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**Leisure participation of autistic adults: An ecological momentary assessment feasibility study**

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**Abstract:**

Autistic adults participate less and express lower satisfaction in leisure activities than nonautistic adults, although literature is limited. The multifaceted nature of leisure participation makes it challenging to measure, with most measures being retrospective. Ecological momentary assessments (EMA) can reduce recall bias. This pilot study assesses the feasibility and acceptability of EMA among autistic adults. Participants (N = 40) were recruited via email and online. After completing a baseline interview, participants were asked to complete a once-daily survey for 30 days, in which they received survey links through a text messaging smartphone app. Surveys asked participants to report whether they participated in any leisure activities during the day, their level of enjoyment, with whom they interacted, and where they participated. The EMA appeared feasible in this sample, as participants completed the daily survey on average 27.05 (SD = 3.92) days. Regarding acceptability, most agreed that survey timing was convenient, that it was easy to enter responses and answer questions daily, and that they had enough response time. Overall, this study supports the use of EMA methodology among autistic adults. Future research should follow and improve upon these EMA data collection practices to examine daily behavior and wellbeing among autistic adults.
Leisure participation of autistic adults:

An ecological momentary assessment feasibility study

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Abstract

Autistic adults participate less and express lower satisfaction in leisure activities than nonautistic adults, although literature is limited. The multifaceted nature of leisure participation makes it challenging to measure, with most measures being retrospective. Ecological momentary assessments (EMA) can reduce recall bias. This pilot study assessed the feasibility and acceptability of EMA among autistic adults. Participants ($N = 40$) were recruited via email and online. After completing a baseline interview, participants were asked to complete a once-daily survey for 30 days, in which they received survey links through a text messaging smartphone app. Surveys asked participants to report whether they participated in any leisure activities during the day, their level of enjoyment, with whom they interacted, and where they participated. The EMA appeared feasible in this sample, as participants completed the daily survey on average 27.05 ($SD = 3.92$) days. Regarding acceptability, most agreed that survey timing was convenient, that it was easy to enter responses and answer questions daily, and that they had enough response time. Overall, this study supports the use of EMA methodology among autistic adults. Future research should follow and improve upon these EMA data collection practices to examine daily behavior and wellbeing among autistic adults.

*Keywords:* ecological momentary assessment, daily diary, autism, leisure, wellbeing
Everyday leisure participation of autistic adults living independently: A feasibility and acceptability study of ecological momentary assessment

Adults on the autism spectrum participate in fewer leisure activities (Shattuck et al., 2011; Ormond et al., 2013) and express significantly lower satisfaction with their leisure participation than nonautistic adults (Stacey et al., 2019). This is concerning given the positive benefits that leisure participation has on one’s psychological and physical wellbeing, including decreased perceived stress (Bishop-Fitzpatrick et al., 2017), improved quality of life (Bishop-Fitzpatrick et al., 2017; García-Villamisar & Dattilo, 2010), fewer depressive symptoms, less loneliness, and better friendship qualities (Bohnert et al., 2019). Despite the important role that leisure participation plays in one’s wellbeing, the existing literature provides a limited understanding of leisure participation experiences among autistic adults. Please note that this article uses identity-first language (e.g., autistic adults rather than adults with autism), which has emerged as the preferred way of being addressed in the autistic community (Bottema-Beutel et al., 2016; Kenny et al., 2016).

Leisure activities, in their broadest sense, are typically activities in which individuals voluntarily choose to participate in during their free time because they find such activities enjoyable (Majnemer et al., 2008). The International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001) defines leisure in a manner that captures its multifaceted nature: “Engaging in any form of play, recreational or leisure activity, such as informal or organized play and sports, programs of physical fitness, relaxation, amusement or diversion, going to art galleries, museums, cinemas or theatres; engaging in crafts or hobbies, reading for enjoyment, playing musical instruments; sightseeing, tourism and travelling for pleasure.” The multifaceted nature of leisure participation engenders continuous debate that
makes it challenging to obtain a global definition of leisure. Thus, selecting the best methodology to examine subjective, multifaceted leisure experiences across diverse daily contexts is critical.

