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Navigating Adulthood With Extreme Demand Avoidance: A Qualitative Exploration of Differences, Accommodations, and Lived Experiences

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Abstract

Adulthood is characterized by demands and expectations, including increased independence and responsibility, career and personal growth, and relationship stability. For adults with extreme demand avoidance (EDA) traits, characterized by an anxiety-driven need for autonomy and a pervasive resistance to everyday demands, these expectations can evoke an overwhelming anxiety, where avoidance functions as a form of self-preservation rather than disinterest or amotivation. This phenomenological qualitative study explored the lived experiences of Australian adults with EDA traits and the ways they navigate adulthood. Fifty-three participants completed an online survey that included the EDA Questionnaire-Adult version to determine the presence of EDA traits and study eligibility. Fourteen adults aged 21–50 years with suspected EDA then went on to complete open-ended questions exploring everyday demands and coping strategies. Their responses were analyzed using thematic analysis, and five themes were observed, which we called: 24/7 Turmoil, A Tug-of-War Within, Hell is Other People, Misunderstanding and Stigma, and I Will Survive. Collectively, the findings depict adulthood as a demand-saturated environment marked by chronic overwhelm, exhaustion, and guilt. This study addresses an important gap in the literature, emphasizing the need for autonomy-supportive, compassion-focused, and neurodiversity-affirming approaches across clinical, workplace, and social contexts.

Lay Abstract

Adulthood often involves many demands, such as working, managing daily tasks, maintaining relationships, and taking on more responsibility. For adults with extreme demand avoidance (EDA), these everyday expectations can feel overwhelming. EDA is linked to high anxiety and a strong need for autonomy. Avoiding demands is not about laziness or lack of motivation, but instead works as a way to protect oneself from intense anxiety. This study explored the experiences of Australian adults with EDA and how they manage the demands of adulthood. Fifty-three adults took part in an online study and completed a questionnaire to identify EDA traits. Fourteen people aged between 21 and 50 went on to answer open-ended questions about daily demands and coping strategies. We analyzed their responses to identify common patterns and experiences. Five key themes were identified: *24/7 Turmoil*, *A Tug-of-War Within*, *Hell is Other People*, *Misunderstanding and Stigma*, and *I Will Survive* (also see Infographic in supplementary material). Together, these themes show that adulthood can feel like a constant source of pressure, leading to ongoing overwhelm, exhaustion, guilt, and self-doubt. At the same time, participants described resilience, creativity, and ways of adapting their lives to protect their well-being. This study highlights the need for greater understanding of EDA in adulthood and supports approaches that are flexible, autonomy-supportive, compassionate, and affirm neurodiversity in clinical, workplace, and social settings.

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Introduction

Demand avoidance is a natural human trait; most people at some point avoid doing tasks they find challenging, overwhelming, or tedious. For some individuals, demand avoidance is a pervasive, persistent, and anxiety-driven pattern significantly shaping everyday functioning and well-being, sometimes described as extreme demand avoidance (EDA; Newson et al., 2003; O'Nions et al., 2014). Individuals with EDA traits often display a strong need for autonomy and an anxiety-driven resistance to everyday demands, including those that are direct (e.g., requests), indirect (e.g., praise), or internal (e.g., hunger; Newson et al., 2003; PDA Society, 2022).

EDA is often explored within the context of children, particularly in relation to autism (Gillberg et al., 2015; O'Nions et al., 2016). However, a growing number of adults describe similar experiences as they navigate various roles, responsibilities, and expectations of adulthood (Cat, 2018; Kenny & Doyle, 2024; PDA Society, 2024). While adulthood is often described as a period of increasing independence, self-determination, personal growth, and role stability (Mehta et al., 2020; Scales et al., 2016), for adults with EDA, the occupational, societal, and emotional pressures may become overwhelming, with psychological and functional implications (Cat, 2018; Kenny & Doyle, 2024; PDA Society, 2024).

Originally termed pathological demand avoidance (PDA) by Newson et al. (2003), the concept has since been subject to increasing critique within the literature which has highlighted the potentially stigmatizing nature of the term "pathological," arguing that it may frame protective or distress-based responses within neurotypical environments as deliberate defiance rather than understandable reactions to overwhelming circumstances (Gillberg, 2014; Green et al., 2018; Moore, 2020). The current study adopts the term EDA (Gillberg, 2014; Green et al., 2018; Moore, 2020; O'Nions et al., 2014) to convey the intensity of avoidance behaviors while maintaining a more person-centered and inclusive framework. Notably, participants' accounts may use the terms PDA and EDA interchangeably.

The concept was first used by Newson et al. (2003) to describe a group of children who appeared to exhibit an atypical profile of autism due to their extreme resistance to everyday demands. Subsequent research has identified anxiety, an intolerance of uncertainty, and perceived loss of control as factors underpinning EDA behaviors, whereby avoidance temporarily restores a sense of control but in doing so maintains anxiety-avoidance cycles (Stuart et al., 2020; White et al., 2023). While avoidance-based coping has been associated with other mental health disorders such as anxiety (Hollocks et al., 2019; Wilmer et al., 2021), individuals with EDA describe avoidance across several contexts, including seemingly neutral or positive situations (Cat, 2018; Green et al., 2018).

