

Toward Becoming a Better Self: Understanding Self-Tracking Experiences of Adolescents with Autism Spectrum Disorder Using Custom Trackers

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Abstract

Adolescence is a challenging period, particularly for individuals with autism spectrum disorder (ASD), due to having little knowledge about themselves. Self-management is a strategy to enhance self-understanding through continuous self-monitoring, which can support adaptive transitions to adulthood. Meanwhile, the advent of digital self-tracking tools enables users to collect and reflect on data about themselves. In this work, we investigated how adolescents with ASD kept track of their everyday lives to better understand themselves using a custom self-tracking platform, OmniTrack, over a two-week period. Our findings indicate that personalized self-tracking experiences enable adolescents to monitor the detailed contexts, causes, and consequences of problematic situations; regulate negative emotion and anxiety while interacting with the tracker; and communicate through data with their caregivers, teachers, and therapists. Building on these findings, we suggest the design of a new form of flexible, scaffolded self-tracking technique that can inform both researchers for designing pervasive health technologies for adolescents with ASD and clinicians for guiding adolescents with ASD toward better self-management using such technologies.

CCS Concepts

• **Human-centered computing** → **Empirical studies in interaction design**;

Keywords

Autism, adolescents, self-tracking, participatory design workshop.

ACM Reference Format:

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1 INTRODUCTION

Adolescence is a period of both vulnerability and opportunity, as individuals undergo drastic physical, cognitive, and social changes. All adolescents develop a *sense of self*—a basis of self-management—through self-identity formation, self-reflection, and increased autonomy during this stage [7]. However, developing a robust sense of self, which is one of the critical developmental tasks, is often fundamentally challenging for adolescents with autism spectrum disorder (ASD) [22]. Several of the defining characteristics of autism, such as deficit in social communication and interactions across multiple contexts; restricted, repetitive patterns of behavior; and limited interests and activities, can negatively impact identity formation and interfere with developing a clear sense of self [11]. To address these issues, self-management interventions have been widely adopted to assist adolescents with ASD in goal setting, self-monitoring, and self-regulation, with an ultimate goal of enhancing several aspects of the adolescents' daily functioning [2]. In this work, we aim to empower adolescents with ASD to develop a sense of self through self-management strategies augmented by pervasive self-tracking technologies.

Self-tracking is an increasingly ubiquitous, pervasive activity. A desire to gain insight into various aspects of one's everyday life motivates systematic recording of one's behaviors, activities, and emotions [1, 8]. Self-tracking technologies are also gaining attention, as they help individuals to better self-manage a wide range of health conditions such as diabetes [34], arthritis [15], and

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¹From this point on, "ASD" will refer to the high-functioning end of the autism spectrum, unless otherwise specified.

bipolar disorder [24]. The majority of health-related self-tracking tools focus on the problem-solving nature of diagnostic practices, requiring quantifiable health goals such as managing blood sugar for diabetes. Unlike other health conditions, however, autism spans a spectrum of behaviors and abilities resulting in each individual's goal, presenting unique needs and challenges. This calls for the creation of a flexible, custom self-tracking tool that best suits each individual. To do this, we need a better understanding of the role self-tracking has played as adolescents with ASD experience radical changes in various aspects of everyday life and struggle to develop a sense of self.

The characteristics of self-tracking technologies that enable everyday self-monitoring to enhance self-knowledge for behavioral changes provide an ideal opportunity to address the challenges that adolescents with ASD face. In this study, we propose the use of customizable self-tracking technology to help adolescents with ASD collect data about themselves, reflect on the data, and in turn, manage their behaviors by themselves. Five Korean adolescents with ASD, six parents and five clinical experts participated in a series of studies including interviews, questionnaires, a participatory design workshop, and use of self-tracking technology for two weeks via *OmniTrack* [21], a platform for creating custom trackers. The contribution of this study is threefold:

- We investigate the lived self-tracking experiences of five adolescents with ASD resulting in a rich description of how and why the participants engaged in tracking, the impact of self-tracking practices on the sense of self, and their attitudes and expectations on the potential of technology to support these activities through the two-week use of custom self-trackers.
- We suggest a special form of participatory workshop to engage adolescents with ASD in co-creation of custom trackers and co-review of data resulting in greater motivation and compliance.
- We inform the design of self-tracking processes and tools specialized for adolescents with ASD by outlining two directions: 1) motivating them to perform self-management through open-ended, personalized goal-setting using a self-tracking tool that can be customizable; and 2) incorporating self-tracking processes into existing clinical programs for social skills interventions as well as promoting the mental wellbeing of individuals with ASD.

2 RELATED WORK

2.1 Understanding Adolescents with ASD

Adolescence is a challenging period for individuals with ASD because they undergo radical physical, emotional, and social transitions. It is also a period requiring the development of skills critical to independence, such as self-identity formation, self-monitoring, self-regulation, and evaluation of life experiences [6]. However, many of these developmental skills are dependent on abilities lacking in individuals with ASD, such as social competence, emotion decoding, cognitive flexibility, perspective taking, and abstract reasoning skills [11]. Therefore, clinical interventions for adolescents with ASD, especially for those with high-functioning autism, often focus on helping them improve such social skills. For instance,

PEERS (Program for the Education and Enrichment of Relational Skills)[®] [22] is a 16-week evidence-based intervention for adolescents and young adults with ASD to help them make and keep friends by practicing various social skills in a group setting during socialization activities (e.g. playing sports, board games).

