

Brief Report

Feasibility and usability of experience sampling methodology for capturing everyday experiences of individuals with autism spectrum disorders

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Abstract

Background: Understanding experiences from the perspective of adults with autism spectrum disorders (ASD), in the myriad of circumstances in which they find themselves every day, is crucial for developing client-centered interventions. However, capturing these experiences can be difficult.

Objective: To investigate the feasibility and usability of experience sampling method (ESM), an ecological momentary assessment, for studying individuals with ASD.

Methods: Four participants (2 males) with Asperger's syndrome or high functioning autism aged 16–32 years carried an iPod touch or iPhone with a pre-installed ESM survey exploring the situation and their perceived internal experiences. Participants were asked to respond to the survey 7 times daily, at random times generated by the device, for 7 days.

Results: A high signal response rate (mean = 71%) and a short average time required for survey completion (mean = 1 min 42 s) supported feasibility of the ESM for use in research with individuals with ASD. Participants reported that the questions were straightforward and that survey completion interfered very little with everyday activities, supporting acceptability of the method. Results of a split-week analysis revealed consistency of experiences; correlations among experiences that are linked logically provided evidence of the internal logic of data gathered using the ESM. Through graphic analysis, we illustrated the usability of ESM for capturing the influence of everyday contexts on internal experiences/perceptions.

Conclusions: The ESM holds promise for examining the impact of social context on the everyday experiences of individuals with ASD. © 2014 Elsevier Inc. All rights reserved.

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Individuals with autism spectrum disorders (ASD) often encounter challenges in social participation.^{1–7} Thus a number of interventions have been developed to enhance their social skills or behavior regulation.^{8–10} However, everyday social challenges are influenced by the myriad of contexts in which they occur. Although previous researchers have used interviews and global ratings to gather information about social experiences in people with ASD,^{4–7} these methods do not readily capture the influence of context on experiences. More importantly, retrospective

methods do not allow for the examination of individuals' values regarding social participation or what they desire in everyday life. Having knowledge of day-to-day social experiences and the expectations of individuals within the heterogeneous population of people with ASD allows for greater understanding and for improved targeting of client-centered interventions.^{11–14}

Experience sampling method (ESM),^{15,16} an ecological momentary assessment,^{12,17} allows participants to report real-time actions, thoughts, and feelings in everyday settings, over time and across contexts. Such data enable exploration of the dynamic relationships between subjective experiences and everyday contexts.¹⁷ ESM has been used with a range of populations, including people with disabilities, to measure quality of life and impact of illness.^{18–22} Recently, researchers have used electronic

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The authors declare that they have no competing interests.

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devices instead of paper-and-pencil methods to prompt participants to complete ESM surveys.^{15,23}

ESM enables researchers to identify fluctuations of perceptions about everyday experiences within a person.²⁴ As such, it can be used to capture the variability inherent in the ASD population. Unlike single-case studies, data collected with ESM can be aggregated and analyzed at within- and between-person levels simultaneously.²⁴ In addition, compared with retrospective method, data collected through ESM have greater ecological validity and the effects of recall bias and socially desirable reporting are reduced.^{12,13,15,17} However, few researchers have adopted the method when studying adults with ASD,^{25,26} and no one to date has investigated the psychometric properties of data gathered from this population.

The willingness of participants to interrupt ongoing activity to complete ESM surveys, seen in signal response rates, required investigation given the belief that people with ASD often resist change in daily routines.^{27,28} Previous researchers have identified average signal response rates in adults with schizophrenia at 67%²⁹ and 57% in children with ASD³⁰ using the computerized ESM. Although an 80% response rate was found in adults with ASD using the paper-and-pencil reporting,²⁵ the use of computerized methods with this population requires investigation since preferring the use of technology may influence survey compliance. Thus, we examined signal response rates and time spent in survey completion with a newly-developed ESM platform (Participation in Everyday Life Survey Application [PIEL App]) for iOS devices.³¹ We also gathered feedback from participants to determine the acceptability of the method.

Validity and reliability of ESM data collected with individuals with ASD pose additional concerns, particularly related to the requirement to reflect on emotional experiences. While some researchers have indicated that people with mild forms of ASD understand emotions and reflect on social experiences,^{4–6} others disagree.^{32,33} Thus we examined evidence for internal reliability and validity by examining consistency of the data and the internal logic of responses reflecting subjective experiences.

Cognitive requirements are of some, but generally lesser, concern to validity. ESM survey questions are short, straightforward and address only immediate experiences. They therefore place less cognitive demand on participants than retrospective methods.¹² A recent study showed evidence of validity for ESM data gathered with children with mild forms of ASD.³⁰ Previous researchers also have confirmed the validity of data collected with adults with schizophrenia who commonly present cognitive deficits.^{29,34}

Therefore the purpose of this study was to examine the feasibility and the usability of ESM for exploring everyday experiences. We hoped to set the stage for further research using this methodology in this population.

Methods

The study had approval from the University of Sydney Human Research Ethics Committee and The Autism Spectrum Australia Research Approval Committee. Written consent was obtained from all participants and from parents of participants younger than 18.

Participants

Advertisements were circulated around Australia for the purpose of recruiting participants. Interested adults and parents of adolescents contacted the researchers for further information. Four individuals (2 males) with Asperger's Syndrome or high functioning autism aged 16–32 years (mean = 22.5; SD = 6.8) who met the criteria responded. All had been formally diagnosed according to DSM-IV criteria.¹ All had sufficient reading comprehension to comprehend the surveys easily, confirmed by a Woodcock Reading Mastery Test (WRMT-III)³⁵ score of Grade 3.1 for one participant and scores above Grade 12.9 for the others. While all participants had concomitant mental health diagnoses (e.g., depression, anxiety, ADHD), they did not meet the exclusion criteria: diagnosis of intellectual disability or neurological or developmental disorder (e.g., cerebral palsy), or difficulty comprehending or speaking English.

ESM survey

The survey comprised 20 questions about: the situation at the time of the signal (i.e., place, activities and company status), participants' perceived internal experiences (i.e., interest in the situation, degree of involvement, perceived reciprocity [being listened to, caring about others], anxiety, loneliness and enjoyment). In order to ensure that the internal experiences had high shared meaningfulness and allowed participants to answer according to their understanding, we explored the clarity and shared meaning of the variables in pre-pilot work with patients with psychosis and depressive disorder as well as experts in the ASD field when developing the survey. The format of the questions included multiple choice, yes/no, and visual analog scales for the internal experiences (from “not at all” to “very much”). The Flesch–Kincaid readability test³⁶ showed that the grade level of the survey questions was 1.6, lower than the participants' reading comprehension levels identified by the WRMT-III.

Procedure

All participants were provided with the PIEL App for use on their own iPod Touch or iPhone or one provided by the researchers. Participants were asked to carry the device for 1 week. The device randomly signaled participants to respond to the ESM survey 7 times daily. The survey

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