

Chapter 10

Nonpharmacological Management of Epilepsy in Adults with Intellectual Disabilities

K.J. Trevis and S.J. Wilson

Abstract Psychological treatments are increasingly recognized as beneficial in the care of adults with intellectual disabilities (ID). However, there has been limited research evaluating the efficacy of psychological therapies in people with comorbid epilepsy and ID (E-ID). In this chapter, we provide a context for understanding the role of psychological treatments in adults with E-ID by reviewing the evidence basis for the benefits of these treatments in adults with ID. Building on this framework, a systematic review of the psychosocial challenges facing individuals with E-ID revealed similar challenges to psychosocial well-being in adults with ID. In contrast, a systematic review of psychological treatment studies in adults with E-ID found no published work addressing the efficacy of these treatments. In light of the current research in adults with ID and the similarities in presenting problems between adults with E-ID and ID, we conclude that there is a basis for the possible effectiveness of adapted psychological treatments to improve the well-being of adults with E-ID, which future research should address.

Keywords Epilepsy • Intellectual disability • Well-being • Psychological treatment • Cognitive-behavioral therapy

Introduction

Psychological therapies, particularly behavior management, have received increasing attention as an important part of treatment plans to improve the psychosocial well-being and quality of life of people with intellectual disabilities (ID) [1–4]. In this setting, psychological therapies typically commence with assessment of an

K.J. Trevis, BSc(Hons), PhD Candidate
Melbourne School of Psychological Services, University of Melbourne,
Melbourne, VIC, Australia

S.J. Wilson, PhD (✉)
Melbourne School of Psychological Sciences, Melbourne, VIC, Australia

individual to diagnose any neurological, cognitive, psychological, or psychosocial problems that then frame the context of treatment and determine the issues to be addressed. Following diagnosis, psychological treatment may incorporate psychoeducation for the patient and carer, behavior management techniques (e.g., behavior modification), skills-based training (e.g., social skills, assertiveness training, problem-solving), mindfulness and somatic strategies (e.g., progressive muscle relaxation), and developing links to social support networks, including employment rehabilitation and community engagement. In individuals with mild ID, a cognitive-behavioral treatment model may also be considered, including the use of cognitive tools to develop greater self-awareness and insight, increased emotional, behavioral, and social self-regulation, and counseling to challenge and reframe cognitive distortions and maladaptive beliefs [4, 5].

Despite increasing research support for the efficacy of psychological therapies in people with ID, [2] there is limited research evaluating the efficacy of psychological therapies in people with comorbid epilepsy and ID (E-ID) [6, 7]. This is worrying given the range of psychosocial challenges faced by people with ID, including trauma and abuse, family stressors, unemployment and poverty, a lack of meaningful friendships or intimate relationships, and elevated rates of mental health difficulties [8–10]. People with E-ID face the added challenge of living with often “hard to treat” epilepsy, for which there is limited information on the long-term effects of seizures on their cognitive and behavioral functioning. There is also increasing recognition of the impact of psychiatric and behavioral comorbidities on the psychosocial well-being and quality of life of people with epilepsy [11, 12] as well as the challenges faced by people with E-ID relating to reduced self-care and daily-living skills, lack of independence and adaptive social behaviors, social stigma and exploitation by others, and increased carer burden and burnout [11, 12].

The emerging evidence for the benefits of psychological therapies in people with ID raises questions about the potential role of psychological therapies in the management and treatment of individuals with E-ID. Both ID and epilepsy are conditions where real and perceived personal control over the environment is reduced. As such, understanding the efficacy of psychological treatments in people with ID may aid our understanding of the use of these treatments to improve the well-being of people with E-ID. In this chapter, we first provide a context of general psychosocial issues arising in adults with ID, and the efficacy of psychological therapies in complementing the management and care of this population as an established field of research. In particular, we draw attention to adaptations to psychological therapies that are recommended for effective engagement when treating adults with ID using cognitive and behavioral strategies. Principles arising from this review are then applied to the comparatively small field of psychological factors in adults with E-ID to address two key aims. First, we examined the nature of psychosocial difficulties in adults with E-ID by systematically reviewing available literature. Second, we assessed the efficacy of psychological treatments to address psychosocial difficulties in the E-ID population by systematically reviewing available psychological treatment studies [1].

