of ADHD. Finally, to represent the experience of beginning new tasks without wrapping up previous ones, participants suggested including comparable mechanisms in games, e.g., intentionally designing in-game tasks that will never lead to closure, and creating virtual worlds in which players are constantly tempted to engage in new aspects of the game without having fully explored their current area of interest.

Navigating Relationships with Others. With respect to direct interactions with other people, participants made detailed observations of their own communication styles, how they differed from that of neurotypical people, and the lengths that they went to adjust their own behavior. For example, one participant pointed out that "[…] in general I talk pretty fast. I am really watching that now for example…so that I don't talk talk too fast. That is certainly one of the things that my parents tell me, or other people who say, can you repeat everything that you just said, but more slowly?" Here, some participants recalled instances where other people had openly asked them to adjust their behavior, e.g., "Eh, yes, people tell me all the time that I have to be quiet because I talk too much."

Additionally, participants were aware of many instances in which their ADHD impacted relationships with others beyond direct conversation. For example, impulsivity and unrest was quoted as a frequent contributor to being seen as a troublemaker when behavior was not intentional, e.g., "At school […] I have to be able to fidget with something. When I sit still, I need something in my hands, and teachers sometimes find that irritating." or "Sitting still in class, I really cannot do it. Especially after lunch, then I like, start telling jokes in class and then everyone is laughing, and then the teacher does not really like that." Likewise, participants reported instances of feeling misunderstood and their efforts to do well-being undervalued by others as a result of a lack of understanding of ADHD. For example, one participant recalled a situation in which a teacher told them "You just have to study harder" in a situation where they had studied extensively, but had not been given enough time to complete their test at school. Generally, we observed a strong desire to fit in and fulfill other people's expectations among the participants, which contradicts the stigmatizing perspective on the child with ADHD as *intentional troublemaker*. Finally, some participants reported being openly discriminated against by others upon disclosing their ADHD, e.g., "I have friends who previously did not know that I have ADHD, they treated me like a regular

person, and when I told them that I had ADHD they immediately started to treat me as if I was a psychopath or something like that."

Design ideas associated with this subtheme were strongly shaped by the experience of being misunderstood and received negatively by others. Here, participants focused on the potential to leverage in-game characters to communicate negative emotions to the player. For example, it was suggested to include "characters that respond angrily to player actions," but to ensure that this does not exclusively happen in situations where players could have predicted a negative response and instead expand it to specific and often unintentional behaviors associated with ADHD (e.g., shifts in attention because of external stimuli, or fidgeting). Re-emphasizing negative experiences with others, participants suggested to include a *bully* in the game, i.e., a non-player character that has the specific role of harassing the player and making them feel uncomfortable during play.

3.5.2 Theme 2: Identifying Coping Strategies and Maintaining a Life beyond ADHD. This theme describes how participants coped with the challenges related to ADHD, leveraging tools and in some cases the people around them to manage their daily lives, while highlighting the importance of accommodations. It further illustrates how effective coping enabled them to lead fulfilling lives that expand beyond ADHD and often included a range of hobbies, interests, and friends. In terms of tools, these fell into different categories, e.g., tools that support concentration such as wearing headphones to block out environmental noise, or using colored pens in school work to help direct focus and create structure. Additionally, participants reported that objects were intentionally leveraged to deal with frustration, e.g., "punching a pillow when feeling frustrated." Medication was similarly mentioned as a tool to mitigate consequences of ADHD; however, there was broad consensus among participants that this came with the consequence of a range of side effects and was therefore not seen as an ideal solution to manage the symptoms of ADHD. Additionally, participants reported engaging in scheduling activities—sometimes together with family members—to help them get the most out of their day, and intentionally doing homework together with friends who helped them stay on track. However, they emphasized that tools and the support of others could only provide so much support and pointed out the difference that accommodations such as being given more time to complete tasks made at school, highlighting the importance of an environment that understands respects the needs of young people with ADHD. Finally, participants reported taking part in a range of activities and hobbies, including sports that helped them manage their energy levels, but also quiet and somewhat repetitive activities that would allow them to "lose oneself in and relax," such as reading, doing puzzles, or building with Lego bricks. While they understood that these activities served as a coping strategy that could help mitigate consequences of ADHD, participants highlighted that they genuinely enjoyed engaging in them. However, we observed no instances of participants experiencing *hyperfocus* in our data, i.e., losing oneself in an activity at high intensity for a number of hours [31].