Emotional changes also occur more rapidly during this period. Adolescents with ASD find it even more difficult to regulate their emotions, which exacerbate problematic behaviors, such as temper tantrums and aggressive behavior. They often experience emotional distress (e.g., feelings of loneliness, anxiety, and depression) with poor social adjustment [22]. While it is known that many individuals with ASD tend to be socially isolated, some present increased interest in social relationships, as do other neurotypical adolescents in the pubertal period [30]. However, their lack of communication skills and/or the presence of limited interests may further increase the risk that adolescents with autism will become targets of bullying by friends [40].

In this regard, puberty-related challenges faced by adolescents with ASD have negative impacts on their self-image and identity. Therefore, there is a need for empowering adolescents with ASD to cope with the problems they face and to build positive self-images. In this research, we seek to understand the role flexible self-tracking plays as adolescents with ASD experience radical changes in aspects of everyday life and struggle to develop a sense of self.

2.2 Self-Management Strategy for Behavioral Change

Self-management is an evidence-based behavior management intervention used to improve behavior of individuals with ASD by engaging them in everyday and social activities [27]. Self-management strategy is composed of four critical procedures: 1) goal setting by making a contract with caregivers, 2) monitoring one's own behaviors by recording relevant information, 3) processing feedback by reflecting upon data collected, and 4) receiving rewards for behaving appropriately [37]. Self-management intervention is proven to be useful for students with autism in that it teaches them to learn regulating behaviors, enabling them to act appropriately in various settings; reduce inappropriate and interfering behaviors; and increase social, adaptive, and communication skills [27].

Self-management interventions grounded in social, cognitive and behavioral theories are also often employed to deal with various chronic diseases beyond ASD [2, 24]. The contents of the interventions are designed to enhance the individuals' mastery experiences, role modeling, reinterpretation of symptoms, and physical and psychological consequences, which in turn increase self-efficacy [3]. It has been found that many intervention approaches include not only symptom-monitoring and critical self-care (e.g., blood glucose monitoring), but also general problem-solving, habit-forming or changing, and goal setting that could address psychological issues [2]. However, unlike other chronic health issues, it is difficult to design a universal self-management program that can be applied to individuals with ASD due to the wide spectrum of behaviors and abilities of each individual. This calls for a flexible, customizable self-management tool that can be modified to fit each individual's needs and challenges. In this study, we engaged adolescents with ASD in open-ended and flexible self-tracking practices not only

to help them deal with problematic behaviors, but also to provide opportunities to enhance self-knowledge through data collection.

2.3 Self-Tracking Technologies for Individuals with Special Needs

Increasingly, self-tracking technologies are gaining attention for supporting self-management of individuals because of their effectiveness on self-understanding and behavioral change in various aspects of daily lives, such as sleeping behaviour [19], mental wellness [23], and caregiving [39]. Self-tracking is also used by individuals with special needs to manage health conditions. For example, studies in this field indicate that self-trackers can promote the independence of adolescents with chronic disease by providing the opportunity to monitor and manage their health conditions on their own [9]. However, existing tracking technologies are limited to particular health needs support. This calls for the customization of tools to meet each ASD adolescent’s interests and/or needs as prior studies suggested [35].

To customize tools to best serve the needs of the patients, a participatory design approach is adopted to elicit the underlying user needs and co-create artifacts they desire to use [33]. Inspired by prior work, we designed our study to investigate the opportunities and challenges faced by adolescents with ASD through co-creation of custom trackers that capture the lived experience of the adolescents with ASD using the trackers.

Self-tracking tools benefit not only individuals with health issues but also their family members and clinicians. Yamashita et al. investigated the collaborative use of a self-tracker among family caregivers that enables collaborative recording of the mood of an individual experiencing depression [39]. Studies in information management work involving the care of individuals with special needs indicate that information gathered through collaborative tracking could facilitate communication among various stakeholders including caregivers, teachers, and clinicians, in turn impacting the physical and emotional responses of the patients [29]. Thus, it is important to consider further opportunities to facilitate communication and cooperation surrounding self-tracking practice of an individual with ASD among the individual, caregivers, and therapists. In this regard, we investigated the benefits and challenges of involving caregivers and therapists in the process of adolescents’ self-tracking by interviewing both the group of adolescents and the group of caregivers and therapists.

3 METHOD

Our aim was to investigate whether adolescents with ASD engage in self-management using a customizable self-tracking tool to cope with puberty, and to examine the potential and challenge of the self-tracking tool to empower these adolescents as well as the caregivers. To that end, we enrolled five adolescents with autism and their parents in a two-week self-tracking usage study. In this section, we outline the specifics of our study, giving particular attention to the ways in which people were invited to a series of events, aimed at creating a personal tracker that could support an individual’s practical or emotional needs and at providing an opportunity to reflect on the collected data and discuss various aspects of an individual’s day-to-day experiences with the self-tracker.