While presentations are diverse, individuals with EDA typically display a hierarchy of avoidance strategies that escalate in response to increasing demand-related anxiety (Newson et al., 2003; O'Nions et al., 2016). Strategies can include socially mediated ways to avoid complying with demands (e.g., distraction, negotiation, and procrastination), in addition to more overt responses such as withdrawal, shutdown, or heightened fight, flight, or freeze reactions when autonomy continues to be challenged (O'Nions et al., 2016; PDA Society, 2018, 2024). Some of the features of EDA appear to overlap with the concept of autistic inertia, a term used to describe difficulties initiating, stopping, or transitioning between tasks (Buckle et al., 2021). Autistic adults describe task paralysis and a disconnection between intention and action that is not fully explained by motivation or oppositionality (Buckle et al., 2021). While these experiences may overlap with EDA, in relation to initiation difficulties and overwhelm, autistic inertia alone does not fully account for the pervasive maintenance of avoidance.

Importantly, EDA is not currently recognized within established diagnostic frameworks, such as the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, Text Revision (American Psychiatric Association, 2022) and International Classification of Diseases 11th Revision (World Health Organization, 2019). Determining prevalence rates is therefore challenging. Gillberg et al. (2015) estimated that 0.18% of autistic children in the Faroe Islands had features consistent with an EDA profile, decreasing to 1 out of 50 in adolescence. Although these prevalence estimates are widely cited, an overreliance on estimates likely compromises the study's interpretive accuracy, contributing to an underestimation of EDA traits among adult populations. The absence of robust prevalence estimates does not negate the lived significance of EDA; rather, it reflects broader challenges associated with researching emerging constructs (Kildahl et al., 2021; Woods, 2019).

EDA's absence from diagnostic frameworks generates debate about whether it is best conceptualized as a distinct construct, a profile of autism, or a broader behavioral pattern associated with other neurodevelopmental and psychological disorders (Kildahl et al., 2021; Woods, 2019). EDA

is most commonly understood as a behavioral profile of autism, with research recurrently identifying autistic traits as a strong predictor of EDA behavior (Gillberg et al., 2015; O'Nions & Eaton, 2020; O'Nions et al., 2014, 2016; White et al., 2023). However, much of the existing research examines EDA within autistic cohorts, making it difficult to determine whether EDA is uniquely associated with autism or rather reflects broader behavioral characteristics present across other neurodevelopmental and psychological conditions (Kildahl et al., 2021). Emerging research that examines EDA within more diverse populations suggests that EDA may be associated with other neurodevelopmental conditions and psychiatric disorders, such as attention-deficit hyperactivity disorder (Egan et al., 2019; Reilly et al., 2014), conduct problems (O'Nions et al., 2014), sensory differences, and phobias (O'Nions et al., 2018). This is consistent with bioecological and transactional models of EDA, which emphasize dynamic interactions between individual characteristics (e.g., neurodivergence and emotional dysregulation) and environmental stressors, as opposed to fixed psychopathology (Green et al., 2018; Johnson & Saunderson, 2023; Kildahl et al., 2021; Milton, 2012).

Whilst systematic reviews suggest that there is currently insufficient evidence within the existing body of literature to determine mechanisms for EDA and clear diagnostic boundaries (Haire et al., 2023; Kildahl et al., 2021), many educators, researchers, clinicians, and people with lived-experience recognize EDA as a pattern associated with significant functional and psychological implications (Kenny & Doyle, 2024; O'Nions & Eaton, 2020; PDA Society, 2022). Research exploring how EDA is experienced in everyday life allows for the investigation of meaning, context, and support needs without assuming diagnostic status, which is a particularly useful approach for adults whose experiences are often misunderstood and obscured within existing frameworks (Eaton & Banting, 2012; Haire et al., 2023).

EDA in Adulthood

While some findings suggest that EDA traits may decrease with age (Gillberg et al., 2015; O'Nions et al., 2016), research demonstrates that the fundamental characteristics of EDA, including anxiety-driven avoidance, intolerance of uncertainty, and a persistent need for autonomy, remain in adulthood across a variety of contexts (Cat, 2018; Eaton & Banting, 2012; Egan et al., 2019, 2020; Kenny & Doyle, 2024; PDA Society 2018, 2024).

In adulthood, individuals are often expected to independently navigate increasingly complex and competing demands, such as employment, romantic relationships, and financial responsibility (Scales et al., 2016), highlighting the theoretical and clinical importance of exploring EDA within the context of adulthood. Adults with EDA traits often report that the cumulative and persistent demands of everyday life heighten anxiety, leading to chronic stress, occupational instability, difficulties maintaining relationships, barriers to accessing appropriate support, and financial dependency (Cat, 2018; Kenny & Doyle, 2024; PDA Society, 2024). Such difficulties may be amplified within adulthood as expectations of independence, self-regulation, and productivity are high, and formal supports are often limited (Scales et al., 2016).