Design ideas associated with this theme included a strong focus on the inclusion of in-game actions that reflect coping strategies typically leveraged by the participants, e.g., keeping one's body moving when fidgeting. Here, medication was discussed by participants, but overall, there was consensus that no coping strategy including medical management of ADHD should be offered as a *magic bullet* in an effort to reflect their lived experience. On a meta-level, participants were very clear about their preference for integration of representation of ADHD into games in a way that does not only focus on aspects directly related to manifestations of ADHD but that also emphasizes that individuals—or game characters—with ADHD are more than just that.

3.5.3 Theme 3: The Impact of a Lack of Knowledge and Empathy in Others. This theme summarizes how the lived experience of ADHD among young people is strongly impacted by a lack of knowledge of ADHD in people around them, which in some instances extended to a lack of empathy toward

them and the challenges that they face. Most importantly, participants reported being viewed as "ill-behaved children" rather than understanding that "ADHD really is something in your head, something that you can do nothing about." Here, one participant highlighted that "if someone uses a wheelchair, yes, that person is [visibly] disabled, and if they need help, they are helped," leaving the notion that ADHD may be an invisible disability hanging for a moment before quickly pointing out that "[...] I don't want to compare myself to disabled people." Here, another participant pointed out that "people will often view behaviour as a result of a poor upbringing [...], but I think that it is a lack of knowledge." Generally, participants highlighted that they struggled to communicate their experience of ADHD to others, reporting many instances in which they had attempted to explain themselves, often in an effort to avoid conflict, e.g., at school, or among friends. At school in particular, participants reported exchanges with teaching staff who had been informed about ADHD and how to best manage it in the classroom, but would still show "very little understanding, even when communicated with on a monthly basis, so it is important that something [to increase understanding] will be directed toward teachers." In turn, this led to discouraging situations, e.g., "It is really so frustrating, that you know that you need more time, and that you know that you can get it right, but that you don't get enough time from your environment, because they don't get, yes, that person has ADHD, so they can't do anything about it, they simply need more time." This was contrasted by the experience of being listened to and being received with empathy, e.g., "If you manage to explain it and people understand that [ADHD] is a lot more [than poor behaviour], then you can really see how people have a moment of understanding." Finally, across participants we observed a strong desire to be treated with respect, with one participant asking, "How do you treat people with ADHD? Well, treat them like you would treat everyone else."

Design ideas associated with this theme mostly focused on a meta-level without concrete suggestions for implementation, with participants highlighting the perceived potential of games to share a comprehensive, nuanced view on the lived experience of ADHD, moving beyond what participants called the stereotype of "children who are just loud and annoying." We further unpack this suggestion in Section 4.1 where we discuss implications for design more generally, and we address it in the context of different perspectives on disability simulation in the discussion of our work (see Section 5.4).

4 Phase 2: Creation of and Reflection on Game Concepts That Include Representation of ADHD

In this section, we synthesize the outcomes of the previous phase to create game concepts that include representation of ADHD. First, we summarize design considerations on the basis of the main findings, then we detail the design process and present the game concepts. Finally, we report on outcomes of an initial evaluation of these concepts together with adolescents with ADHD in an effort to critically appraise the considerations for design. Through this phase, we seek to address our *second RQ (RQ2)*: What are the challenges and opportunities when creating a game that includes ADHD with respect to respectful and accurate representation of ADHD?

4.1 Initial Considerations for the Representation of ADHD in Games Resulting from Focus Group Sessions

Based on the initial focus group sessions, we reflected upon participants' accounts of their lived experience of ADHD as well as their suggestions for game design to devise a set of design considerations for the representation of ADHD in games. Within the research team, we discussed the main themes of the previous stage and their implications for design, thereby deriving four main considerations.