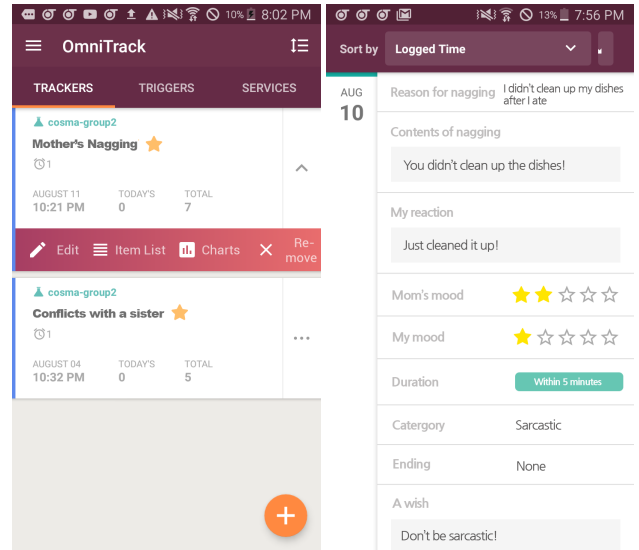


Figure 1: Screenshots of Lucas’s trackers created on OmniTrack. Lucas created two trackers, mom’s nagging and conflicts with a sister (left). To log the context of nagging, he created a variety of input fields (right). Data was originally logged in Korean.

3.1 Study Instrument for Flexible Self-Tracking

To assess how individuals with ASD capitalize on a flexible self-tracking tool, we conducted technology probes [18] by exploiting a smartphone application, *OmniTrack* [21]. *OmniTrack* enables each user to create a personalized tracker by customizing tracking items to support practical or emotional needs, as well as personal curiosity (see Figure 1). Furthermore, *OmniTrack* benefits both users, by allowing them to collect micro data on interesting aspects of their daily activities, and researchers, by providing an experimental toolkit to manage experiments and analyze the collected data. We, therefore, installed *OmniTrack* on the participants’ smartphones to observe how they used it over a period of time, to elicit feedback on how the use of *OmniTrack* may or may not have addressed their needs and concerns, and to critique the technology by describing their experiences with it.

3.2 Recruitment

We advertised the study as a research activity that could provide adolescents with ASD with the opportunity to learn about self-tracking, create their own digital trackers, and socialize with their peers and young researchers by reflecting on data about themselves. We solicited participants through word of mouth, mailing lists, and flyers at a clinic. Because a researcher on our team is a psychiatrist who has led a localized PEERS® program [40], we were also able to reach out to parents who visited the clinic with their children, as well as students who had attended the program in Korea. The parents of five adolescents with ASD expressed an interest in the study. In turn, we recruited five teenage smartphone users, whose ages ranged from 16 to 19 and who are on the high-functioning spectrum, meaning that they are able to read, write, and interact with others, but, they often experience day-to-day challenges (e.g., mood swings) as they transit through adolescence (see the



Figure 2: A study participant brainstorming items for tracking (top left). Adolescents with ASD and researchers celebrating the completion of the self-tracking study.

demographic summary in Table 1). Before starting the study, we confirmed that each participant’s technical proficiency through a preliminary interview with his/her caregiver. Note that involving a small number of participants was within our discretion. Our aim was not to thoroughly examine the impact of self-tracking intervention nor to identify usability issues of OmniTrack but to explore the viability of using a self-tracking tool for self-management through an in-depth understanding of a focused set of adolescents with ASD. Having a small number of participants allowed us to effectively interact with each participant as a design partner as presented in other similar studies [13, 14, 33]. Each adolescent was compensated with a \$20 gift card for completing two weeks of self-tracking. Parents also received \$30 in gratitude for scheduling the meetings with the adolescents and for participating in the follow-up interview.

3.2.1 Participants. **Ella** was a high school student with ASD who was diagnosed at a very young age. As she grew into adolescence, she began to desire and seek intimacy in social and romantic relationships and was concerned about her extreme mood swings. Ella was dating a boy on the autism spectrum, and this relationship had become a source of conflict with her mother.

Justin was a high school student who was diagnosed with ASD shortly before entering high school. He had moderate verbal skills and was often hesitant to express his opinion. Justin tended to rely on his mother’s prompting to manage his daily chores, such as shaving, but recently started to express a desire to be independent.

Lucas was a high-functioning middle school student diagnosed with ASD and ADHD three years ago. He displayed excellent intellectual abilities and verbal skills. Lucas engaged animatedly in verbal discussions about his favorite topics, such as computer games and animations, but struggled with managing his temper, repeatedly leading to difficult situations in class with his classmates and conflicts at home with his mother and younger sister.

Ethan was a middle school student with ASD. Although Ethan was very amenable and tolerant, he was concerned about feeling and acting “different” from others. Therefore, he expressed a strong desire to acquire adaptive communicative skills.

Sam was a late teen who faced academic stress as he prepared for college. He was diagnosed with ASD at a very early age and

had received substantive behavior and speech interventions. Sam displayed somewhat obsessive characteristics that led him to set strict routines and rituals. However, he often felt frustrated and fearful when facing unexpected situations.

3.3 Study Procedure

To foster the participants’ autonomy, we orchestrated the study using a participatory approach [33], in which three groups of individuals with ASD worked together with research personnel to customize self-trackers to address each user’s interests and needs. Over the course of two weeks, we conducted three participatory workshop sessions: (1) co-creating a personal tracker, (2) revising the tracker, and (3) co-reviewing tracking data. The first week of self-tracking practices provided a chance for participants to try out the self-tracker constructed during the first meeting. Participants also had one more week to use the revised trackers following the second meeting. Finally, participants were invited to the last meeting, in which they shared collected data and reflected on the results in a group setting (see Figure 2).