Despite such challenges, adults remain significantly underrepresented in research. To date, Kenny and Doyle (2024) provide the only empirical study to explore the lived experiences of adults with EDA, revealing that many demands are perceived as threats to autonomy, leading to panic and avoidance across various aspects of life, including work and relationships (Kenny & Doyle, 2024). While the small cohort of interview participants may impact transferability, the richness of their responses reveals the impact EDA characteristics have on everyday functioning and emphasizes the need for continued research (Kenny & Doyle, 2024).

Importantly, EDA is difficult to identify in adults, as its features are often obscured by co-morbid mental health problems, variability in trait expression, a lack of professional expertise, and masking (a strategy used by individuals to suppress their difficulties in order to conform to social norms; Goodall et al., 2023; PDA Society, 2022). Many adults with EDA may be misdiagnosed, receiving interventions that inadequately account for demand-related anxiety (Cat, 2018; Eaton & Banting, 2012; Kenny & Doyle, 2024). The consequences of inadequate understanding and delayed or inappropriate support of EDA can be significant. The case-based and lived-experience literature reveals that when EDA-related experiences are inadequately recognized or framed solely through deficit-based or compliance-focused lenses, mental health and functional outcomes deteriorate (Cat, 2018; Eaton & Banting, 2012; Kenny & Doyle, 2024; PDA Society, 2018, 2024). Adults describe chronic anxiety, depression, burnout, and diminished self-esteem, arising from repeated experiences of misunderstanding and unmet support needs (Cat, 2018; Kenny & Doyle, 2024; PDA Society, 2018, 2024). As such, exploring the lived experiences of adults with EDA allows for a deeper understanding of how EDA-related experiences intersect with developmental expectations, social contexts, and support systems over time. Informing more appropriate formulations, improving understanding, and identifying forms of support that prioritize autonomy and well-being. Collectively, existing literature emphasizes EDA as a complex construct, with implications for well-being and everyday functioning, particularly beyond childhood (Cat, 2018; Eaton & Banting, 2012; Kenny & Doyle, 2024; PDA Society, 2022, 2024).

Current Study

The current study aims to explore the lived experiences of adults with EDA to understand the ways in which they

experience and navigate the demands of adulthood and how experiences shape their well-being and functioning. Using a qualitative approach, the study is shaped by two research questions: (1) How do adults with EDA experience the demands and expectations of adulthood? (2) How do adults address the challenges they may encounter? In centering participants' lived experiences, this study hopes to capture the complexity of EDA-related experiences, move beyond categorical and diagnostic debates, and provide nuanced insight into the experiential and contextual dimensions of EDA in adulthood. It aims to enhance understanding of EDA within adulthood, contribute to more appropriate formulations, and compassionate supports.

Methodology

This study employed a phenomenological qualitative methodology and was guided by principles of reflexive thematic analysis (TA), due to its theoretical flexibility and focus on the researcher's active role in theme development (Braun & Clarke, 2022b). It adopted a philosophical framework grounded in critical realism with an interpretivist epistemology (Braun & Clarke, 2022a).

From an ontological perspective, the realist approach acknowledges the reality of EDA as a phenomenon that has tangible consequences (Braun & Clarke, 2022a, 2022b). An interpretivist epistemology acknowledges that knowledge about this reality is filtered through subjective experiences and interpretations (Braun & Clarke, 2022a, 2022b). This enables the study to explore how participants view, interpret, and respond to demands and expectations throughout adulthood, recognizing the real-life challenges as well as the socially and psychologically constructed nature of the individual's lived experience.

Participants

A purposive sample of adults who met the following eligibility criteria was included in the study: (1) currently residing in Australia, (2) aged ≥18 years old, and (3) obtained an EDA Questionnaire-Adult version (EDA-QA) total score ≥40. This ensured the study captured the experiences of individuals where demand avoidance reflects a pervasive and meaningful aspect of functioning, as opposed to experiences attributable to situational or general forms of avoidance.

A total of 53 participants completed the EDA-QA (Egan et al., 2019); 33 did not sufficiently meet the inclusion criteria for EDA, while six discontinued for unknown reasons. A final cohort of 14 adults, aged between 21 and 50 years ($M = 35.57$, $SD = 9.01$), was included in the analysis (see Table 1 for demographic information).

Data collection concluded when the dataset was considered to possess sufficient information power (Braun & Clarke, 2022b). This was demonstrated by the richness and diversity of participant responses, aims that were clearly defined, and a dense sample specificity (i.e., participant characteristics are highly specific to the central phenomenon; Malterud et al., 2016). Thus, the available dataset was suitable to adequately respond to research questions, and new participants were unlikely to have contributed to new discoveries.

Measures

EDA-QA

A 26-item self-report screening questionnaire developed to identify EDA traits in adults (Egan et al., 2019). Using a 4-point scale, from "not true" to "very true," participants were asked to reflect on their behavior over the last six months and rate the extent to which each item was consistent with their behavior (e.g., "I obsessively resist and avoid ordinary demands and requests"; Egan et al., 2019). Responses are summed for a total EDA score, with higher scores representing more EDA traits (Egan et al., 2019). While a previously established cut-off score of ≥45 is used to identify an elevated likelihood of EDA, a more inclusive approach (≥40) was used in the current study to capture a broader range of relevant characteristics. This increased sensitivity to subthreshold but meaningful EDA characteristics ensures inclusion of individuals who experience demand-related anxiety, emotional variability, and autonomy-threat sensitivity without extreme scores. It has demonstrated high internal reliability (Cronbach's $\alpha = 0.92$) and good interrater consistency (Egan et al., 2019). In the present study, internal reliability remained high (Cronbach's $\alpha = 0.88$).