4.1.1 Design Consideration 1: ADHD Is Experienced as Energy-Consuming Impairment. First and foremost, the teenagers in our research experienced ADHD as impairing. For instance, many participants reported difficulties with aspects such as focus and attention, impulsivity and restlessness, or maintaining structure and overview, all of which they reported to have consequences for their quality of life. Participants made clear that they had these experiences despite their best efforts and willingness to comply with what was expected of them, which introduced an extra level of stress and frustration. Therefore, game design needs to ensure that game characters with ADHD share these characteristics and experiences if the aim is to have realistic representation, e.g., that a character with ADHD experiences difficulties maintaining attention despite making an effort to remain focused on a given task. *Here, it is crucial not only to represent the impairment, but also to demonstrate the energy that the individual is investing into coping strategies* (see following section) to prevent re-creating the trope of what participants called *the poorly behaved kid*. Generally, these key symptoms are in line with clinical literature on ADHD (see Section 2.1), which can serve as additional source of information for designers (albeit one that needs to be reflected upon against the backdrop of lived experience).

4.1.2 Design Consideration 2: Coping Strategies Exist, but There Are Strings Attached. Teenagers employed a number of strategies to manage ADHD; however, these need to be portrayed in a way that makes it clear that they can only alleviate some of the issues they experience and do not provide permanent relief. Participants were particularly outspoken about the limitations of medication, which was a temporary help for some, but did not offer any benefits for others. In turn, *games should showcase coping strategies and highlight how effective young people with ADHD are in their application but also be open about the effort that they require, and the limitations that they have*. In this context, our findings suggest that games should be critical of the use of medication and should never offer these as a way of simply removing symptoms of ADHD, but instead should highlight the complexity and the tradeoffs of medical management of ADHD. Likewise, some of the coping strategies that were reported in our work were also sanctioned by others (e.g., fidgeting), which is another tension that could be portrayed within games.

4.1.3 Design Consideration 3: The Negative Experience of ADHD Is Amplified by the (Social) Environment. Our work provides ample evidence that the experience of young people with ADHD is heavily shaped by their environments, often contributing to negative experiences rather than supporting and lifting them up. First, our work contains reports of young people with ADHD navigating environments that are not suitable for them (e.g., needing to sit still for prolonged periods). Second, our findings include many examples where other people's actions were inappropriate (e.g., being met with ableism, fear, or a lack of understanding). The main opportunity that participants saw for game design in this context was to mirror their negative experiences (with people in particular) so that they could be observed or experienced by others. Hence, *if the goal of game design is to portray a realistic image of the status quo, games should feature inaccessible environments and non-player characters that respond negatively toward the character with ADHD*. However, game design also needs to ensure to draw a balanced picture: despite negative experiences with some characters, young people in our work established friendships, which should be reflected in the context of play.

4.1.4 Design Consideration 4: ADHD Is Not All the Person Is. Participants in our work led rich, varied lives, had a range of hobbies and were individuals with ambitions and aspirations who experienced success. To them, it was very important that they were seen as rounded individuals with characteristics beyond ADHD, i.e., that other aspects of a character's personality and life would be included in games that touched upon ADHD. Hence, *game design needs to make an effort to*

holistically portray in-game characters with ADHD, ensuring to display their unique personality, with ADHD being a part thereof, but not necessarily the defining feature. This implies that a character's interactions and fate should not exclusively be determined by symptoms of ADHD and also extends to the wider integration of an individual with ADHD within the game. While not directly concerned with disability, we suggest that game design can draw upon the large body of knowledge on issues related to the design of female characters in games (e.g., reduction to secondary characters [44], or stereotypical portrayal [35]).

4.2 Game Concepts

Here, we give an overview of the game concepts that we created to further evaluate our considerations for design. First, we detail our design process, then we describe the resulting game concepts to be critically reflected upon with teenagers with ADHD in the context of one final focus group.

4.2.1 Game Design Process. The goal of the design process was the creation of three distinct design concepts to critically appraise our considerations for design. Three members of the research team (the main researcher who directly worked with the adolescents—a psychologist, an HCI expert, and a game designer/developer) took part in game design. Taking the guidelines into account, each member first developed a personal set of design ideas. In a joint ideation session, these initial ideas were discussed against the backdrop of the recommendations and with respect to diversity of concepts (e.g., whether they represented a breadth of game genres that would require different approaches to the representation of ADHD). Afterward, overlapping ideas were identified and combined, and certain ideas were refined. Finally, three full game concepts were decided upon and detailed via Miro regarding their unique features and relationship with ADHD. For each concept, we carefully matched game mechanics with participant quotes on their lived experience of ADHD in an effort to accurately reflect it in the designs. In a final step, we created a poster to present the story and graphical look and feel of each of the concepts using stock photos, as well as explain the way in which characteristics of ADHD would be translated into game mechanics. These posters were written in the local language, since their main purpose was to present the concepts to teenagers with ADHD in a final focus group to critically appraise the game ideas, and, by extension, our recommendations for design.