3.3.1 Session I: Co-Creating a Personal Tracker. Participants were grouped together to participate jointly in a 90-minute instruction and activity session to construct their self-trackers. Ella and Justin formed a pair because they knew each other. Lucas and Ethan, who were the same age, also participated in this session as a pair. Due to Sam’s packed schedule, he attended all sessions alone. Because three of our researchers, who ranged in age from 26 to 28, had participated in the PEERS® program for one year as observers, the adolescent participants were readily open to interacting with them and often asked questions about concerns relevant to puberty (e.g., broken voice). Because none of the participants had experience with self-tracking, we began by introducing the concept of self-tracking. We emphasized that self-tracking is not a special activity, but rather it is a casual experience that enables exploration of various aspects of one’s daily life through data relevant to oneself. Next, we moved on to a personal data tracker design session comprised of two steps: brainstorming possible topics for tracking and making a personal tracker using OmniTrack. A brainstorming worksheet was provided to help the participants come up with topics they wanted to track by suggesting four objectives of tracking: to record one’s hobbies or interests (e.g., YouTube videos one has watched), to understand one’s current physical and emotional state (e.g., mood or fatigue), to practice new skills one desires to acquire (e.g., playing basketball), and to create, change, or break habits (e.g., biting nails). Participants were freely allowed to write down topics on their worksheets. They then were asked to choose three subjects reflecting their preferences, provide reasons for each selection, and select one that will be transferred to OmniTrack. While doing so, we guided them to select a topic relevant to reoccurring everyday activities without additional expenditure. We worked with each individual to make a custom tracker that could address the selected topic. Each participant then installed OmniTrack on his or her smartphone, named the tracker, defined data entries, and set a reminder for recording. We concluded the session by presenting each participant’s tracker and providing feedback. At the end of the co-design session, participants were asked to complete the pre-study questionnaire.

3.3.2 Session II: Revising a Tracker. After a one-week trial, we conducted an in-depth, one-on-one interview with each participant

to revise their trackers based on their first week of tracking experience. While going over data collected through OmniTrack with participants, they raised issues related to the use of the tracker and modified their trackers to address the issues for the next week's use. Participants then took part in another week of self-tracking with their revised trackers.

3.3.3 Session III: Co-Reviewing Tracking Data. In the final session, which lasted about one hour, we invited all participants (except Sam) to a group interview in order to reflect upon the resulting data after the second week of self-tracking. Participants were first debriefed about the overall experience during the two-week study period. In a group setting, they presented what data they had collected so far and whether they could identify interesting facts about themselves by digging through the data. Then, each participant met with the researchers individually to discuss the data more deeply, including some sensitive matters they might not want to share in the group. Lastly, participants completed a post-questionnaire.

3.4 Questionnaire Measures

To identify various aspects of changes in each individual before and after the study participation, three validated measuring tools were used for pre- and post-questionnaires. These measures consisted of self-reporting questionnaires to determine how the use of a self-tracker impacted each participant's sense of self, including self-esteem and self-efficacy, and influenced their motivation for sustaining self-tracking practices.

3.4.1 Rosenberg's Self-Esteem Scale. Self-esteem refers to an individual's overall subjective evaluation of his or her worth. In a recent study, individuals with ASD were reported as being at risk for having low self-esteem [25]. We adopted Rosenberg's Self-Esteem Scale [28] containing a total of ten questions rated on a 4-point scale ranging from strongly disagree to strongly agree to identify how self-tracking affected the attitudes and thoughts each adolescent had about himself or herself. The total score ranges from 10 to 40, with a higher total score indicating greater self-esteem.

3.4.2 Self-Efficacy Scale. We also gauged self-efficacy, which is known as the most powerful determinant of behavioral change by impacting the initial decision to perform a behavior, the effort expended, and persistence in the face of adversity, using the Self-Efficacy Scale developed by Sherer et al. [31]. This scale includes seventeen questions to measure efficacy expectancies in general situations and six questions to measure efficacy expectancies in social situations that were rated through a five-item Likert scale.

3.4.3 Program Motivation Inventory. The Program Motivation Inventory was grounded in a study that examined children's perceived competency and subjective task values in the context of education [12] and a study that identified motives for attending an educational program [4]. Ten questions about individuals' expectancies for success and the value they have for succeeding, which are important determinants of their motivation to perform achievement tasks, and their choices of whether to pursue them were rated on a five-item Likert scale. A higher score implies greater motivation for participation.

3.5 Parents and Experts Interviews

To understand better how the use of self-trackers impacted the adolescents' everyday behaviors from the perspectives of the parents,

we conducted semi-structured phone interviews with four mothers and an on-site interview with Sam's parents, who worked as special teachers for individuals with developmental disabilities. We also conducted interviews to discuss the extent to which they wanted to see their children's data and how data produced by OmniTrack could be used to help a child navigate everyday life with autism. To gain expert opinions about the validity of the study results and the efficacy of self-tracking for a therapeutic purpose, we organized a special focus group interview session with a psychiatrist and four clinical therapists.

3.6 Analysis

We audio recorded all the first (co-creation), second (revision), and final (co-review) sessions, as well as parents' interviews. In turn, we generated verbatim transcripts of 916 minutes of all audio recordings. We also captured reactions of the participants (e.g., facial expressions) and atmospheres by creating observational field notes for each meeting. The worksheets that participants created for their tracker themes and the usage logs and data collected on OmniTrack during the two-week study were also included for analysis. A thematic analysis was used as a qualitative method to analyze the data. Four researchers each independently reviewed the dataset to identify reoccurring patterns and discuss ways to organize these patterns into themes [5]. Measures for the pre- and post-study were compared with two-tailed paired t-tests reported in Table 1. Despite the small number of samples, the statistical analysis allowed us to assess how the use of OmniTrack impacted a sense of self of each adolescent with ASD. From the lived experiences of adolescents with ASD, we sought to understand how they engaged in self-tracking, how self-tracking practices impacted the sense of self, and how customizable self-tracking tools empowered not only adolescents with ASD to address a wide range of challenges, but also their parents and therapists to understand the adolescents.