Open-Ended Questions

Qualitative data was gathered through three open-ended questions, including, "thinking specifically about extreme demand avoidance, can you describe challenges you experience in adulthood (for example, relationships, work, education, family)," "in what ways has extreme demand avoidance affected specific parts of your adult life? (for example, you might consider how it has impacted your routines, relationships)," and "can you describe any strategies, supports, or resources have been helpful in navigating adulthood? (for example, specific accommodations in the workplace, communication strategies/styles, professional supports)." These were designed to reveal aspects of adulthood which participants found challenging, and the strategies used to navigate such challenges. For each item, participants had the option to provide a written response or an audio recording.

Dataset Generation

Following ethical approval, recruitment material was shared on social media (e.g., Facebook, LinkedIn, and Discord)

Table 1. Participant Demographic Data.

Pseudonym	Age	Preferred Gender	Living Arrangement	Employment Status	Relationship Status	Number of Dependents	Highest Educational Level
Claire	43	Female	Living with spouse/partner	Self-employed	Married	2	Undergraduate
Laura	39	Female	Living with spouse/partner	Self-employed	Married	4	Graduate and/or Advanced Diploma
Jayme	21	Nonbinary	Living with parents/extended family	Unemployed	Single	0	Undergraduate
Kylie	32	Female	Living alone	Self-employed	Single	0	Graduate and/or Advanced Diploma
Toni	22	Prefer not to say	Living with parents/extended family	Unemployed	In a relationship	0	Year 7
Dave	41	Male	Living with spouse/partner	Employed by an organization or business	Married	2	Undergraduate
Jen	50	Female	Living with spouse/partner	Employed by an organization or business	Married	4	Graduate and/or Advanced Diploma
Lisa	44	Female	Living with parents/extended family	Employed by an organization or business	Separated/ divorced	2	Certificate III level or above
Kate	45	Female	Living with a child, flatmate, and ex-partner	Unemployed	Separated/ divorced	0	Certificate III level or above
Olivia	28	Female	Living on my own	Employed by an organization or business	Single	1	Certificate III level or above
Mel	40	Female	Living on my own	Employed by an organization or business	Separated/ divorced	2	Post Graduate (e.g., Doctorate, Master's)
Mary	35	Female	Living with children	Employed by an organization or business	Separated/ divorced	2	Undergraduate
Caris	32	Female	Living with parents/extended family	Unemployed	Separated/ divorced	2	Graduate and/or Advanced Diploma
Chloe	26	Female	Living with parents/extended family	Unemployed	Single	0	Undergraduate

sites linked to EDA and in allied health practices. This outlined the study's aim and purpose, eligibility criteria, and what participation involved. Interested participants were directed to scan a QR code or follow a link to a cloud-based platform designed to create, distribute, and analyze surveys for gathering stakeholder feedback. The survey included eligibility screening questions related to age and geographic criteria, the online version of the EDA-QA, a demographic questionnaire, and open-ended questions.

Data was collected between May and August 2025. Participants were required to complete the survey using a personal electronic device. Participants who met age and geographic inclusion criteria completed the EDA-QA to determine whether their experiences were consistent with patterns of EDA traits. Those with EDA-QA total scores ≥40 completed the remainder of the online survey, including a demographic questionnaire and open-ended survey questions. The demographic questionnaire collected information relating to participants' everyday lives as adults, including gender, educational attainment, living arrangement, relationship status, employment status, and number of dependents. Those with total scores ≥40 were automatically redirected to the end of the survey.

Data Analysis

Participant data from the demographic questionnaire, EDA-QA, and open-ended questions were reviewed. Identifiable information was removed to protect confidentiality and maintain anonymity, and participants were assigned a pseudonym.

Reflexive TA was used to analyze data as it offers an adaptable yet rigorous approach to exploring patterns of meaning (Braun & Clarke, 2022b). It was largely inductive, in that the coding and themes were heavily influenced by the participants' accounts, allowing for a rich understanding of experiences (Braun & Clarke, 2022b). Researchers were considered co-constructors of meaning; therefore, reflexivity was integral in ensuring that the findings remained grounded in participant experiences.

The analytic process was systematic and iterative. Responses were read several times to ascertain familiarity with the participants' contexts, experiences, and breadth of information. During this process, the researchers engaged in reflexive journalling to document initial observations, interpretive reflections, and evolving understandings of the data. Each response was then manually coded several times by using electronic annotations, margin notes, highlighting, and code categorization tables to organize and collate patterns across responses. Coding began descriptively, focusing on explicit content within responses, before evolving to more latent coding that explores implicit meanings underpinning participants' experiences.