4.2.2 Overview of Game Concepts. The first concept, *Restaurant disaster!*, is a restaurant kitchen simulator in a style similar to games such as *Overcooked*. Players control a charming, successful chef of a busy kitchen who prepares delicious meals for their customers. The game includes a continuous stream of orders, with new ones coming in before the previous one has been fully processed. Throughout, unexpected emergencies pop up (e.g., a stray dog finds its way into the kitchen and has to be driven out, or a stove catches on fire). The game intentionally doesn't provide a clear user interface for these tasks, and the kitchen is disorganized, thereby making it more difficult for the player to maintain focus. Meanwhile, compulsory minigames in which the player character starts fidgeting (e.g., playing with cutlery or flicking peas across the room) allude to unrest and inhibition; the internal game clock is sped up while these minigames are in progress to simulate distorted time perception. Finally, customers and kitchen staff grow increasingly frustrated and impatient with the player character, and comment on their behavior.

The second concept, *The Census*, is a role-playing game with quests and combat, set in a medieval fantasy world. The player is a knight, tasked by the king to perform a census and count every inhabitant of the kingdom. Focusing on this main quest is made difficult by side quests, many of which seem more enjoyable than the straightforward job at hand, or offer more enticing rewards. The lack of a clear quest log or map, as well as the tendency for random thoughts to pop into the knight's head and obscure important dialog or quest text represent problems with structure

Fig. 1. The poster for the concept *Restaurant disaster!*, a cooking game.

Fig. 2. The poster for the concept *The Census*, a role-playing/adventure game.

and focus. The player inventory, which is cluttered and seemingly randomly organized, further contributes to this. While the knight is a skilled fighter, combat is complicated by the player character's impulsivity (they may automatically attack before the player decides to) and visual frustration effects that make it harder to see and hit enemies when the players gets hurt or misses attacks. A companion NPC (non-player character) is introduced in the form of the knight's talking horse. Its role is twofold: not only does the horse contribute to distraction by pointing outside quests, but it also acts as a stand-in for people that lack empathy and are judgmental.

The final concept, *Lanesplitter*, describes a simple, single-screen game resembling casual games, in which the player performs a variety of actions by tapping the screen. The screen is divided into five vertical lanes, where the three center are important to the progress of the game. Each

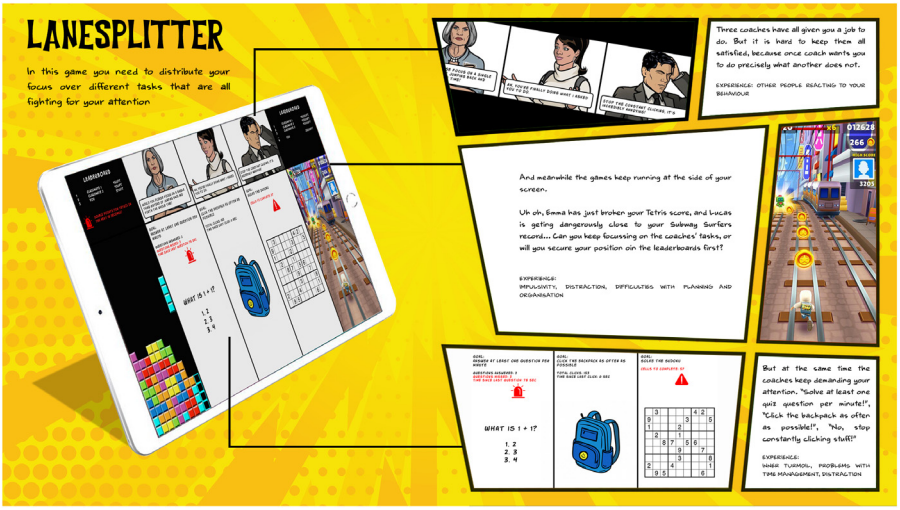

Fig. 3. The poster for the concept *Lanesplitter.*

of these three lanes contains a simple task for the player to perform, for instance, solving a basic math problem or a Sudoku, or tapping on an image as often as possible. Each lane also contains a constantly visible coach character, who urges the player to focus on their task instead of the others, and grows verbally and visually impatient when the player does not comply. The outer two lanes, meanwhile, contain minigames (variations on well-known games such as Tetris, Bejeweled or Temple Run) that are enjoyable to play, but irrelevant to progress in the game. The game's interface constantly tries to pull the player's attention between lanes, not only through the reactions of the coaches but also through audiovisual prompts that grow increasingly intrusive. Contrary to the previous two concepts, there is no player character here; instead, the player is the main character.