The frequently used approaches for quantifying the amount and type of participation of people with disabilities primarily rely on retrospective questionnaires, mostly proxy report, which require respondents to recall and summarize their past experiences during a specific period, such as in the last month or week (e.g., Chang et al., 2013; Taylor-Roberts et al., 2019). Likewise, previous studies of autistic individuals used national datasets, such as National Longitudinal Transition Study-2 to study participation of autistic individuals, asking caregivers and youth to think about social and community participation of the autistic individuals (e.g., out-of-school activities, frequency of friends call) in the past 12 months based on an ordinal scale (e.g., Orsmond et al., 2013; Shattuck et al., 2011). Other studies adapted questions from the national surveys asking respondents how often autistic youth and adults participate in different social activities (e.g., hang out with friends, attending social events) and recreational activities (e.g., do hobbies, watch TV, or play video games) in the past year (Taylor-Roberts et al., 2019) or past week (Bishop-Fitzpatrick et al., 2017) on a Likert-like scale. Another study used a self-constructed measure to examine self-reported leisure participation of autistic adults and continued to use similar questions about engagement frequency of 14 activities from “everyday” to “never” (Stacey et al., 2019). A recent study used an established measure – Temple University Community Participation measure, which was based on the ICF framework and originally designed for adults with mental illness, among autistic adults (Song et al., 2021). Like all other measures, it requests respondents to report accumulative experiences of community participation over the last 30 days.
Retrospective survey instruments predominantly used in cross-sectional participation studies can offer a relatively quick and simple way to gather data from large samples. However, they have some limitations that put the validity of the results into question. First, retrospective questionnaires ask for aggregated experiences and events over time (e.g., over the last month), and memory is likely to suffer from recall errors and be contaminated by the emotional state elicited by researchers asking reflective questions (Schneider & Stone, 2016; Schuler et al., 2021; Shiffman et al., 2008). For instance, there is a general tendency for people to overestimate the frequency or duration of the most intense or most recent events (Oreel et al., 2020; Schneider & Stone, 2016; Schuler et al., 2021; Shiffman et al., 2008) and underestimate short and frequently occurring activities (Araujo et al., 2017; Droit-Volet et al., 2018). Moreover, survey instruments or questionnaires are limited because they rely on respondents’ ability to report accumulative experiences over a period of time, which can be influenced by both cognitive (e.g., reference period) and psychological process (e.g., emotions; Jobe, 2003). Such individual differences can introduce variability and put the validity of interpersonal comparison into question. Furthermore, since these questionnaires are often administered once, they cannot capture the within-subject fluctuations in participation over time.

Ecological momentary assessment (EMA), an increasingly popular methodology in psychological and clinical research (May et al., 2018), collects data at multiple time points over a set period about participants’ experiences and feelings in their natural environment (Shiffman et al., 2008). There are three common types of EMA: (1) diaries, typically assessing experience in fixed intervals, most often daily; (2) experience sampling, assessing experience at random times during the day; (3) event-based sampling, assessing experience at the time of a particular event (Moskowitz & Young, 2006). EMA has two main advantages that are relevant to the present
study. First, it greatly reduces the recall bias compared to retrospective assessments because participants are asked to recall their past engagement and experiences at a given moment or during the day (Oreel et al., 2020; Schneider & Stone, 2016). Second, compared with traditional questionnaires, EMA provides rich within-person contextual data, which allows for the study of within-person dynamics over a substantial time (e.g., how participation change from one day to another). These advantages of EMA may facilitate a better understanding of the everyday participation experiences by focusing on current or very recent events for autistic individuals.

Although EMA has these advantages and is increasingly used, study designs and the examined populations differ across studies, which may systematically affect the data quality. Existing autism research that applied EMA has demonstrated that EMA is a reliable and valid method for this population (see Hare & Chen, 2019, for a review). However, most of the studies primarily involved autistic children and adolescents. There are still questions about the use of EMA in autistic adults, and it is important to establish the feasibility and validity of EMA in comparison with retrospective surveys for this population. First, it is crucial that participants respond to the EMA schedule consistently and regularly as promoted. Previous studies have identified that the average signal response rates were between 57% and 85% for children and adolescents on the autism spectrum (Chen et al., 2015; Cordier et al., 2016; Khor et al., 2014; Kovac et al., 2016; Lim et al., 2021) and between 71% and 78% for autistic adults (Chen et al., 2014, 2017). Second, several studies have examined reliability and validity of EMA data collected from autistic individuals (Chen et al., 2014; Chen et al., 2015; Kovac et al., 2016). The researchers explored split half reliability and revealed consistent reporting of momentary experiences between the first and the second week of the EMA data (Chen et al., 2015; Kovac et al., 2016). Several researchers tested the concordance of EMA with retrospective measures.
(Khor et al., 2014). They found small to moderate correlations between retrospective questionnaire (both self-report and parent-report) and EMA of coping responses.

Although EMA can be effectively used among autistic individuals with average or above average cognitive ability, there is still a lack of evidence for autistic adults in general. Chen and colleagues (2014, 2016, 2017) have explored social experiences of autistic adults using the EMA methodology, with one of them (Chen et al., 2014) evaluating feasibility and usability of EMA among a very small group of autistic adults ($N = 4$). More research investigating the feasibility of EMA using a larger and more diverse adult sample is needed. More importantly, no studies have validated an EMA approach to understand leisure participation, which is particularly important given that leisure is an important aspect of one’s daily life and it needs to be understood for this population.