As coding progressed and understanding deepened, codes were refined, merged, and grouped into broader categories representing shared patterns of meaning across participants. The researchers then reviewed participant data, annotations, reflective notes, and developing categories collaboratively to generate themes. Themes were subsequently reviewed, refined, and mapped to evaluate whether they demonstrate coherent, meaningful, and conceptually distinct patterns across the dataset. Through this iterative process, several themes were merged due to conceptual overlap, resulting in a final set of themes and subthemes was developed to capture common experiences among participants while also preserving the nuance and complexity of individual perspectives.

Researcher Reflexivity and Trustworthiness

The researchers acknowledge their own identities and potential influence on data collection and analysis. The first author is a neurodivergent female and student researcher in her 20s, whose interest in EDA developed through prior professional experience in administrative roles within a psychology practice providing EDA-informed support. Prior to commencing the study, her understanding of EDA was primarily shaped by clinical perspectives, emphasizing anxiety-driven avoidance and the importance of autonomy-supportive environments. The second author is a neurotypical middle-aged male; he is a senior clinical psychologist with clinical, academic, and research experience within the area of disability and challenging behaviors. Neither researcher had prior relationships with participants. Reflexivity was maintained throughout the research process by regular supervision, which provided structured opportunities to discuss assumptions, ensuring analytic decisions were grounded in participants' experiences rather than professional familiarity.

The first author completed the initial coding and theme development, keeping a reflexive journal to avoid privileging existing assumptions during data collection and analysis by identifying, recording, and examining assumptions, emotional responses, and emerging interpretations. Experts in the field (e.g., clinical psychologists) provided external assistance, reviewing the methodological framework, ensuring it remained free from preexisting assumptions. Codes and themes were then reviewed by the second author, and discrepancies were resolved by discussion and consensus.

Analysis

Reflexive TA generated five superordinate themes, some with several subordinate themes (see Table 2), each representing an aspect of navigating adulthood with EDA, which we named 24/7 Turmoil, A Tug-of-War Within, Hell is Other People, Misunderstanding and Stigma, and I Will Survive. These themes depict adulthood as a demand-saturated environment characterized by overwhelm, exhaustion, and guilt. Participants illustrate how demand

Table 2. Superordinate and Subordinate Themes.

Superordinate Theme	Subordinate Themes
24/7 Turmoil	Overwhelm from everyday demands
	Parenting-related emotional exhaustion
	Internalized inadequacy and self-blame
A Tug-of-War Within	Conflict between desire and capacity
	Loss of autonomy in meaningful activities
	Shame, isolation, and perceived failure
Hell is Other People	Social withdrawal and avoidance
	Parenting and relational burnout
Misunderstanding and Stigma	Misinterpretation of EDA experiences
	Occupational and interpersonal consequences
	Scrutiny, masking, and identity strain
	Validation through understanding and community
I Will Survive	Adaptation through flexibility and autonomy
	Creative demand reframing strategies
	Self-compassion and identity reconstruction

Note. EDA = extreme demand avoidance.

avoidance is an anxiety-driven, self-preserving response to perceived threats to autonomy, rather than amotivation or oppositionality.

24/7 Turmoil

This theme demonstrates the pervasive and multifaceted nature of EDA within adulthood, capturing the disproportionate emotional intensity of routine demands, including work, self-care, chores, and parenting. For participants, the weight of everyday responsibilities was "incapacitating," "mentally draining," "paralysing," and "exhausting." Claire shared, "just day to day adult stuff is a constant battle with myself….I've had to accept that 'motivation' isn't my issue…." Mary wrote, "I feel extremely disabled by my allergy to demands. I don't just avoid demands, I'm incapacitated by them." These accounts indicate that demand avoidance was not a reflection of amotivation, incompetence, or defiance, but emerges as an anxiety-driven physiological and emotional survival response (Egan et al., 2019; Gillberg et al., 2015; Johnson & Saunderson, 2023; Kenny & Doyle, 2024).

The demands of parenting were particularly burdensome. Caregiving demands left Mel feeling constantly "overwhelmed," describing her experience as one of "24/7 turmoil." Lisa explained, "I am finding that I am having to regulate my emotions to the extent I have difficulty connecting with my children because I feel I have nothing left for them patience wise," whilst Laura wrote, "I struggle with my parenting because I'm not always able to be flexible with my kids needs, I get overwhelmed…and then I reach a point in the evening that I can't make anymore decisions…." Decision fatigue and reduced emotional availability to attend to their children's needs were often accompanied by emotional exhaustion and guilt, reinforcing feelings of inadequacy.

Participants' descriptions capture the deeply affective nature of navigating adulthood with EDA, characterized by enduring turmoil and perceived failure to meet societal expectations of competence. Participants appeared to misattribute unfinished chores, parenting struggles, and disrupted work routines as personal failures, rather than recognizing capacity-based limitations related to anxiety-driven demand avoidance. Previous literature demonstrates that perceived failure to meet expectations can contribute to diminished self-worth, heightened anxiety, and depression (Carlson & Williams, 2011; Culatta & Clay-Warner,

2021). Thus, participants' self-criticism, guilt, and exhaustion may reflect an internalization of challenges, fostering negative self-perceptions and diminished self-worth (Carlson & Williams, 2011; Culatta & Clay-Warner, 2021).