4.3 Reflection on the Game Concepts

The game concepts were reviewed in two stages. First, we engaged in a general review of the concepts together with lived experience experts and a clinical stakeholder. Then, we discussed the concepts with teenagers with ADHD to examine whether game concepts aligned with their lived experience of ADHD.

4.3.1 Initial Screening. We worked with two lived experience experts (one young adult and one teenager who have ADHD) as well as one clinical expert to ensure that the initial attempt of translating feedback from the initial focus groups into design recommendations and game concepts was successful, and that representation of ADHD was accurate from a clinical viewpoint. Through short, individual interviews, each person was given opportunity to review the game posters, and provide feedback to the main researcher; we summarize the main points here. Generally, there was consensus that the aspects of ADHD included in the game concepts were accurate, and covered all relevant areas from a clinical perspective. There were some specific comments on the language used in the posters (e.g., framing tasks as *boring*, which was considered unfortunate because experts thought it would be easy to make a link to the stereotype of the *lazy person with ADHD who does not try hard enough*), which we adjusted for. With respect to the game, the main feedback from lived experience experts concerned the absence of strengths related to ADHD, and applied to all game concepts. In particular, the adult lived experience expert commented on their ability to achieve

hyperfocus and become deeply engaged in specific tasks, which was very satisfying for them. Likewise, they highlighted their own creativity (e.g., in the context of their careers) as individual strengths which they would like to see reflected in the game concepts. We further explore this tension between the lived experience of teenagers in the following step of our research, and discuss differences at the end of our paper in Section 5.5. Overall, all participants highlighted the relevance of coping strategies which was not yet considered prominent enough, which we also took into account and emphasized in the final version of the concepts.

4.3.2 Review of the Game Concepts with Young People with ADHD. In a second step, we invited the initial group of young people with ADHD to engage in discussion of the game concepts. Here, we focused on the accuracy of representation of ADHD when compared to their lived experience in an effort to reflect on our considerations for the representation of ADHD in games (see Section 4.1).

Participants and Procedure. We invited the participants of the initial focus groups to engage with the final review of game concepts. Thirteen young people with ADHD participated in this step of our research (age range 13–15, nine men, four women). We prepared a focus group format in line with previous focus groups employed in this project that they were already familiar with, engaging them in conversation about the game concepts on the basis of a slideshow that included the posters, went into detail on main mechanics of each of the concepts, and offered additional explanation by the main researcher. Through a series of questions (e.g., "Do you think that ADHD is accurately represented in this game?", "Which elements of ADHD are missing in this game?"), we wanted to understand whether and to which extent the representation of ADHD in each of the concepts reflected participants' lived experience. Additionally, we took the opportunity to explore participants' perspectives on the outcomes of the initial screening of game concepts.

Data Analysis. Data were analyzed following the principle of deductive Thematic Analysis [9]. We opted for a deductive analysis approach because we wanted to focus on two main aspects in a top-down fashion, accurate representation of ADHD, and the depiction of strengths and challenges associated with ADHD in the game concepts. The coding process was carried out by a psychology researcher, who repeatedly read through the transcripts, and iteratively coded the data into the two categories. For a subset of the data, allocation of codes was discussed with another member of the research team to ensure correct interpretation of participant feedback. For author positionality, please see Section 3.3.

Results. Here, we present the two main themes that we crafted from our data, *(1) Accuracy of Representation of ADHD in Our Concepts and Need for Nuance* and *(2) Reflection on Strengths and Challenges Associated with ADHD.* We relate each of the themes to the game concepts to illustrate challenges in the achievement of accurate representation.

