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Capturing emotional experience of children and adolescents with intellectual disabilities using the experience sampling method

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Background: While the Experience Sampling Method (ESM) is particularly suitable for assessing subjective views and inner phenomena such as emotional experience, it is still rarely used in research involving individuals with intellectual disabilities (ID)—especially children and adolescents. In an innovative attempt, the present study aimed to develop an ESM survey incorporating self-report measures to assess the emotional experience of children and adolescents with ID, and to examine the feasibility of this approach.

Methods: We developed an ESM survey design through a stepwise, participatory procedure guided by predefined criteria. To evaluate feasibility, we conducted a pilot study over an 8-week period involving 9 children and adolescents with mild to moderate ID (aged 5–15) and interviewed both the participants and their parents.

Results: The findings revealed intraindividual variability in participants' emotional experience and interindividual variation in their assessment of different situations and activities. Evaluation meetings with participants and their parents supported the feasibility of the ESM approach.

Conclusion: Based on our pilot study, it can be cautiously concluded that the adapted ESM survey design is suitable for assessing the emotional experience of children and adolescents with mild to moderate ID. Future studies with larger sample sizes and more rigorous approaches are needed to further develop this approach.

KEYWORDS

digital assessment, emotional experience, experience sampling method, intellectual disability, self-report

1 Introduction

“Capturing life as it is lived” (Bolger et al., 2003, p. 579). This concise phrase encapsulates the primary objective of the Experience Sampling Method (ESM): to collect data in real life and in or close to real time (Hektner et al., 2007; Reis, 2012). This approach helps reduce the cognitive burden of retrospection and thereby minimises recall bias, which is often associated with conventional retrospective questionnaires (Stone and Litcher-Kelly, 2006; Zurbriggen et al., 2021). Owing to this peculiarity, ESM is particularly suitable for research involving individuals with intellectual disabilities (ID). Employing the ESM to investigate intraindividual variability in their emotional experience can help identify predictors of mental health or behavioral problems—often associated

with ID (Buckley et al., 2020)—and effects of social contexts on their well-being (Bakkum et al., 2023).

ESM studies typically focus on internal phenomena such as emotional experience, thus self-reports are frequently employed. This aligns with the long-standing ‘issue of voice’ in ID research (Jen-Yi et al., 2015). Although there is increasing recognition that self-reports should be preferred to gain insight into the subjective experience of children and adolescents with ID, proxy reports (i.e., parent or caregiver reports) remain the predominant approach (Scott and Haverkamp, 2018). This may be due to the relative difficulty of collecting self-reported data in this population, as ID is typically associated with lower literacy and conceptual skills, and overall lower adaptive functioning (American Psychiatric Association, 2022; Tassé, 2013). To address this challenge, researchers must adapt mainstream instruments or develop new measures specifically designed for individuals with ID (Kooijmans et al., 2022). Against this backdrop, the present study aimed to develop and implement an ESM design that enables children and adolescents with ID to report on their emotional experience in daily life.

ESM is part of a broader group of approaches known as intensive longitudinal methods (ILM) (Bolger and Laurenceau, 2013; Hamaker and Wichers, 2017). These methods are characterised by the collection of longitudinal data at high frequency—typically multiple times per day over a period of several days or weeks (Walls and Schafer, 2006). ESM has rarely been used in research with participants with ID and only with adults or adolescents from the age of 14 onwards—despite several advantages (Bakkum et al., 2023; Venetz and Zurbriggen, 2015). As ESM is conducted in real-life settings and in real time, participants are only required to briefly recall information when reporting, for example, on their feelings or activities. Additionally, ESM questionnaires are typically short, with simple items, and consistently repeated, which is further reduces cognitive demands (Fritz et al., 2024).

Nevertheless, ESM poses several challenges, some of which are specific to the ID context. First, ESM studies are usually designed for participants who can read, which is often not the case for individuals with ID—especially during childhood. Second, participants must be able to comprehend the questions. Third, ESM generally assumes independent participation, requiring individuals to carry a booklet or device, respond to alerts, and complete the questionnaire promptly at each signal. It is therefore likely that children and adolescents with ID require tailored support to complete some or all of these tasks. Finally, ESM studies require high level of participant compliance, as engagement is expected over a prolonged period of several days or weeks (Hektner et al., 2007; Scollon et al., 2003; Wrzus and Neubauer, 2023).