4 FINDINGS

4.1 OmniTrack Usage Patterns

All the participants engaged in the study by actively creating trackers and logging data using OmniTrack on a daily basis. Over the course of two weeks, each participant logged 13.2 items on average ($SD = 2.1$). The evenly distributed logged data showed that each participant constantly engaged in tracking activity throughout the study period.

The types of tracking ranged from a simple time-stamping of events on an exercise logger to complex journaling that described the participant's mood or thoughts, as presented in Table 1. During the study, two participants made changes to their trackers. Justin wanted to stop tracking his sleep because he became bored with the task and instead created an exercise tracker. While keeping the initial tracker (conflict tracker), Lucas added a "nagging tracker" to examine the circumstances when his mother scolded him.

4.2 Impacts on Self-Esteem, Self-Efficacy, and Motives for Participation

Of particular interest to this study is the broad impact of self-tracking practices on the self-concept of adolescents with ASD. We found that use of OmniTrack brought about a significant improvement in self-esteem for Ella, whereas the other four participants

Table 1: Participants Demographics and Results of Pre- and Post-Questionnaire.

Name ¹	Gender	Age	IQ	Diagnosis	Designed tracker(s) to record...	RSE	SES	PMI
Ella	Female	18	72	ASD	Mood toward boyfriend	26→30*	27→31*	43→47
Justin	Male	18	70~80	ASD	Sleep/Exercise	33→32	36→37	44→39
Lucas	Male	16	~120	ASD/ADHD	Conflicts with a sister/Mother's nagging	31→31	38→36	42→43
Ethan	Male	16	~90	ASD	Cases of being considerate of others	22→23	25→28*	49→48
Sam	Male	19	94	ASD	Situations I feel anxious or overwhelmed	22→19	24→20*	34→32

¹ Names are pseudonyms.

* $p < 0.05$

showed improvements that were not significant. However, self-efficacy was significantly improved for two of these participants, while Sam demonstrated decreased self-efficacy, indicating that tracking his anxiety may have led him to remember frustrating situations, which, in turn, adversely affected his self-esteem. Sam stated, *"I did not like to recall my anxiety. The more I think about it, the worse it gets."* The ASD participants' ranked their motivation and expectation for participation before the study ($M = 42.4$, $SD = 4.8$) relatively high compared to those of typically developing adolescents ($M = 38.5$, $SD = 3.8$). However, the participants' motivation slightly decreased ($\Delta = -0.6$) between the pre- and post-study questionnaires, but not significantly. Despite this reported decrease in motivation reported, however, four of the participants in the interview session were eager to continue self-tracking through OmniTrack. Sam, who scored the lowest on the Program Motivation Inventory, surprisingly continued logging data every day even after the completion of study.

4.3 Qualitative Findings

We describe the findings of this research based on the tracker log data, findings from workshop sessions, parental and expert interview data, and the metrics of the previous section.

4.3.1 Theme of Trackers: A Desire to be a Better Self. Four out of the five participants with ASD decided to track the daily challenges resulting from their autistic characteristics, mostly related to social challenges. In the tracking topic selection process, participants with ASD actively told us about their challenges and difficulties without prompting. For example, Lucas, who made a conflict tracker, was experiencing more frequent conflicts with his younger sister and his mother because of deficits in his communication skills. Lucas' mother said he did not consider his sister's situation or preferences (she is also an adolescent and sometimes wants to be alone). Instead, Lucas just kept trying to get closer to her. After reaching adolescence, Ethan, who tracked instances where he showed consideration to others, came to realize that he does not have "Nunchi," which is a skill of mind-reading or caring about others' responses [32]. He was stressed by his lack of this characteristic. Ella and Sam were worried about their emotional states. Ella was concerned about her extreme mood swings. Sam was anxious about his frustrations and fears when facing unexpected situations, especially due to academic pressure.

The adolescents with ASD reported that they chose to track their problematic behavior in order to identify and improve their problems. In particular, they wanted to address issues that were

closely related to relationships with family and/or peers. Ethan said, *"Because I am so unsociable and severely lack Nunchi, I don't think I can make female friends. I'm training my Nunchi to reach the level to make female friends."* On the other hand, Lucas used the tracker to search for ways to avoid situations in which he feels frustrated. He said, *"Mom's nagging has a repertory. Sometimes I don't know how to respond, even to the ones from the same repertory. So, I want to be able to respond better to end mom's nagging faster."* This clearly shows that the adolescents have strong desires to better their relationships with the people around them.

4.3.2 Mindfulness through Self-Tracking. The adolescents with ASD indicated that the trackers helped them understand and regulate their emotions. First, the recording process served as momentum toward understanding their emotional states. Both Ella and her mother were worried that Ella cannot control her extremely negative emotions, which results in her yelling at other people who are not involved in the situation. After tracking practices, Ella began to feel better about herself because she was able to figure out why she was experiencing mood swings, and she came to think that she could cope with the issue. She said, *"What I came to realize is that I'm not insane."*

Our findings also suggest that the tracker can serve as a space where adolescents can vent their emotions without fear of judgment. Lucas reported, *"When I fought with my sister, there was nowhere I could vent my anger. But since using the tracker, I have at least been able to vent my emotion here."* The fact that there was no access by caregivers or clinicians seemed to allow the adolescents to view the tracker as their personal space for freely recording their feelings and thoughts. Sam said that he was freely able to record whatever he wanted because his parents were not able to access the tracker, unlike a paper-based diary. Also, as Lucas said, *"I'm free to write whatever I want here, anything I have on my mind."* We also found that the recording process could serve as an alternative to the negative behaviors used to reduce stress with a therapeutic effects. By recording data regarding their negative emotions, which includes what made them angry or how angry they are, they had a chance to express themselves as well as objectively view their emotions. Sam reported that the recording process helped him relieve the frustration that comes from academic pressure. Lucas, who had been trying to reduce his stress through aggressive behaviors such as hitting the wall, said that he was able to relieve his negative emotions by recording data using his tracker, instead.