Thus, the present pilot study aimed to assess the feasibility and validity of this intensive method among autistic adults ($N = 40$). This study used daily end-of-day diary to examine the daily leisure participation among autistic adults who lived independently for 30 days because it allowed the estimation of total activities and frequency. Individuals who live independently were of interest because social isolation is more prevalent among this population when supports (e.g., family members) are not readily available (Povey & Mills 2011; Wallace et al., 2016). We hypothesized that (1) it would be feasible to repeatedly administer the leisure participation measure via EMA over 30 days; (2) autistic adults would report the data collection procedure to be acceptable and would complete at least 70% of the administered measure; (3) autistic adults’ retrospective data would significantly and moderately correlate with EMA data.

**Method**

**Participants**
Participants were recruited through social media groups related to autism advocacy, web posts (e.g., Autism Society of Minnesota, Autistic Self Advocacy Network), ResearchMatch, referrals from organizations, and word-of-mouth \( (n = 2) \) from August 2020 to June 2021. Inclusion criteria required participants to have a formal diagnosis of autism spectrum disorder (ASD), be 18 years old or older, live independently or with nonfamilial roommate(s), have a study-compatible smartphone or other iOS or Android-based device, live in the United States, and be fluent in English. An ASD diagnosis was self-reported by participants. Individuals who did not meet all the inclusion criteria were excluded from the study.

At baseline, 40 autistic adults (women: \( n = 19 \); men: \( n = 11 \); nonbinary: \( n = 9 \); prefer not to answer: \( n = 1 \)) with an average age of 31.2 years \( (SD = 9.5) \) participated in this study. Our sample consisted of 32 \( (80\%) \) non-Hispanic White participants. One participant reported a co-occurring intellectual disability. Thirty-six participants \( (90\%) \) reported at least one co-occurring mental health diagnosis. All our participants lived in metropolitan areas. Given that our study was conducted online during the COVID-19 pandemic, our sample was geographically diverse, with 19 states represented in the sample. Sample characteristics are displayed in Table 1.

**Procedure**

The Institutional Review Board of the University of Minnesota granted approval for this study. Two graduate students and three upper-level undergraduate/post-baccalaureate students received a 2-hour training on consenting procedures, conducting interviews, and enrolling participants with one optional refresher training offered two months after the required training. One of the Principal Investigators (doctoral-level counseling psychologist) provided live supervision and feedback of initial interviews for each interviewer. Given that intellectual disability is associated with a large and significant portion of autistic people (McKenzie et al.,
participants’ capacity to consent was assessed using the University of California, San Diego Brief Assessment of Capacity to Consent (Jeste et al., 2007). All participants provided written informed consent.

Participants were invited to the initial video-conferencing session and completed demographic information, retrospective leisure participation, and other questionnaire measures via verbal interview. At the end of this visit, the trained interviewer introduced the EMA procedure to each participant. Participants’ information and phone number were registered to a web-based application, SurveySignal (https://www.surveysignal.com; Hofmann & Patel, 2015). SurveySignal is a survey management platform that manages the signal and sends text messages to participants’ registered smartphones. Hofmann and Patel (2015) demonstrate reliability and usability regarding SurveySignal. After completing their registration, the participants were shown an example of what the daily surveys looked like and how to complete them.

Participants were asked to complete a once-daily online Qualtrics survey for up to 30 days. They received text messages that were automatically generated by SurveySignal at 9 p.m. local time. Text messages included a web link to access the smartphone-compatible Qualtrics survey. If participants did not complete the survey after receiving the text message, participants received a subsequent notification after an hour to remind them to complete the survey. The link to the survey became inactive after 11:59 p.m. on the same day.

After the 30-day EMA data collection period, participants were invited to the second and final video-conferencing appointment. At the end of the study, participants were reimbursed with up to $65 via a Greenphire ClinCard that was mailed to them for their participation in the study. To encourage the completion of EMA surveys, participants received $0.50 for the completion of each daily survey as well as a $10 bonus if they completed 80% of all 30 EMA surveys.
Measures

Retrospective Leisure Participation

A retrospective leisure participation survey was administered at the initial study session via videoconferencing. Participants were asked “How often do you participate in the following activities in a typical month?” for a list of 18 activities (Table 2). Frequency was rated on a 4-point scale where 1 = rarely or never, 2 = a few times per month, 3 = a few times per week, and 4 = at least daily. Follow-up questions included level of enjoyment (1 = not at all, 2 = slightly, 3 = moderately, and 4 = extremely), companion (1 = alone, 2 = with people I know well, 3 = with people I don’t know well, and 4 = with animals), and places (1 = at home, 2 = online, at home, and 3 = outside the home). Participants were also given the option to report additional leisure activities that were not listed in the table. The leisure participation survey was developed by the researchers from literature on leisure participation and satisfaction in autistic adults (Bishop-Fitzpatrick et al., 2017; Stacey et al., 2019) as well as previously validated related measures (Baker, 2020; Salzer et al., 2014).