Planning an ESM study involving children and adolescents with ID presents numerous challenges frequently associated with the issue of self-reports. Drawing on their systematic review of evidence-based recommendations, Kooijmans et al. (2022) outlined five stages in the development and adaptation of self-report measures for individuals with borderline to mild ID. Stage 1 involves item generation; Stage 2 pertains to content development, including considerations around language, response format, visual presentation, and layout. The process should be participatory, including the piloting of draft versions (Stage 3). Stage 4 concerns implementation of the instrument, while Stage 5 emphasises the importance of ongoing development and evaluation.

A key recommendation by Kooijmans et al. (2022) is to begin with an existing measurement instrument with good psychometric

properties. For the assessment of emotional experience, one such instrument is the PANAVA short scales (Schallberger, 2005), which have previously been applied in ESM studies involving children and adolescents with learning difficulties (Zurbriggen et al., 2018). The short scales measure positive activation (PA), negative activation (NA), and valence (VA), and are based on the concept of core effect—a well-established concept for investigating emotional experience in daily life (Kuppens et al., 2012). An adapted version of the PANAVA short scales incorporates non-verbal emoticons for digital ESM assessments and has demonstrated acceptable psychometric properties in a sample of adults without ID (Schreiber and Jenny, 2020).

As one of the first of its kind, this study aimed to develop an ESM survey incorporating self-report measures to assess the emotional experience of children and adolescents with ID in their everyday lives and to examine the feasibility of this approach. We followed the five-stage development framework by Kooijmans et al. (2022) and conducted a pilot study with children and adolescents with ID. Given the characteristics of the population, we established the following criteria:

1. Children and adolescents report on their emotional experience themselves (i.e., *self-report*).
2. The survey accommodates varying levels of *adaptive skills*, allowing participation by individuals with mild to moderate ID.
3. The ESM survey can be completed by participants *without or low reading skills*.
4. The ESM survey is suitable for use in a range of *everyday life situations* (i.e., capturing inter- and intraindividual variability).
5. The *ESM study design* (i.e., duration, assessment frequency, density of the questionnaire) is *manageable* for children and adolescents with ID.

2 Methods

2.1 Sample

This pilot study was part of the project Pilot project on social participation in the UNIFIED sports programme (UNIFIED-GR). Participants were children and adolescents with ID who took part in the Unified Sports Programme by Special Olympics Switzerland. The participants were selected in collaboration with an experienced liaison familiar with members of the participating sports clubs. According to the information provided, the sports club members had mild to moderate ID.

The sample was intended to be exploratory. We selected 10 participants, aged 5–15 years, with a range of adaptive skills (Table 1), as the severity of ID is primarily defined by adaptive functioning. This includes conceptual, social, and practical skills for managing daily life (American Psychiatric Association, 2022; Tassé, 2013). Adaptive functioning was assessed using a German translation of the Adaptive Behavior Assessment System (ABAS; Harrison and Oakland, 2015).

2.2 Signalling devices and ESM design

Tablets and smartphones served as signaling and survey devices due to their ease of use. The ESM survey was created using the platform *m-Path*, which offers a user-friendly and customisable framework for

TABLE 1 Participants' age and means of eight adaptive behavior skill domains.

P	Age in years	CO	CU	FP	HS	LS	SC	SD	SO
1	10	2.50	2.17	1.67	2.83	2.50	1.17	0.20	2.40
2	10	2.20	2.17	1.67	2.17	2.50	1.83	0.80	2.60
3	7	2.00	1.67	0.00	1.60	1.83	0.67	0.00	2.60
4	5	2.17	0.33	0.00	1.67	0.83	0.83	0.80	1.40
5	10	2.67	2.33	2.00	2.60	2.20	2.67	2.00	2.20
6	10	2.83	2.67	3.00	2.17	1.67	2.00	1.20	2.00
7	15	2.33	2.67	2.00	2.67	1.83	2.67	2.40	2.40
8	10	2.50	1.67	1.33	1.67	2.50	2.50	-	2.33
9	13	3.00	2.33	2.83	2.00	1.67	2.17	2.00	2.60
10	15	2.67	3.00	2.80	2.67	2.50	2.33	2.33	1.75

P, Participant. Adaptive behavior skill domains (based on ABAS; Harrison and Oakland, 2015): CO, Communication; CU, Community use; FP, Functional pre-academics; HS, Health and safety; LS, Leisure; SC, Self-care; SD, Self-direction; SO, Social. Scale: 0, not able; 1, never (when necessary); 2, sometimes (when necessary); 3, always (when necessary).

app-based ESM implementation (Mestdagh et al., 2023). The platform also supports additional media such as visual and auditory assistance.