4.3.3 Constructing Identity through Exploration of the Self. The experience of self-tracking also offered opportunities for the adolescents to discover what they can do to be the better selves they wish to be. Ella showed the most significant changes in self-efficacy. She stated that she fulfilled her goal for tracking because the intervals between her severe mood swings increased. She even initiated a new goal by suggesting that she add a new topic to track conflict with her boyfriend because she wanted to identify the reasons for these conflicts and fix the problems. Ethan also became more motivated to improve his social skills through tracking, expecting to acquire “Nunchi” and to become more socially appropriate. However, not every participant came to have positive expectations about themselves through the self-tracking practices. Sam showed a significant decrease in self-efficacy, which demonstrates that tracking negative emotions does not necessarily provide individuals with methods for coping with them. However, Sam was still engaging in tracking more than two months after the study had ended, and he showed a strong will to deal with his challenges despite the decrease in quantitative metrics.

4.3.4 Data-Mediated Communication. We found it interesting that the adolescents with ASD actively used the self-tracking process and the data gathered as a way to achieve better communication with others. The adolescents with ASD expected that their self-tracking data would help others understand their emotional status. However, they wanted to share their data only with those they expected to understand them and only to the extent they allowed. Justin said that he would be comfortable with sharing all of his data with his family because he thought that his family would understand his status better that way. In contrast, Ella had ambivalent feelings about sharing her data. She wanted to share the data with her mother and her boyfriend, but only the data about her emotional status and not the detailed descriptions of the reasons why she became angry or what she did after a meltdown. Also, during the study, some of our participants let others know that they were doing the tracking with the expectation that others would better understand their status. Lucas said, *“I said to my sister that I was doing this tracking and the data would be shared with others, so she better be more careful with me. But she didn’t care at all.”* Additionally, the adolescents with ASD had a desire to be understood and respected by others by sharing their tracking process and the data they collected. Ethan stated that because he was proud of some behaviors in which he was considerate of others, he wanted to be acknowledged by others. However, all the participants expressed a strong desire to control who had access to their shared data and the extent of the data they shared.

4.3.5 A Translucent Window between Parents and an Adolescent. Adolescents typically hesitate to share personal, sensitive issues with their caregivers, but caregivers need at least some of this information to help them better deal with the challenges that arise during adolescence. Although our participating parents were curious about what their children recorded, they did not seek to view the data out of respect for their children’s privacy. Lucas’s mother said, *“If I got to know what he was tracking, I may push him more. So, it would be better to let the data remain unknown. I quickly lose my patience with him, so knowing too much might be rather bad.”* Ella’s mother also said that she would not check her daughter’s data because her daughter would feel bad if she did.

However, the caregivers said just knowing the topics being tracked, without checking the data in detail, would be beneficial because it would help them understand their children’s status, needs, and problems. Sam’s father said, *“I just thought he doesn’t like socializing with friends at all. I didn’t know he has a desire for a friendship. I feel sorry that I wasn’t aware of that he feels such anxiety or frustration because of his lack of friends.”* Both the caregivers and therapists indicated that even checking the tracking topics and the overall trends would help them make plans for providing appropriate interventions. Ella’s mother said she and the rest of her family would be more careful with Ella if they could check whether Ella’s emotional status were positive or negative. Interestingly, Ella’s mother’s views directly correspond with Ella’s own indication that she would be willing to share her emotional status with her mother. In sum, adolescents with ASD and their caregivers would benefit from sharing the tracking data collected by the adolescents to the extent that the adolescents would be willing to share.

5 DISCUSSION

The analysis of the self-tracking experiences of the five adolescents with ASD showed most of them were deeply engaged in the practice of self-tracking, which involved the creation of custom trackers that best suited their needs, and the collection of and reflection on data about themselves using OmniTrack. The process of co-creating trackers with young researchers encouraged the adolescents to put their everyday challenges on the table and motivated them to understand the contexts for their problematic behaviors and the challenging situations. The two-week self-tracking practice through OmniTrack also affected the self-conceptions of some participants as they discovered what steps they can take to become their better selves. OmniTrack served as a self-soothing, therapeutic tool that provided a mindful moment and an expressive space for venting without fear of judgment. The study also suggested that data collected through OmniTrack mediated communications between adolescents and their caregivers. In the following section, we discuss design opportunities to incorporate this self-tracking framework into existing self-management practices designed to empower individuals with ASD as well as caregivers and clinicians.

5.1 Empowering Active Self-Management

Self-tracking is not merely the simple process of collecting data about oneself. It involves a cycle of practices aimed at increasing self-knowledge through systematic collection, quantification, reflection, and interpretation of data, with the ultimate goal of improving some aspects of daily functioning [1, 21, 24]. A study on patient-initiated tracking found that this practice helped patients develop self-awareness and self-management skills [41]. We also found that the adolescents-driven self-tracking fostered the practices of self-management, a widely adopted behavioral intervention that helps individuals with ASD act appropriately through preparation, self-monitoring, implementation of a plan, execution, and feedback.