EMA Survey

In the daily EMA survey, the same leisure activities in the retrospective survey were used when asking participants “What leisure activities did you do in your free time today?” An “other” option was also provided so that participants could report any other leisure activities that were not in the provided list of activities. To explore the quality of experiences, participants also reported the level of enjoyment for each activity they participated in during the day. Given that solitary leisure patterns are commonly observed in autistic adults, we also asked whether participants did the activities with someone else. Locations of the activities were also explored to
distinguish activities occurred at home or outside the home. The questions related to enjoyment, with whom, and locations were the same as the retrospective leisure participation survey.

**Feedback Questionnaire**

A self-constructed feedback questionnaire was used to learn participants’ perspectives on the EMA procedure. Participants responded to five items: “The timing of the survey was convenient,” “It was easy to enter my responses,” “It was easy to answer the same questions every day,” “I had to deal with interruptions while filling out the survey,” and “I had enough time to respond to the survey”) on a 6-point scale where 1 = *strongly disagree*, 2 = *disagree*, 3 = *somewhat disagree*, 4 = *somewhat agree*, 5 = *agree*, and 6 = *strongly agree*. Participants were also asked an open-ended question: “In general, are there any suggestions to make this a better experience?”

Additional measures not pertaining to feasibility and acceptability were used in the original study and not included in the present study. Please see preregistration for full list of study variables as well as the proposed data analysis: [https://osf.io/gjb58/](https://osf.io/gjb58/).

**Data Analysis**

EMA feasibility was examined by EMA survey completion rates, withdrawal rates, nonresponse rates, any reported technical issues, and survey response time. Validity and reliability of the EMA survey was assessed. First, criterion validity of EMA-reported frequency and types of leisure activities was examined by comparison with the retrospective leisure participation using paired t-tests and Pearson correlations. Internal reliability of the EMA data was examined by comparing the average days of leisure participation for each participant in the first 15 days with that from the second 15 days using paired sample *t*-tests, as in Chen et al.’s (2014) study. Leisure participation in the two halves of the EMA period was expected to be
highly correlated. Correlations ($r$) smaller than .30 were considered as small, $r = .30$ to .49 considered as medium, and $r > .50$ considered as large (Cohen, 1988). Study acceptability was assessed by feedback questions at the end of the study.

Results

Feasibility

Study Enrollment

Figure 1 displays the flow of participant enrollment. Of 90 unique contacts for enrollment from September 2020 to May 2021, 67 were screened, and 40 were enrolled by June 30, 2021 (44% of those initially contacted). Although all adults owned a smartphone, one participant requested that the daily web link to the survey be sent to their email rather than their phone via text message due to not having internet access on their smartphone. Another participant requested a daily reminder email to fill out the survey because they reported that they did not check their phone regularly.

Study Adherence

Of 1,200 prompts (over 30 days, across 40 participants), the overall response rate was 90.2%. Four responses were removed because of missing identity information. Across the 30-day EMA, participants completed the daily survey on average 27.05 ($SD = 3.92$) days, ranging from 15 to 30 days. Based on visual inspection of histograms, there was not a notable drop-off response rate over the EMA period. We also examined whether response rates varied as a function of adult sociodemographic factors. Having a paid job, whether full time or part time, was also associated with higher response rates (94.8% vs. 83.9%, $p = .01$). Responses were not significantly related to participants’ age, gender identity, annual household income, or race and ethnicity.
Several technical issues occurred. One participant informed us that they might not have received messages to fill out the survey due to the loss of cell services. However, the participants had already fully completed the 30-day EMA period, so their concerns did not affect their participation. Four participants delayed the start of their EMA period due to the loss of cell signal, not receiving messages, wrong time zone entered during registration, and medical issues.

The average time spent on the survey was 4.02 minutes ($SD = 25.39$). After removing outliers that were two standard deviations above the mean, the average time spent on daily surveys became 2.40 minutes ($SD = 4.36$). It was expected to complete the daily survey within 5 minutes, and 94% ($n = 1,014$) of the total responses used less than 5 minutes.

**Reliability and Validity**

In the examination of the concordance between the EMA and retrospective measures, correlations of retrospective and EMA measures at the item level are calculated (Table 2). The participation frequency of the EMA report was significantly and positively correlated with the frequency from the retrospective reports for most of the leisure activities, with correlations ranging from 0.32 to 0.65. No significant correlations were found for attending a sports event, going shopping, going to a zoo or park, and informal social communication with others. Taken together, the correlations suggest the agreement between the EMA and retrospective measures varied by types of activities.