The ESM prompts were planned in a semi-random sampling scheme (cf. Dejonckheere and Erbas, 2021). Signals were aligned with participants' weekly training and gym classes at school, with additional signals randomly assigned during leisure time. To generate sufficient data on intraindividual variability and enable comparison across different everyday situations—while avoiding participant overload—we scheduled one signal per day over an eight-week period, resulting in 56 signals (7 days × 8 weeks) per participant.

2.3 Instrument and measures

The ESM questionnaire was divided into two parts: one addressing *internal aspects* (i.e., emotional experience) and the other focused on *external aspects* (i.e., situational conditions, activities). The first part was completed by the participants themselves. The second part was completed either by participants with sufficient reading skills (i.e., the ability to read simple words and short sentences) or, for those with limited or no reading skills, by an instructed adult (e.g., parent, trainer, teacher). Completion of the entire ESM questionnaire required approximately 2–4 min.

Emotional experience was assessed using the LE-PANAVA scales (Schreiber and Jenny, 2020). The VA scale comprised two items, whereas the PA and NA scales each consisted of three items. In line with Kooijmans et al.'s (2022) recommendations, we:

- (1) Applied a concrete concept with visualisation (i.e., emoticons with facial expressions) that had been empirically tested (Schreiber and Jenny, 2020).
- (2) Used a simple response format, retaining the bipolar scaling from the original LE-PANAVA, but simplifying it to a dichotomous scale for PA and NA (e.g., no energy/full of energy) and a 4-point Likert scale for VA items (e.g., unsatisfied, somewhat unsatisfied, somewhat satisfied, satisfied). We created the gradations by morphing the emoticons.

- (3) Incorporated supportive media by providing audio recordings of the questions.
- (4) Presented one question per screen.
- (5) Ensured a focus on the principle of “staying in the here and now” by framing questions in the present tense.
- (6) Employed active, concise phrasing with simple vocabulary.
- (7) Provided guidance throughout the process (e.g., explanation of response options).
- (8) Pretested the initial version.

Situational conditions (i.e., location, companionship) and current activities were assessed using categorical variables. Respondents selected from predefined activity groups (e.g., eating/drinking, homework).

2.4 Instruction and compliance measures

Standardised guidelines were developed for the study, and the two instructors received intensive training. Initial contact with parents and other relevant adults (e.g., general and special education teachers, trainers) was made by telephone to introduce the study, obtain consent, and agree on which device (smartphone or tablet) would be used.

A subsequent in-person meeting was held at participants' homes to:

- (1) Explain the main aim of the ESM study (i.e., investigating participants' emotional experience in different everyday situations with an emphasis on sports activities).
- (2) Present the survey procedure using a weekly schedule with pictograms.
- (3) Demonstrate how to respond to an incoming signal.
- (4) Conduct a short trial to assess comprehension and feasibility, specifically whether the participant could recognise emoticons, assign them to corresponding emotional states, follow the prompt referring to the moment of the signal, and navigate the device manually.
- (5) Obtain informed consent from participants, documented via signature or fingerprint.

Following the short trial (4), one participant was excluded (in consultation with the parents) after repeated difficulties in recognising and applying the emoticons as intended.

During the in-person meeting, we emphasised the participants' role in the study to encourage participation. To further support compliance, parents were contacted by phone the day after the instruction and again 2 weeks later (cf. Section 2.5). A second home visit was conducted at the end of the ESM survey period to evaluate the implementation from the participants' perspective.

2.5 Piloting phases and procedure

The ESM survey was piloted using a stepwise approach comprising four main phases:

- (1) An initial trial to test the preliminary version (V1) of the survey and the instructional process (cf. Section 2.4).
- (2) Implementation of V1.