Theme 1: Accuracy of Representation of ADHD in Our Concepts and Need for Nuance. This theme summarizes participant feedback on the game concepts and the way they represent ADHD. While there was consensus that the concepts generally captured the lived experience of ADHD present within the participant group, our results show that certain aspects need to be portrayed with more nuance and need to be carefully situated within games to facilitate correct interpretation by players. Most importantly, participants highlighted that players would need to distinguish between the symptoms of ADHD and generally chaotic or stressful settings. For example, they highlighted that while "the stress [in Restaurant Disaster] was really recognizable," "anyone would be stressed here." Instead, they commented that the anticipated pacing of The Census (i.e., a role-playing game) would be much more representative of their experience of ADHD: they reflected that often, symptoms are not constant, but that they sometimes intensify, while they also knew periods of focus and calm. One participant commented that "It is better to start in a calm situation so that you can indeed show that…despite having a calm situation, that it is still difficult to maintain structure.", suggesting that

both pacing and setting of the game matter in terms of adequate representation of ADHD. Finally, participants were specific that Lanesplitter provided the least accurate and preferable representation of ADHD. Participants pointed out that as a player, "You have a choice of what you do and what you don't engage in. It's not like that.", with participants explaining that shifts in their attention typically occurred automatically and without them noticing. Instead, they preferred the mini games in Restaurant Disaster or side quests in The Census as examples of losing overview and focus, in the sense that players would follow their interests without immediately noticing a shift in activity and the consequences thereof.

Theme 2: Reflection on Strengths and Challenges Associated with ADHD. This theme addresses the integration of symptoms of ADHD within the game concept. Overall, there was consensus among participants that "The reality is that [ADHD] has more disadvantages than advantages", that "[the absence of strengths] isn't so bad" and that they "thought of challenges first" when reflecting on their lived experience of ADHD. Instead of strengths, participants thought that the inclusion of coping strategies to (partially) alleviate symptoms or manage difficult situations was more suitable. Additionally, this theme shows that participants felt strongly about the overall portrayal of ADHD. Particularly with respect to Restaurant Disaster, they pointed out that games need to ensure they communicate that "Not everything is difficult for people with ADHD.", suggesting that while they did not experience ADHD as a strength, they still thought people with ADHD had strengths. Considering mechanics-driven design approaches such as Lanesplitter, they were concerned that a game that does not provide an engaging player experience (while representing ADHD) may negatively affect player perceptions, whereas games with storylines might offer additional opportunity to include context, once more highlighting the relevance of nuance. Finally, participants pointed out that from their perspective, representation of ADHD in games should offer players an opportunity to improve their understanding of ADHD, rather than attempting to increase empathy.

5 Discussion

We explored opportunities and challenges for the representation of ADHD in games from the perspective of young people with ADHD. In this section, we answer our main RQs, critically appraise our design considerations, and we discuss our findings with a focus on implications for the integration of lived experience in technology, and the representation of disability in games.

5.1 RQ1: What Is the Lived Experience of Teenagers Living with ADHD, and How Can It Be Translated into a Game (i.e., Player Characters, Non-Player Characters, and the Game World)?

Overall, the lived experience of young people with ADHD is shaped by their individual experiences of symptoms of ADHD, e.g., difficulty in maintaining focus and attention in certain situations, or the experience of impulsivity and restlessness. Additionally, their lived experience is heavily affected by their stage of life. Here, their experience of the educational system exacerbating issues that they experience. Likewise, relationships with others were often affected by stereotypical perceptions of ADHD, with many young people expressing that they regularly felt misunderstood. Notably, strengths that adults with ADHD highlighted in later stages of our work (e.g., hyperfocus) were explicitly not part of the lived experience of young people. However, young people with ADHD made extensive efforts to employ coping strategies and did so effectively. Likewise, participants led varied lives, with ADHD being a big part, but not all of it. In terms of translating the lived experience of ADHD into its representation in games, it is important to address both character design and the wider design of the game world both through mechanics and narrative elements (e.g., how other characters respond to ADHD, or to represent elements such as events that may

trigger shifts in attention). However, achieving accurate and respectful representation is associated with unique challenges.

5.2 RQ2: What Are the Challenges and Opportunities When Creating a Game That Includes ADHD with Respect to Respectful and Accurate Representation of ADHD?