Per Chen et al. (2014), we then explored the split-half reliability of the data by comparing the two halves of the 30 days of the total leisure participation. No statistically significant difference was found between the leisure participation of the first 15 days and the second 15 days (59.98 activities vs. 57.15 activities; $t = 1.21, p = .23$). The correlation between the first 15-day leisure participation and second 15-day leisure participation was 0.82 ($p < .001$).
Acceptability

A total of 35 participants responded to feedback questions (see Figure 2). Most participants agreed (i.e., either agree or strongly agreed) that survey timing was convenient (81%, n = 29), that it was easy to enter responses (94%, n = 34), that it was easy to answer questions daily (97%, n = 35), and that they had enough response time (89%, n = 32). One-third of the participants believed that they had to deal with interruptions while filling out the survey (31%, n = 11).

Discussion

This study provided evidence for the feasibility, validity, reliability, and acceptability of administering a leisure participation measure to autistic adults who lived independently (i.e., alone or with nonfamily individuals) via an EMA paradigm. Overall findings support that EMA is a feasible and reliable method for studying daily participation experiences, with most of the activities demonstrating moderate to strong correlations between the EMA and retrospective surveys.

The feasibility was demonstrated through study enrollment, time spent on each daily survey, and EMA response rates. Our enrollment rate is high given that only a small percentage (< 20%) of autistic adults live independently (Anderson et al., 2014; Hewitt et al., 2017) and autistic adults were recruited during the COVID-19 pandemic. Our recruitment strategies were limited to website posting and social media. We were not able to get as many referrals from the autism organizations or advocacy groups because most of the in-person activities and programs were canceled. In terms of time spent on each survey, it is recommended that completion of the survey should require no longer than two-three minutes at each assessment point (Hare & Chen, 2019). Considering that we did not limit response time within the four-hour window, the average
time of below 2.5 minutes after removing outliers should be considered a rather short response
time. This suggests that our EMA survey might be perceived as low participant burden, which
potentially minimized nonresponse (Rolstad et al., 2011).

The response rate of EMA in our study was higher than previous studies of autistic
adolescents and adults (between 62% and 85%; Chen et al., 2014; Chen et al., 2016; Khor et al.,
2014; Kovac et al., 2016). This may be attributed to asking participants to respond to our survey
only once a day at a fixed time, while previous studies were more intensive (e.g., sending
multiple prompts per day). This could also be due to the financial incentives for EMA
completion (e.g., $10 for the completion of 80% of daily surveys), as suggested by how the EMA
completion was also associated with some socio-demographic characteristics. Previous
systematic reviews have found that compliance in EMA studies could be improved through
financial incentives (Heron et al., 2017; Vachon et al., 2019). We found that autistic adults with
lower income and no paid jobs had greater response rates than those with higher income and paid
jobs, possibly because the former might have had more available time to complete the survey.

Moderate ($r = 0.30$ to $0.49$) to high ($r \geq 0.50$) correlations between retrospective leisure
participation and EMA leisure participation at the item level were found in most activities.
Relatively strong correlations were found in physical activities, watching entertainment on a
screen, and playing video games ($r > 0.60$), suggesting high convergence for these areas.
Relatively high correlations also occurred in going to a place of worship, doing arts or hobbies,
listening to radio or music, taking a class for leisure or life skills, and meditating or mindfulness
activity. Participation in these activities may be easier to recall because they are more routinized
and can be performed by individuals alone. Poor correspondence was found in other activities,
including attending a sports event, visiting a zoo or park, informal social communication with
others, and going shopping ($p < .30$), suggesting assessing the frequency of these activities in the past through participants’ recall may not be sufficient. For instance, 57% of the autistic adults reported high frequency of informal social communication (i.e., at least daily in a typical month) in the retrospective survey. However, only 37% of autistic adults reported informal social communication for more than 21 days in the EMA data. This result indicates that autistic adults tend to overestimate their frequency of informal social communication with others in retrospect.

Previous research has revealed that people tend to overestimate typical behaviors, such as the use of internet, social media, and phone, when asking about a specific time period (Araujo et al., 2017; Jerit et al., 2016). It is possible that autistic adults overestimate their frequency of informal social communication (e.g., online communication, phone call) because it typically occurs at nonspecific moments throughout the day without location restrictions, and this type of irregular behaviors may complicate the accurate recall or estimation as opposed to more regular behaviors that is easier to recall.

To examine the reliability of the EMA data, we calculated its split-half reliability following procedures from Chen et al. (2014). No significant difference was found when comparing the two halves of the EMA period of leisure participation, which is consistent with the previous studies that used the same method (Chen et al., 2014, 2015). Our reliability was also similar to a previous report ($r = 0.87$; Kovac et al., 2016). Thus, the EMA data were reported consistently.