A Tug-of-War Within

This theme encapsulates participants' descriptions of a "brutal contradiction" between wanting to engage but simultaneously feeling incapacitated to act. This extended beyond merely externally imposed and undesirable demands, affecting intrinsically motivating activities, contributing to feelings of inadequacy, loneliness, and guilt. Toni shared, "I find it hard to have hobbies. That is what hurts me most. Not being able to pick up a book and finish it." Jayme wrote, "People want to engage deeply with my subject…the moment it's tied to a deadline or grade, I freeze…most of the time I'm struggling. I often feel isolated and like I'm a failure even when I really try."

Participants' experiences of wanting to engage in meaningful activities while simultaneously feeling unable to act may reflect aspects of autistic inertia (Buckle et al., 2021). While autistic inertia may partially explain difficulties with task initiation, it may not fully account for the pervasive maintenance of avoidance and heightened autonomy-threat responses described by participants, suggesting these experiences may reflect broader transdiagnostic processes underpinning EDA-related difficulties.

Additionally, their accounts reflected the affective consequences of an intrapersonal conflict between desire and capacity. Self-Determination Theory (Ryan & Deci, 2000) proposed that inherent psychological needs for competence, relatedness, and autonomy facilitate motivation and promote well-being. Within this framework, once activities or responsibilities are perceived as demands, the perceived threat to autonomy diminishes emotional security, evoking distress, amotivation, and self-criticism. Moreover, broader psychological frameworks illustrate how a perceived failure to meet personal goals or societal expectations can result in rumination and self-criticism, exacerbating feelings of inadequacy (Jones et al., 2009; Rosi et al., 2019). For adults with EDA, difficulty engaging with meaningful roles and hobbies may be interpreted as evidence of personal shortcomings. The resulting intrapersonal conflict becomes internalized, cultivating feelings of shame, guilt, and inadequacy (Jones et al., 2009; PDA Society, 2024; Rosi et al., 2019).

Hell is Other People

This theme encapsulates participants' experiences of relational and social contexts, including their intimate, family, and social relations. Participants described interpersonal relationships as sources of pressure, anger, and emotional exhaustion. Their experiences reflected a continuum of interpersonal patterns, including anxiety-avoidance behaviors and periods of complete isolation. Kylie wrote that she "regularly cancel on plans with friends even when I want to see them." Toni shared that "I'm a very isolated person which isn't great but sometimes it feels a lot better than trying to meet with anyone."

Mirroring findings from previous literature, participants oscillated between sociability and withdrawal once relational demands became overwhelming (Johnson & Saunderson, 2023; O'Nions et al., 2014; PDA Society, 2024). Relationships involved balancing personal well-being with managing others' expectations and maintaining responsiveness, requiring sustained emotional regulation; a process compromised among individuals with EDA by heightened anxiety and hypervigilance (Doyle & Kenny, 2023; Egan et al., 2020; Haire et al., 2024). Hence, withdrawal did not resemble disinterest but functioned as a means of preserving limited emotional resources.

Parents and familial dynamics further demonstrated this emotional load. Lisa explained, "I am finding that I am having to regulate my emotions to the extent I have difficulty connecting with my children because I feel I have nothing left for them patience wise." Olivia reflected, "I get angry a lot around my daughter…I really struggle to be present and spend time with my daughter, especially doing what she wants to do." The demands of parenting required continuous adaptation, which participants experienced as decision fatigue and emotional exhaustion. This not only impacted their ability to connect and engage with their children but also intensified guilt and reinforced withdrawal.

Existing literature largely focuses on the challenges of parenting EDA children, including the emotional toll it has on parents (Curtis & Izett, 2025; PDA Society, 2018, 2024). The current accounts reveal the difficulty experienced by parents with EDA, as they attempt to balance meeting their own needs and those of their children.

Collectively, participants' descriptions highlight a long-term emotional labor inherent to relationships and social interaction that was incompatible with their fluctuating capacity for demands, producing patterns of engagement, burnout, and withdrawal (Egan et al., 2020; Haire et al., 2024; Kenny & Doyle, 2024). The concept of relational burnout may intersect with psychological theories of compassion fatigue, whereby sustained empathy, without adequate time to replenish emotional resources, may lead to exhaustion or depersonalization (Chu, 2024; Malone, 2022; Sinclair et al., 2017). Although these models have primarily been applied to caregiving professions, they also appear to reflect the experiences of participants in this study, suggesting similar emotional mechanisms may be relevant in interpersonal relationships.

Misunderstanding and Stigma

This theme illustrates the widespread impact of misunderstanding and scrutiny across social, occupational, and

psychological domains. Participants described work-related insecurities, relationship difficulties, heightened distrust, loneliness, and self-criticism. Kate explained, "I often get accused of causing arguments because I might be quite passionate about a subject and it looks like I am fighting with the person." Similarly, Chloe wrote:

> I feel like I constantly need to explain myself to people, particularly friends, family and employers. They don't seem to understand my constant need for autonomy and flexibility but rather think I am just stubborn or lazy or depressed. This has cost me a lot of jobs and ruined some really close friendships…

Participants repeatedly recounted that family, friends, and professionals misattributed their distress and behaviors to laziness, stubbornness, or anxiety, failing to recognize the complexity and intensity of their experiences. Such mislabeling undermined their relationships, self-perception, and occupational stability. While existing EDA literature largely relies on caregivers' accounts, these findings mirror findings, demonstrating how misunderstanding served as a barrier to appropriate support and fostered self-blame (Curtis & Izett, 2025; Kenny & Doyle, 2024; PDA Society, 2018).