A number of challenges need to be accounted for by researchers and designers when creating representation of ADHD in games. With respect to its portrayal, everyone's lived experience of ADHD differs in relevant ways (e.g., the presence of intensity of certain aspects of ADHD) and is shaped by environmental factors that may differ across cultures and age groups (e.g., the experience of the educational system). Additionally, our work adds nuance to the presence of symptoms of ADHD, highlighting that they are not stable over time, and can be more or less present in a given situation, suggesting that even within one character, adequate representation requires careful adjustment. At the same time, young people with ADHD are more than what stereotypical depiction often reduces them to, highlighting the opportunity for design to showcase individuals with ADHD as rounded characters beyond the portrayal of neurodivergence. Finally, our results illustrate how often negative interactions with others and environmental barriers shaped the lived experience of ADHD. Here, designers need to address the challenge of accurately reflecting this experience, while at the same time ensuring they do not perpetuate stigmatizing perspectives on ADHD.

5.3 Reflections on Our Considerations for the Representation of ADHD in Games

When reflecting on our initial set of considerations for the representation of ADHD in games (see Section 4.1), the second step of our work in which we discussed resulting game concepts with young people with ADHD suggests that they need to be applied with nuance. Most importantly, we stress the importance of portraying ADHD in a way that accurately represents symptoms, both with respect to their type, but also in terms of intensity and duration. For example, an individual can experience issues with focus and attention in certain settings (e.g., in a busy classroom), or symptoms may be exacerbated in certain situations (e.g., when they are tired). In terms of game design, this should be accurately represented, i.e., an in-game character with ADHD should not exhibit static symptoms throughout the course of the game. We therefore expand our first consideration to also encompass this aspect and rename it to *Design consideration 1: ADHD is experienced as an energy-consuming impairment, but symptom strength differs.* Additionally, settings in which individuals have little autonomy (e.g., adolescents who regularly have to attend school and do not have control over the school environment, also see Section 3.5.1 for examples in our data) harm their ability to experience strengths of ADHD that adult lived experience experts may tap into. Therefore, the degree of autonomy that an individual has in a given situation will impact their experience of ADHD and should be considered in game design accordingly. In particular, we recommend to take into account this perspective along with *Design consideration 3: The negative experience of ADHD is amplified by the (social) environment.*

5.4 Representation of Disability in Games and the Pitfalls of Disability Simulation

Including disability in games particularly when it is a first-person player experience in which the player controls a disabled character raises questions about the relationship between games and the often harmful implications of disability simulation [37, 42]. Core criticisms of disability simulation include the delivery of inaccurate experiences (e.g., if a non-disabled person is blindfolded, they do not have the same expert skillset as a blind person and therefore do not develop understanding of a blind person's navigation competence [37]) and an unrealistic ability to simply step in and out of experiences [37] that result in an incomplete understanding and increased stigma rather than a better perspective of the lived experience of disability [4]. The portrayal of disability in games needs

to consider these aspects. While the most common issue in commercially available games currently is the inappropriate depiction of disability as tragedy or evil (e.g., see [59]) we, too, must take care that games do not perpetuate stereotypes even when designed with the best intention. Here, working with lived experience experts is one way of ensuring that the representation of disability in games is rooted in perspectives of disabled people (an approach recommended to counteract negative elements of disability simulation [52]). Additionally, games offer the opportunity of enriching experiences through narrative elements, guiding players and supporting them in their reflection on specific experiences, an aspect that could be leveraged to contextualize representation of disability and achieve more appropriate outcomes such as allyship [49] or attunement [38]. Likewise, through game mechanics, coping strategies and difficulty can be modulated, potentially supporting the provision of more nuanced experiences. Finally, we recommend that designers are explicit about their own positionality as well as the positionality and purpose of their games as a means of reflecting upon their own attitudes and biases that may transpire into design artifacts. This could be implemented following a two-step approach: First, there is value in individual reflection similar to best practices in qualitative research [7] that needs to take place throughout design and development. Second, this is relevant when communicating about games. In the case of games as research tools, research teams should be explicit about the goals that their game seeks to achieve and the assumptions and rationale which underpin the choice of that goal. In the case of commercial games, we would like to encourage developers and publishers to actively reflect upon the ways in which they represent disability when communicating accessibility features of their products.