Autistic adults also reported that the EMA method was acceptable. The overall positive feedback increases confidence in the validity of the data collected using EMA methods. Although 81% of the sample believed that the timing of surveys was convenient, one-third of our sample also reported disruptions while completing the survey. This indicates that a fixed time
may not fit everyone’s schedules. It is possible that some people are not able to fill out the daily survey due to the timing of the survey, which potentially impacted the overall response rates. Future studies could consider asking participants for their preferred time to send the survey and provide a custom time that fit individuals’ schedule.

**Limitations and Future Directions**

Limitations of this study suggest important areas for future research. Our study used daily diary method with a fixed-interval schedule (i.e., 9 pm daily) to explore leisure experiences of autistic adults during a period (i.e., 30 days). It is possible that participants were engaging in an activity while completing the EMA survey or engaged in other activities after completing the EMA survey, which were not captured. Also, the diary method used in this study required recall of events during the day, which might be more challenging compared with methods required shorter intervals (e.g., every three hours). Further, operationalization of leisure activities is subjective, and thus participants might have completed activities that they did not conceptualize as leisure (e.g., grocery shopping) and thus failed to recall such activities as leisure. Future studies could explore other methods that support effective and accurate leisure activity logging throughout the day.

Similar to previously published EMA studies, participants in our study might have had average or above-average intelligence, as only one participant reported cognitive impairments. Although individuals with cognitive impairments were not deliberately excluded from participation, a focus on autistic adults who lived independently may have automatically excluded individuals who experience more disruptive symptoms. Most autistic adults, especially young adults, live with their families (Anderson et al., 2014; Hewitt et al., 2017; Song et al., 2021). The rates of those living independently are even lower for those with intellectual
disabilities compared to those without intellectual disabilities (Song et al., 2021). Although the prevalence of intellectual disabilities in autistic adults varied across studies (from 19% to 79%; Croen et al., 2015; Jones et al., 2016; Rydzewksa et al., 2018; van Naarden et al., 2015), there is still a significant proportion of the autistic adult population having intellectual impairment. Future research with people with cognitive impairment is crucial to investigate whether EMA methodology is suitable for people with different levels of intellectual disabilities. Generalizability of our sample could be further improved by including autistic adults who live independently alongside a family member. Such individuals were excluded in the present study due to factors that limited our ability to confirm that their family members did not provide a caregiver role; however, a more inclusive definition of living independently could be helpful in future research.

Our study did not include autistic adults who did not have access to a mobile phone. Although about 97% of adults in the general population own a cellphone and 85% own a smartphone in the United States (Pew Research Center, 2021), smartphone use among autistic adults is unknown. Some individuals may prefer not to use smartphones or other technology devices due to privacy or security concerns. Additionally, some individual may live in areas with unstable cellular service and internet connection (e.g., in rural area), which limits their opportunity to participate in this study. Another related limitation is that we did not offer internet services, a data plan, or cellular devices to participants who did not have access to them. Future research would benefit from employing such strategies as approaches to improve generalizability and include people who do not have access to a cell phone or internet.

Although this study was not designed to examine the impact of COVID-19, our data collection was conducted during the pandemic. Thus, our study procedure, participants
recruitment, and results might be influenced by the COVID-19 pandemic. For instance, we were not able to recruit participants in person in the local organizations, and our recruitment strategies were limited to web postings (e.g., Autism Society of Minnesota, Autistic Self Advocacy Network), newsletters, and social media, which could have decreased our recruitment rates. To increase the accessibility of this study, we capitalized on digital technologies and conducted the study remotely. Despite being conducted from Minnesota, all participants were recruited from different states across the United States. Additionally, the COVID-19 restrictions might have limited participation in outside home activities and forced the transition of many aspects of daily life online, which potentially changed the patterns of leisure participation compared with before the pandemic. Research on the effects of the COVID-19 pandemic on autistic adults is limited but has demonstrated a decrease in daily activities (e.g., going to the gym, museums) and socialization with friends and family (Fridell et al., 2022; Maljaars et al., 2022; Pfeiffer et al., 2021). Some individuals perceived the reduction in social and everyday demands as a positive experience and were able to engage in their hobbies more and socialize online (Fridell et al., 2022; Maljaars et al., 2022). However, this study provides a one-and-only chance to examine the leisure participation and experiences of autistic adults living independently under the ongoing COVID-19 pandemic. Given the psychological and emotional distress associated with the pandemic (Pellicano et al., 2021), this study could provide a novel approach for future study on capturing daily experiences of autistic individuals under the COVID-19 pandemic.