Our co-creation workshop, which corresponds to the preparation phase in self-management, motivated our participants to examine various aspects of themselves, such as their interests, desires, strengths, weaknesses, and challenges. Since we wanted to explore the unique characteristics of self-tracking practices by adolescents with autism, we never asked them to design self-trackers to “correct”

their problematic situations or behaviors. Rather, the workshop was aimed at engaging participants in understanding themselves through OmniTrack, an open-ended and flexible self-tracking creation platform, which they used with only minimal guidance to prevent them from creating a tracker with a misleading purpose. While researchers never reinforced participants' choices to track their problematic behaviors, four of the participants designed trackers to identify these issues with a goal toward mitigating them. Therefore, an open-ended and flexible preparation stage could motivate adolescents with ASD to engage in active self-management as their goals are carefully addressed.

The results of the two-week self-monitoring trial with OmniTrack reflect a high degree of compliance by all the participants. The use of a smartphone tracking application is especially appropriate for individuals with autism, who often display an interest in technology [16], and the OmniTrack application's design features such as pre-defined data entry with various visual stimuli (e.g., five-pointed star) readily accommodates the characteristics of adolescents with ASD. We also speculate that respecting the autonomy of these adolescents might encourage their willingness to use a self-tracker. Our participants brainstormed ideas and selected their tracker topics on their own initiative. Moreover, our participants liked the fact that OmniTrack did not provide prompts or feedback; as Lucas reported, *"The machine never nags. It's quiet. It does not judge whatever I do. I feel comfortable with confession here."* The obsessive characteristics of autistic behavior might also contribute to the high rate of compliance. As shown in the case of Sam, who still maintains his practice of recording anxiety on his tracker, this process closely matches the characteristics of autism, suggesting that self-tracking can be employed successfully in a self-monitoring process if the tracking becomes a routine without excessive, unwanted prompting.

5.2 Self-Tracking for Clinical Uses for ASD

Our study of adolescents with ASD and clinical professionals shows that technology-mediated self-tracking can support self-management strategies. Some of the participating adolescents who had already engaged in the PEERS® program attempted to apply target behaviors emphasized in that program (e.g., observe a reaction of a conversation partner) when designing their own self-trackers. Our clinical experts responded that a self-tracking tool could empower individuals to enhance their executive and social skills by practicing what they learned. We discuss below how technology-mediated self-tracking can be applied to various clinical settings for individuals with neurodevelopmental disorders.

First, the group format of a self-tracking workshop can be employed in a group therapy setting. Adolescents with a neurodevelopmental disorder have limited socialization opportunities to form peer relationships with other adolescents. Some of these adolescents often show difficulties in conversing with their friends because they frequently shift topics, fail to listen to others, initiate conversations at inappropriate times, and interrupt or intrude on others [10]. These behaviors can contribute a socially deprived status, decreasing their chances to form an identity through peer relationships [36]. We expect that a group-based self-tracking workshop for the individuals with a neurodevelopmental disorder involving peers who may or may not have the same disorders could serve as group

therapy for practicing a variety of interaction skills (e.g., start, enter, and exit conversations between peers; identify mutual interests between peers; or handle arguments and disagreements).

A self-tracking practice could also support one-on-one therapy sessions at hospitals or counseling centers. Involving clinicians in the early stage (i.e., preparation) of patient-initiated tracking has been suggested as a way to collect clinically useful data that is accurate, reliable and relevant [41]. Self-tracking could assist caregivers and therapists in designing an adaptive therapeutic program that takes into account the adolescent's emotional state and confronts challenges. Caregivers and therapists could leverage the technology-mediated self-tracking tool to enhance compliance with medication or behavioral interventions and even to set mindful goals that can impact self-efficacy and self-esteem. In our study, a clinical psychologist expressed concerns that many adolescents with neurodevelopmental disorders display depressive episodes or severe anxiety as they experience a radical transition to adulthood without preparation. These individuals are provided with a personalized education to learn how to adequately deal with negative moods and how to manage a medication schedule independently. Since self-tracking has some therapeutic properties (e.g., mindfulness, expressive therapy), it can serve as a tool to regulate negative emotions in the adolescent's daily life.

5.3 Design Implications

In this section, we discuss how we can improve upon and employ the new form of self-tracking technologies in everyday lives of adolescents with ASD, as well as in clinical practices.

First, it is important to assist adolescents with ASD in constructing their own "narrative" with the custom tracker as they establish the theme for their casual logging system providing the story's plot. A study investigating a sense of self perceived by individuals with ASD indicated that building a narrative about oneself can contribute to an increased sense of self [17]. Similarly, we found that OmniTrack served as a self-presentation tool by organizing various aspects of themselves (e.g., activities, mood, feeling toward others). Self-tracking with a purpose of narration led the participants to decide what to track, how to track, and with whom to share data in a distinct way. For example, our study participants creatively and proficiently utilized OmniTrack's customizing features for self-expression through naming a tracker (e.g. Nunchi, mom's nagging) and using metaphors to express emotion creatively (e.g. mapping feelings to weather).