5.5 Challenges for Technology Design Informed by Lived Experience

Our work has implications for the way that we leverage lived experience in technology design. While it is often understood as a way of including the experiences and perspectives of specific audiences in technology (e.g., see [30, 58]), our results suggest that there may be distinct differences within groups that result from intersecting identities and limit the potential of general applicability. For example, in our work, the lived experience of teenagers with ADHD was distinctly different from that of adults. Likewise, we hypothesize that because of the impact of environment on the experience of ADHD, teenagers living in different countries than Belgium may likewise have distinct experiences of living with ADHD. Our data also included instances of ableism, and we feel that this is important to highlight because it opens up an additional perspective on lived experience and the implications of self-stigma. For example, one participant pointed out that "it is not like I am Autistic," suggesting that he constructed his own identity against that of a group that he perceived as *more disabled* than his own (also see [63] for reflections on ableism in participatory design). Thus, designers need to carefully unpack not only their own positionality but also that of lived experience experts, interrogating how societal structures and norms affect lived experience, and which aspects thereof should or should not be included in design. In the context of participatory and user-centered design, this implies that we need to develop research methods that are not only sensitive to societal values and designers' biases [21], but that we also need to engage in research practices that allow research participants to unpack their own positionality, with all members of design teams holding each other responsible and encouraging each other to reflect upon their experiences and assumptions. A challenge that remains to be addressed in this context is the tension between designerly freedom and power to make decisions, and the duty to respect lived experience: Here, we would like our research community to reflect upon how to carefully and respectfully address issues as complex as internalized ableism and how we can establish research processes that help all of us unpack our own positionality. Likewise, we want to remind our research community that lived experience always needs to be interpreted in the light of the backgrounds of participants,

and the cultures and societies we live in (also see [1]), limiting generalizability of findings, and in turn artifacts that were shaped in this way.

6 Limitations and Future Work

Our work needs to be interpreted in the light of a number of limitations. Most importantly, our research was carried out in a wealthy region of Western Europe with comparably good access to healthcare and mental health services, which will have impacted the lived experience of ADHD within our participant sample. Additionally, our sample was heavily based toward male participants, which we suspect is both a result of ADHD diagnosis being biased toward boys and men [12], as well as potential self-selection bias for participation in research that focuses on gaming. Likewise, our work only includes the experiences of young people; exchanges with older lived experience experts in the context of our work suggests that the experience of ADHD can change across the lifespan. Therefore, additional research is needed to accurately grasp the representation of ADHD in later life. Here, we are also curious about the breadth of experiences of ADHD: In our work, lived experience was predominantly related to challenges associated with ADHD and resulted in approaches to representation that emphasize negative aspects of ADHD. However, expert review also alluded to strengths and positive elements, which is something that we wish to explore further in the future. Likewise, there is an opportunity for future work to explore perspectives of other stakeholders (e.g., parents, teachers, and clinical stakeholders with experience with adolescents with ADHD) to further contextualize some of the observations made in our work here. From a methodological perspective, focus groups which were planned to take place in person had to be moved online in response to the COVID-19 pandemic. While this is typically considered a limitation, our experience suggests that it facilitated participation of young people and met their needs in terms of easy access to focus groups, but introduced limitations with respect to being able to engage with actual artifacts, e.g., game ideas only being described through posters that we shared rather than as playable prototypes. This is something worth exploring in the context of future work in an effort to make design decisions tangible, offering an opportunity to validate implications for design derived from the work presented here. Here, we would like to further examine the different design options available to introduce representation of ADHD (i.e., character design, world design or narration) and overarching implications for player experience. Finally, our work only addressed one form of neurodivergence, and there are many other groups of people included under this umbrella term [17]. Here, we see an opportunity for future work to explore other forms of invisible disability in an effort to facilitate their representation in games, thereby contributing to more diverse play experiences.

7 Conclusion

Having diverse representation in games is important to facilitate inclusive experiences that accurately reflect the diversity of our societies. We provide a first exploration of how representation of invisible disability could be integrated, building upon adolescent's lived experience of ADHD as an example. Representation of ADHD needs to be facilitated through integration of specific behaviors of either player or non-player characters and has to be supported by adjustments to the design of the wider virtual world to include wider societal attitudes that shape the experiences of young people with ADHD. However, the game research and design community also needs to be mindful of the unique challenges associated with the representation of disability in games, avoiding representation that is stereotypical or otherwise harmful, and carefully exploring our own positionality as well as that of the games that we create.

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