**Conclusion**

The current study is among the first to use an EMA design to investigate the daily leisure experiences of autistic adults who live independently. To date, retrospective measures have failed to capture the accurate day-to-day experiences of autistic people. However, the current
study has supported the feasibility, acceptability, and validity of EMA research among autistic adults. Importantly, EMA research with this population may help identify mechanisms of change as well as modifiable targets for intervention. Future research should follow and improve upon these EMA data collection practices when examining daily behavior and wellbeing among autistic adults.
Open Practices Statement

The preregistration materials for this study can be accessed at https://osf.io/9yazj. Deidentified data along with a codebook and the data analysis scripts are available by contacting the researchers. Access to the data is limited to qualified researchers.
References


Schneider, S., & Stone, A. A. (2016). Ambulatory and diary methods can facilitate the measurement of patient-reported outcomes. *Quality of Life Research, 25*(3), 497-506. [https://doi.org/10.1007/s11136-015-10540z](https://doi.org/10.1007/s11136-015-10540z)


Vachon, H., Viechtbauer, W., Rintala, A., & Myin-Germeys, I. (2019). Compliance and retention with the experience sampling method over the continuum of severe mental disorders: Meta-analysis and recommendations. *Journal of Medical Internet Research, 21*(12), Article e14475. [https://doi.org/10.2196/14475](https://doi.org/10.2196/14475)


https://doi.org/10.1371/journal.pone.0124120


https://doi.org/10.1007/s10803-015-2655-7
## Table 1

**Sample characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Baseline (N = 40)</th>
<th>Follow up (N = 36)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Age (range: 18-61 years old)</td>
<td>31.15</td>
<td>9.46</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>19</td>
<td>48.7</td>
</tr>
<tr>
<td>Men</td>
<td>11</td>
<td>28.2</td>
</tr>
<tr>
<td>Nonbinary</td>
<td>9</td>
<td>23.0</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>32</td>
<td>80.0</td>
</tr>
<tr>
<td>Mixed</td>
<td>5</td>
<td>12.5</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2</td>
<td>5.0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>Formal education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>5</td>
<td>12.5</td>
</tr>
<tr>
<td>Some college or associate degree</td>
<td>16</td>
<td>40.0</td>
</tr>
<tr>
<td>Bachelor's degree or above</td>
<td>19</td>
<td>47.5</td>
</tr>
<tr>
<td>Annual household income&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $30,000</td>
<td>24</td>
<td>61.5</td>
</tr>
<tr>
<td>≥ $30,000</td>
<td>15</td>
<td>37.5</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/Divorced</td>
<td>36</td>
<td>90.0</td>
</tr>
<tr>
<td>Married</td>
<td>4</td>
<td>10.0</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed (full time)</td>
<td>11</td>
<td>27.5</td>
</tr>
<tr>
<td>Employed (part time)</td>
<td>7</td>
<td>17.5</td>
</tr>
<tr>
<td>Unemployed/Unable to work</td>
<td>13</td>
<td>37.5</td>
</tr>
<tr>
<td>Student</td>
<td>9</td>
<td>22.5</td>
</tr>
<tr>
<td>Mental health problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>29</td>
<td>72.5</td>
</tr>
<tr>
<td>Depression</td>
<td>28</td>
<td>70.0</td>
</tr>
<tr>
<td>ADHD/ADD</td>
<td>21</td>
<td>52.5</td>
</tr>
<tr>
<td>Post-Traumatic Stress Disorder</td>
<td>12</td>
<td>30.0</td>
</tr>
<tr>
<td>Bipolar</td>
<td>6</td>
<td>15.0</td>
</tr>
<tr>
<td>Medical Diagnosis</td>
<td>Count</td>
<td>Percentage</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Obsessive Compulsive Disorder</td>
<td>4</td>
<td>10.0</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>10.0</td>
</tr>
<tr>
<td>Other medical diagnoses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning disability</td>
<td>12</td>
<td>30.0</td>
</tr>
<tr>
<td>Seizures/Seizure Disorder</td>
<td>5</td>
<td>12.5</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>4</td>
<td>10.0</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>None</td>
<td>21</td>
<td>52.5</td>
</tr>
</tbody>
</table>

*Note. Percents may not sum to 100% due to rounding. Nonresponders are not included in percentage calculations. ADHD = attention deficit/hyperactivity disorder. ADD = attention deficit disorder. *Household poverty level = $26,500 (US DHHS, 2021)*
Table 2