Claire highlighted that professional misinterpretation heightened distress, "…the professionals I saw just treated me like I was just anxious or oppositional. That mislabelling led to a lot of frustration and to some extent mistrust…" Echoing experiences reported in previous literature, many felt invalidated and unsupported as avoidance was understood as defiance and anxiety (Curtis & Izett, 2025; Kildahl et al., 2021; PDA Society, 2018; Woods, 2021). Woods (2021) explained that repeated false appraisals can foster circular reasoning and reinforce internalized stigma and feelings of inadequacy, positioning misunderstanding as a fundamental mechanism of harm.

Participants also described the impact of scrutiny. Jayme explained that living at home "…often feels like I'm being watched, like I'm supposed to be constantly functioning in a way that meets someone else's standard…." Caris also shared the difficulties of living with her parents, "…they can put pressure on me to get a job and 'be an adult'…." This reveals how adults with EDA must not only navigate the challenges of daily life but are simultaneously coping with social, psychological, and functional costs of stigma and scrutiny.

Such experiences parallel research on social evaluative threat responses, whereby hypervigilance to external scrutiny evokes stress and self-monitoring (Park et al., 2023). Across neurodiverse and neurotypical populations, research has shown that hypervigilance to external judgment and constant self-monitoring drive individuals to hide their genuine self and define self-worth through external validation (Cox et al., 2017; Crişan et al., 2016; Park et al., 2023; Pitura, 2019). Among adults with EDA, masking behaviors are particularly common (Cat, 2018; Kenny & Doyle, 2024; PDA Society, 2022), potentially increasing their vulnerability to anxiety and identity strain.

Nevertheless, participants took it upon themselves to seek validation through self-education and supportive relationships. Kylie explained "surrounding myself with people who understand my experience and educating myself on PDA," while Lisa wrote, "I read a lot about PDA and try to educate others so they can understand." Supportive relationships were vital; Dave described his wife as a "big supporter," explaining that they have had to learn to "navigate our marriage to suit both our needs." Online communities were also key sources of validation and hope, as Chloe noted that they "have been very validating, helping me to understand that my experiences are normal for a PDAer." Such findings align with existing literature highlighting the role of positive relationships in emotional regulation, positive self-perceptions, and a sense of belonging (Brede et al., 2022; Crompton et al., 2023; Haire et al., 2023; Johnson & Saunderson, 2023; Kenny & Doyle, 2024).

I Will Survive

This final theme highlights participants' remarkable resilience, creativity, and adaptive strategies in navigating adulthood. Participants repeatedly described feeling "alone" and finding adequate support "impossible," often relying on "trial and error" to develop strategies. Participant accounts demonstrate how participants reimagined societal notions of success and productivity to sustainably and autonomously navigate adulthood.

Flexibility and autonomy emerged as key conditions for functioning. Participants emphasized the importance of having a flexible workplace, with many often opting to work from home. Claire explained that being self-employed was more desirable as "being employed in a conventional sense just wasn't sustainable." Such accommodations served to increase flexibility, regain a sense of autonomy, and decrease anxiety, echoing previous literature demonstrating that autonomy was a key driver for escalating EDA behaviors (Johnson & Saunderson, 2023; O'Nions et al., 2018; PDA Society, 2022).

Participants also described reclaiming autonomy by creatively reframing demands through collaboration, humor, and play to make them feel less imposed. Olivia wrote, "communication strategies help me, when things are presented as challenges, puzzles, games or as comments and not questions." While Jen explained:

> I find that if I break down a task I am avoiding into micro parts and I intersperse enjoyable activities I can find that sometimes the dopamine hit from the enjoyable task is enough to get me through the component part of the task.

These findings demonstrate how participants were not rejecting adulthood but redefining it, leveraging creativity

and external resources (e.g., artificial intelligence) to reduce the emotional intensity of demands, positioning them as personally meaningful rather than imposed (Kenny & Doyle, 2024; O'Nions et al., 2014; PDA Society, 2018, 2024; Woods, 2021).

Self-compassion emerged as central to redefining self-worth. Jayme reflected, "I used to think I was broken and while I [am] learning to be compassionate to myself I still often feel ashamed because I want to do these things, but something in me won't let me," capturing the tension between striving and self-forgiveness. Kylie echoed this, noting the value of "self-reflection and compassion rather than getting angry with myself." These accounts highlight a continuous process of identity reconstruction, whereby participants consciously sought to move away from cycles of guilt, frustration, and self-blame toward self-acceptance, acknowledging their own fluctuating capacity as part of an authentic human experience.

Consistent with broader research across both neurodiverse and neurotypical populations, self-compassion as a buffer against isolation, anxiety, and depression, supporting well-being and self-esteem (Clarke et al., 2024; Galvin & Richards, 2023; Heng et al., 2025; Liu et al., 2022; Niolaki et al., 2025; Ren et al., 2025). In this way, participant experiences resemble a shift beyond merely understanding EDA, toward actively integrating self-compassion, transforming EDA not solely as a challenge to be managed but rather into a meaningful aspect of self.