Second, suggesting various scaffolding methods based on one's interests and abilities could allow a flexible tracker to make a structure suitable for each individual because individuals with autism display a low level of organizational skills in executive functions [38]. In our co-creation workshop, researchers suggested ways to leverage existing thought processes to align with the functions of the self-tracker. Interestingly, when we suggested the ABC (antecedent-behavior-consequence) methodology, a behavior management strategy, to help adolescents with ASD understand the situation before and after an event [26], Lucas suggested making his tracking structure as a "detective's journal," which consists of the beginning, the course, and the end of the case.

Third, future self-tracking tools can be designed to support cooperative self-management of adolescents with ASD between the individual and his/her caregiver in the domestic settings. In our study, having even limited access to collected data from adolescents can be beneficial for caregivers in understanding their children's current status, needs, and problems. Therefore, we call for the possibility of selective data sharing feature that can promote data-mediated communication between adolescents with ASD and their caregivers. Because the range of data which each adolescent is willing to share with their caregivers can be various, self-tracking tool for adolescents with ASD should provide a high degree of freedom to control the range of shared data. Also, when communicating through data, the system should inform caregivers to provide constructive and/or positive feedback instead of negative and judgmental feedback that could be demotivating and disengaging.

Lastly, when it comes to a clinical purpose, both adolescents and clinicians should understand the ultimate goal of self-tracking, collecting data that can be useful for designing behavioral interventions and therapeutic programs specialized to each individual. We found that both adolescents and clinicians could benefit from sharing in-situ data to achieve better communication by improving clinicians' understanding about adolescents' emotional status and daily challenges grounded on data. However, the clinicians and adolescents might have different perspectives on tracking, as presented in [24, 41]. Clinician-oriented tracking focuses on eliciting standardized data that they need for assessing and treating their patients, which has a benefit that clinicians can directly relate the collected data by their patients and the clinical trials. On the other hand, patient-centered tracking emphasizes a flexible and personalized aspect of self-tracking, which has a benefit in capturing in-situ experiences of patients in creative ways. Meanwhile, there are some challenges associated with the usefulness of patient-centered tracking in clinical settings (i.e., clinical relevance, data accuracy, time constraints, privacy) [41]. Further research is required in order to investigate ways to achieve balance between the two approaches for better data-mediated communication between adolescents with ASD and clinicians, while considering ways to mitigate the challenges of the patient-centered tracking.

5.4 Ethical Considerations

Our study was approved by the Institutional Review Board of Seoul National University Bundang hospital, and informed consent was obtained from each participant's parent as well assent from each adolescent. Due to the vulnerability of our participants, our study materials and protocols were scrutinized by a group that included a psychiatrist and a clinical psychologist who each have more than 10 years experience with adolescents and young adults with ASD. Participants were informed that the workshop and OmniTrack was not a clinically validated toolkit. Instead, we informed that the study was designed to collect empirical design evidence for future technologies to empower individuals with ASD. They were also allowed to pause or quit the study at any time. We carefully managed the time to finish within one and a half hours, because adolescents with low levels of concentration could easily be bored as time went too far and it could be a limitation to participate actively. We remarked that participants did not need to feel obligated to do a better job on the study.

6 LIMITATIONS AND FUTURE WORK

Our study indicated that self-tracking techniques could be used to improve self-awareness in adolescents with neurodevelopmental disorders. However, we also found that self-tracking experiences might lead to excessive self-scrutiny, biased thinking and prejudices, along with unrealistic expectations when in setting tracker goals. For example, Lucas explained the original intention of his tracker topic: *"I want to prove that my sister is an evil through data."* Additionally, self-tracking might negatively impact the adolescents' self-confidence and self-esteem, resulting in excessive self-reflection by repeatedly reminding them of their problematic behaviors, considering the cognitive inflexibility of the adolescents with ASD [11] and perfectionist attitudes, which are commonly found in individual with ASD [20].

Further work is needed to provide guidelines for constructing self-tracking experiences. Although we tended to minimize interventions from caregivers and therapists during the study out of respect for the adolescents' autonomy, appropriate oversight by caregivers and clinicians is still expected. In future work, we will investigate the expected role of caregivers and therapists in the process and the extent to which they should be involved in the design and use of self-trackers and in the data reflection process.

The generalizability of our findings is somewhat limited since this study's relatively small number of participants may not be representative of the entire population of individuals with ASD. All participants are from a single country, Korea. The two-week deployment period might be too short to confirm the effectiveness of the self-tracking practices. Nonetheless, we believe it is valuable to explore the lived experiences and self-tracking practices of adolescents with ASD and to investigate how self-tracking practices leverage current clinical therapy procedures. To identify the prevalence of the themes explored in this paper, we would like to engage in a further long-term, broad-scale study regarding how individuals with neurodevelopmental disorders engage in self-tracking.

7 CONCLUSION

In this paper, we seek to understand the role of technology-mediated flexible tracking to empower adolescents with ASD. This understanding is important to guide the design of future self-tracking tools, as well as the design of adaptive self-management strategies to enable adolescents with ASD to play a greater role in navigating their everyday lives. Our findings showed that flexible self-tracking empowers adolescents with ASD to deal with their behavioral challenges, understand and regulate their emotions, discover what they can do to be the better selves they wish to be, and leverage data-mediated communication with their parents within a permissible range. This allowed us to confirm the efficacy of how self-trackers could be utilized in future research into self-management of adolescents with ASD. Further research should address the appropriate role of caregivers and therapists in the process and the extent to which they should be involved in the design and use of self-trackers and in the reflection on the data collected for adolescents with ASD. We believe our study opens up new ways of supporting the goals of adolescents with neurodevelopmental disorders to be their better selves by complementing clinical treatments with digital self-tracking tools.

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