**Pearson’s correlations between EMA and retrospective measures of leisure participation**

<table>
<thead>
<tr>
<th>Leisure Activities</th>
<th>Retrospective report $M$ (SD)</th>
<th>EMA report $M$ (SD)</th>
<th>Correlation ($r$) [95% CI]</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Go to a social event (e.g., party, social clubs)</td>
<td>1.40 (0.55)</td>
<td>1.25 (1.51)</td>
<td>.37 [.07, .61]</td>
<td>.018</td>
</tr>
<tr>
<td>2. Do physical activity, including exercise and playing sports</td>
<td>2.68 (1.07)</td>
<td>8.10 (7.15)</td>
<td>.60 [.35, .77]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>3. Attend a cultural event (e.g., movie, play, concert)</td>
<td>1.30 (0.46)</td>
<td>0.28 (0.64)</td>
<td>.49 [.21, .70]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>4. Attend a sports event</td>
<td>1.08 (0.27)</td>
<td>0.08 (0.35)</td>
<td>-.06 [-.37, .26]</td>
<td>.701</td>
</tr>
<tr>
<td>5. Go shopping (e.g., grocery, shopping center)</td>
<td>2.40 (0.63)</td>
<td>5.45 (4.37)</td>
<td>.30 [-.02, .56]</td>
<td>.065</td>
</tr>
<tr>
<td>6. Go to a restaurant or coffee shop</td>
<td>1.85 (0.80)</td>
<td>3.78 (6.53)</td>
<td>.45 [.17, .67]</td>
<td>.003</td>
</tr>
<tr>
<td>7. Visit museums, art galleries, or libraries</td>
<td>1.43 (0.55)</td>
<td>0.28 (0.64)</td>
<td>.32 [.01, .57]</td>
<td>.047</td>
</tr>
<tr>
<td>8. Visit a zoo or park</td>
<td>1.55 (0.74)</td>
<td>1.23 (3.05)</td>
<td>.18 [-.14, .47]</td>
<td>.266</td>
</tr>
<tr>
<td>9. Go to church, synagogue, or a place of worship</td>
<td>1.31 (0.65)</td>
<td>0.74 (2.36)</td>
<td>.55 [.28, .74]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>10. Do arts, crafts, or hobbies</td>
<td>2.88 (0.99)</td>
<td>4.85 (6.59)</td>
<td>.54 [.28, .73]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>11. Read (e.g., books, news)</td>
<td>3.50 (0.85)</td>
<td>10.93 (10.50)</td>
<td>.43 [.14, .65]</td>
<td>.006</td>
</tr>
<tr>
<td>12. Watch entertainment (e.g., TV, movies, sports, show) on a screen</td>
<td>3.43 (0.90)</td>
<td>17.83 (9.00)</td>
<td>.64 [.42, .80]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>13. Listen to radio, podcast, or music</td>
<td>3.50 (0.82)</td>
<td>12.58 (10.11)</td>
<td>.57 [.32, .75]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>14. Play video games</td>
<td>2.50 (1.18)</td>
<td>10.10 (10.65)</td>
<td>.65 [.42, .80]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>15. Informal social communication with others (e.g., chatting room, electronic forum, coffee hour, phone call)</td>
<td>3.40 (0.87)</td>
<td>16.55 (8.95)</td>
<td>.25 [-.07, .52]</td>
<td>.119</td>
</tr>
<tr>
<td>16. Surf the internet and social media</td>
<td>3.73 (0.64)</td>
<td>16.10 (10.07)</td>
<td>.40 [.10, .63]</td>
<td>.010</td>
</tr>
<tr>
<td>17. Take a class for leisure or life skills</td>
<td>1.35 (0.77)</td>
<td>1.10 (2.49)</td>
<td>.50 [.23, .70]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>18. Meditate, yoga, or mindfulness activity</td>
<td>1.73 (0.98)</td>
<td>2.08 (4.90)</td>
<td>.55 [.28, .73]</td>
<td>&lt; .001</td>
</tr>
</tbody>
</table>

*Note.* Scores of the retrospective report ranged from 1 to 4. Scores of the EMA report ranged from 0 to 30. Participants were also given the option to write in an unlisted activity, in which the following activities were reported five or more times: playing with a pet, writing, playing musical instruments, and baking. CI = Confidence Interval. Bold indicates statistically significant correlations at the alpha = .05 level.
Figure 1

*Study participants contacts and enrollment*

*Note.* EMA = ecological momentary assessment.
Figure 2

*Autistic adults’ average level of agreement about their experiences in the ecological momentary assessment study*

*Note.* $N = 36$. Items were rated on a 6-point scale where 1 = *strongly disagree* and 6 = *strongly agree*. Horizontal axis ranges from 1 to 7 due to standard deviation bars.
90 Expressed interest (Potential participant reached out to us)

90 Contacted (Potential participants we contacted to schedule screening)

19 No response
4 Ineligible prior to screening
   No smartphone (n = 1)
   Lived with family members (n = 2)
   Not in the United States (n = 1)

67 Screened

17 Ineligible
   No formal diagnosis of autism (n = 3)
   Lived with family members (n = 14)

50 Eligible and signed-up for EMA

10 Declined
   No longer interested (n = 3)
   No response (n = 7)

40 Completed baseline assessment and started daily surveys

3 No response
1 Withdrew

36 Completed follow-up assessment
- It was easy to enter my responses.
- It was easy to answer the same questions every day.
- I had enough time to respond to the survey.
- The timing of the survey was convenient.
- I had to deal with interruptions while filling out the survey.