Final Considerations

Limitations and Future Research

Although findings demonstrate the impact of EDA in adulthood, limitations should be considered. Participant eligibility was determined through self-identification and the EDA-QA (Egan et al., 2019); however, experiences may reflect broader neurodivergent traits and internalizing patterns associated with increasing demands of adulthood (Egan et al., 2019, 2020; McKnight et al., 2016; Mehta et al., 2020; Scales et al., 2016; White et al., 2023).

While EDA is often understood as a behavioral profile of autism (Newson et al., 2003; O'Nions & Eaton, 2020), several characteristics described by participants, including emotional dysregulation, task paralysis, and fluctuating motivation, may also overlap with other neurodevelopmental conditions, such as autism and attention-deficit/hyperactivity disorder, and some anxiety-related disorders (Egan et al., 2019; Kildahl et al., 2021; Reilly et al., 2014; White et al., 2023). Whilst participants described a pervasive threat response to all demands and perceived loss of autonomy, which may distinguish EDA-related experiences from broader executive functioning and internalizing patterns (Stuart et al., 2020; White et al., 2023), the methodology used in this study was not able to clarify this possibility, and it remains to be determined whether EDA represents a unique condition or a transdiagnostic factor present in several different types of psychological distress, with constructs such as an intolerance of uncertainty, autonomy-threat sensitivity, emotion dysregulation, and neurodivergent processing contributing to psychological distress across neurodivergent, internalizing and other conditions (Conner et al., 2022; Johnson & Saunderson, 2023; Kildahl et al., 2021; Rodriguez-Seijas et al., 2020; White et al., 2023). This requires further exploration in future research, which should look at the overlap between EDA characteristics and other psychological disorders more carefully.

Open-ended online survey questions were used to collect qualitative data, which may have limited the depth of responses compared with other qualitative methods. While audio responses were offered to support richer reflections, no participants opted for this. The use of an online survey may have been particularly favorable for participants with EDA traits, as it reduced the interpersonal and immediate social demands associated with face-to-face interviews, which may otherwise be experienced as anxiety-inducing. Future research should consider alternative methodologies (e.g., qualitative interviews) that offer opportunities for deeper exploration, particularly given the challenges of accessing research participants with EDA traits (Braun & Clarke, 2022b).

Adulthood is often understood as a socially constructed life stage shaped by sociocultural context rather than a fixed developmental process (Arnett, 2016; Culatta & Clay-Warner, 2021; Mehta et al., 2020), albeit coinciding with a significant biological turning point in brain structure at around age 32 (Mousley et al., 2025). Given this study only included participants residing in Australia and did not report sociocultural factors, findings may reflect Western norms of adulthood, such as individual independence and normative age-based milestones. In contrast, in collectivist cultures where community interdependence and shared group norms are prioritized over individual distinctiveness, EDA may manifest as "over-adaptation," the forcible suppression of internal needs to meet external group expectations (Keating et al., 2024). Within this context, avoidance may be experienced through other-focused emotions, such as shame, as opposed to the self-focused frustration common among individualistic societies (Heiphetz & Oishi, 2022; Keating et al., 2024). Future research should examine how sociocultural context intersects with EDA traits to shape avoidance and experience.

Finally, contrary to existing literature proposing EDA traits reduce across the lifespan (Egan et al., 2019; Gillberg et al., 2015), the current findings illustrate that EDA traits continue to impact various aspects of adulthood. Future research is needed to clarify how EDA-related behaviors evolve across the lifespan and in response to intervention.

Implications

The findings demonstrate that living with EDA can be a pervasive and emotionally burdensome way of experiencing life. Reframing avoidance as a form of self-preservation in response to perceived threats to autonomy had important implications across contexts. While EDA is not a formal diagnosis, the present findings highlight the need for nonpathologizing, neuroaffirming, and context-dependent models. Increased professional awareness and training, particularly within health and education sectors, may encourage a shift away from deficit-based models, improving communication, reducing relationship strain and fostering environments in which adults can engage without a fear of failure or judgment. Our findings also highlight the value of companion-focused approaches across clinical, occupational, and social contexts to improve capacity and well-being. Ultimately, recognizing and accommodating EDA among adults has the potential to reduce stigma, inform more effective practices, and encourage inclusive educational and occupational practices.

Conclusion

Overall, this study demonstrates that EDA persists into adulthood, with pervasive functional, psychological, and emotional consequences in everyday life. Whilst many participants described experiences of adulthood that were marked by chronic fatigue, self-blame, and guilt, they also embodied resilience and creativity. Participant strategies to navigate adulthood through redefining goals, self-compassion, and valuing well-being over normative milestones may help challenge the productivity-focused definition of adulthood, encouraging an alternative and more inclusive way of conceptualizing functioning.

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Ethical Considerations

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Informed Consent

Informed consent to participate in the study and publish the findings was obtained from participants.

Author Contributions

NS: conceptualization, data collection, data analysis, and manuscript drafting. JM: conceptualization, supervision, data analysis, and manuscript editing.

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Supplemental Material

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