- (3) Evaluation of V1 and subsequent revision.
- (4) Implementation of a second, revised version (V2).

Adjustments were made in a participatory manner based on feedback from participants and their parents. We conducted short evaluation meetings with the participants and their parents after the initial trial (Step 1), following the implementation of V1 (Step 3), and at the end of the ESM study (Step 4). Descriptive statistics were generated for the VA, PA, and NA items in order to gain insight into intraindividual variability and variation in situations.

Participants were introduced to the study on a staggered basis. Two participants completed only V1 for the 8-week period; four participants used V1 during the first 4 weeks and V2 during the second 4 weeks; and the remaining four participants completed only V2.

The adult usually carried the smartphone and handed it to the participant when a signal occurred, but did not assist with answering. One participant used his own smartphone. If a signal was missed, the app sent one reminder after 1 h; missed prompts were not reissued thereafter.

3 Results

All 9 participants provided self-reports throughout the study, responding to 332 signals with a median response rate of 84.2% per participant. No decline in response rate was observed over the eight-week period. Feedback from evaluation meetings with participants and their parents further supported feasibility: Children were generally motivated and able to complete the ESM independently or with minimal support. Families described the ESM routine as manageable in everyday life, though some noted the low signal volume and the challenge of distinguishing subtle emoticons.

Evaluation of the responses from the first participants suggested that the format used for the PA and NA items in V1 might have been oversimplified. Consequently, we modified the response format for these items to a 4-point Likert scale (V2). Exploratory internal consistency estimates across all ESM assessments indicated excellent coherence among the PA and NA items ($\alpha = 0.89\text{--}0.92$). At the individual level, exploratory within-person consistency estimates ranged from $\alpha = 0.41$ to 1.00. Figure 1 illustrates the mean levels of PA and NA across the eight-week study period for three participants, selected to exemplify potential differences between the two response formats. Participant P4 used the dichotomous scale (V1) throughout the entire period, reporting consistently high PA and low NA, with some observable variation. Participant P6 used the dichotomous format for the first four weeks and then switched to V2, which seemed to allow for greater differentiation in the reporting of PA and NA. Participant P7 used only V2. Intraindividual day-to-day variability (SD) of mean PA and NA was observed across the full range of overall adaptive skills (AS = 1.00–2.51), including the lowest-scoring participant (AS = 1.00; Figure 2). Overall, participants reported high PA and low NA (Figure 3). Beyond these average levels, Figure 3 illustrates the interindividual variability in PA and NA across different situations and activities. Higher PA and lower NA were reported during sport, watching television, and eating. In contrast, lower PA and higher NA tended to occur during homework, relaxing, and getting ready. Being unwell was associated with notably high NA and low PA.

4 Discussion

The aim of this study was to develop an ESM approach tailored to enable children and adolescents with ID to report their emotional experience in daily life. This population has rarely been included in research involving self-assessment of their real-life experience (Scott and Haverkamp, 2018), and even fewer in ESM studies (Bakkum et al., 2023), likely due to the methodological challenges involved. To

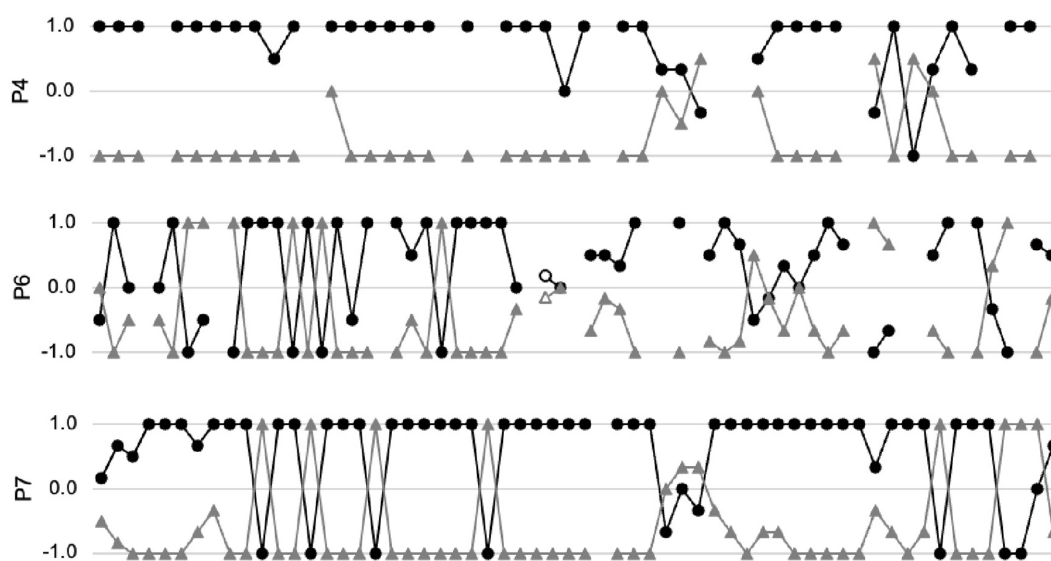


FIGURE 1

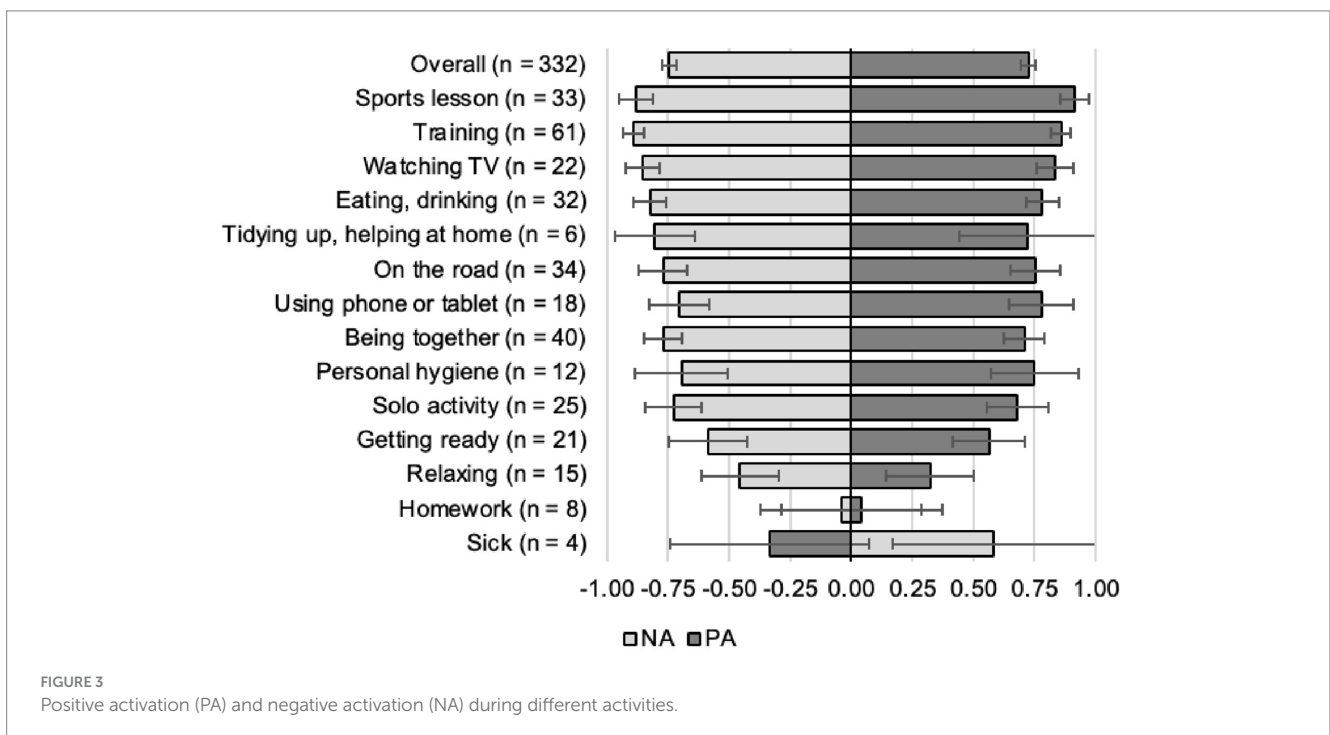
Positive activation (black circles) and negative activation (grey triangles) of three participants. P4: 2-point scale, P6: 2- and 4-point scale (starting from white markings), P7: 4-point scale.

the best of our knowledge, this was the first study using ESM with children with ID.

Our study demonstrates a viable approach by adapting an ESM survey to the specific needs of children and adolescents with ID. The five predefined criteria were largely fulfilled. Participants aged 5 to 15 years with a range of adaptive skill levels (Criterion 2) were able to report on their subjective emotional experience themselves (Criterion 1) across various everyday life situations (Criterion 4), as indicated by intraindividual fluctuations in their emotional experience. Importantly, these intraindividual fluctuations were observed across the full range of adaptive skills, indicating that children with diverse profiles were able to use the scale meaningfully. This was further supported by the relatively high response rate, which was slightly

above the average compliance rate in other studies with general populations (Wrzus and Neubauer, 2023) and the few studies with adolescents or adults with ID (Bakkum et al., 2023). We utilised tablets or smartphones along with the m-Path application, which included visual and auditory support (Mestdagh et al., 2023), thereby eliminating the need for reading skills (Criterion 3). Future studies could incorporate personalised support options, such as sign language videos, to further enhance accessibility. Our findings suggest that both the study duration and assessment frequency were appropriate for the participants (Criterion 5). Overall, the adapted ESM survey was feasible for children and adolescents with mild to moderate ID.

Several notable limitations should be acknowledged. These are primarily related to the pilot nature of the study and the restricted sample size. Because the study followed an exploratory, participatory instrument development approach, the variation in survey versions limited direct comparability. Thus, only descriptive results were reported, and the small sample size hindered formal testing of the psychometric properties of the LE-PANAVA scales for children and adolescents with ID. Although exploratory internal consistency estimates indicated good coherence among the items, these findings should be interpreted cautiously. Another limitation is the broad age range, which could account for differences in participants' responses due to developmental factors. Furthermore, it should be noted that not all aspects of the survey were self-reported. While all participants reported internal aspects like emotional experience, external aspects (e.g., activities, settings) were frequently completed by parents or other adults. This division proved effective but required close coordination with adults in the participants' environments and might have also affected the participants' responses. Additionally, we would like to highlight that the ESM survey approach used in this study needs further development and evaluation (Kooijmans et al., 2022). Future studies could explore, for example, specific age groups, shorter survey periods with more assessments per day or the combination of self-reports with mobile sensing (Mehl et al., 2024).



Finally, the ESM ratings were not compared with other affect-measurement approaches (e.g., retrospective questionnaires, proxy ratings), which limits conclusions about convergent validity. Such comparisons will require a larger sample in future studies.

We hope that our study will assist researchers seeking to apply ESM in the context of ID (for further guidance on ESM: Fritz et al., 2024; Myin-Germeys and Kuppens, 2021; Trull and Ebner-Priemer, 2020; Wrzus and Neubauer, 2023). Although the implementation of ESM in this population requires additional effort from researchers, the opportunity to empower participants to independently report on their emotional experience and to observe their daily lives offers significant value (Bakkum et al., 2023; Mehl and Conner, 2012). Beyond research applications, self-reporting may itself enhance participants' awareness of their emotions and daily experiences (Verhagen et al., 2016).

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

Ethical approval was not required for the study involving human samples in accordance with the local legislation and institutional requirements because the pilot studies consisted of anonymous, voluntary survey participation without sensitive content or intervention, and posed no foreseeable risk to participants. Informed consent was obtained from all participants and, where applicable, from legal guardians. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin. Written informed consent was obtained from the minor(s)' legal guardian/next of kin for the publication of any potentially identifiable images or data included in this article.

Author contributions

CZ: Conceptualization, Resources, Writing – review & editing, Supervision, Writing – original draft, Methodology. MA: Resources, Writing – original draft, Project administration, Conceptualization, Methodology, Data curation. ML: Writing – review & editing, Conceptualization, Investigation. AS: Writing – review & editing, Resources. SS: Data curation, Formal analysis, Visualization, Writing – review & editing, Conceptualization, Funding acquisition.

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Conflict of interest

The author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The author(s) declared that Generative AI was not used in the creation of this manuscript.

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