Psychosocial Challenges in Adults with Intellectual Disabilities

One of the challenges arising in adults with ID is unemployment and poverty, with a national snapshot (USA, 2013), indicating only 34% of adults with ID were employed in some form [13]. This is concerning, given that people with ID who are employed report greater quality of life and psychological well-being, including higher self-esteem [14]. As such, both supportive employment programs and gaining the skills necessary to engage with employment opportunities can be key therapeutic targets. Additional challenges occur in the social and lifestyle domains of people with ID, including less participation in the community when compared to individuals without ID and those with other disabilities [15]. Moreover, a study on friendships indicated that 81% of individuals with ID would like more friends, while 35% indicated they would like more family involvement in their life [16].

The prevalence of psychiatric disorders in people with ID is reported to vary from 13.9 to 75.2% depending on the criteria used for diagnosis (primarily clinical diagnostic criteria vs symptoms experienced) [10]. An additional complication to the detection of psychiatric disorders is “diagnostic overshadowing,” which is the tendency to overlook or misattribute mental health symptoms to the ID itself [17]. An example of this phenomenon is the expression of depression in moderate and severe/profound ID, where “behavioral depressive equivalents” may be observed, such as aggression, self-injurious behaviors, and reduced communication, producing an atypical depression presentation that may be misdiagnosed or overlooked [18].

In considering the poorer psychosocial outlook across the key domains of employment, social engagement, and mental health, it is important to note that people with ID may have fewer psychological resources to help them cope, as well as reduced cognitive resources [9]. As such, a growing field of research has targeted the ability of individuals with ID to meaningfully participate in psychological therapies, such as psychotherapy and cognitive behavior therapy (CBT). Importantly, Taylor and colleagues [9] identified the importance of maintaining perspective when considering psychological therapies for ID, as the majority of people with ID fall in the mild impairment range (>80%). However, this has not been reflected in a significant portion of the research to date, which covers a more even distribution across mild, moderate, severe, and profound ID, or is weighted towards the severe end of the spectrum.

Adapting Psychological Therapies for Adults with Intellectual Disabilities

In light of the challenges faced by individuals with ID, adaptations to psychological treatment models have been identified to enhance the delivery of psychological services to this population. Research has indicated that a key barrier to clinicians

providing psychological therapy relates to self-confidence in the ability to deliver therapy, even more so than perceived treatment effectiveness [19]. Exacerbating this situation is the notion of “therapeutic disdain,” where psychological treatment for people with ID is less attractive to clinicians, as it may be perceived as more demanding, slower, and less effective than psychological treatments for people without ID [9, 20]. Part of the origin of therapeutic disdain stems from the idea that “buy-in” from patients to self-direct therapeutic goals is not possible in ID populations, in part due to a lack of the cognitive skills required. As such, equipping therapists with an evidence base from which to adapt therapy is essential for promoting effective therapy in people with ID.

Table 10.1 contains a summary of the recommendations in the literature for adapting traditional models of psychological therapy. These can be grouped into three main domains: (1) a need to establish patient skills and clearly identify all

Table 10.1 Recommended adaptations to psychological therapy in adults with intellectual disabilities

Therapeutic element	Adaptations recommended
<i>Establishing patient abilities</i>	
Assessment	Full neuropsychological assessment (intellect, language, memory, etc.) Emotion recognition and cognitive regulation of emotions
Developmental Level	Intellectual ability, communication, and social skills Treatment readiness: internal motivation and self-reflective capacity
Diagnosis	Diagnostic overshadowing risk Consider both patient self-report and validation from other stakeholders in patient care (e.g., support services, other health practitioners)
<i>Adaptations focused on improving cognitive and emotional skills</i>	
Scaffolding	Reduce complexity of therapy Use psychoeducation as building blocks to therapy goals
Self-reflection	Reinforce and utilize positive influences (e.g., friendships, hobbies) Encourage areas where self-management is evident Acknowledge challenges (may include disability specific factors)
<i>Adaptations focused on improving communication and patient “buy-in”</i>	
Language	Appropriate for the patient’s level of understanding Paraphrasing to aid reflection and probe questions to confirm mutual understanding of discussion content Use of pictorial representations, games, and nonverbal methods
Rapport	A more directive approach may be required Providing a space for, and encouragement of, self-efficacy Build self-motivation
External Support (e.g., caregivers)	Awareness of influential psychosocial factors (e.g., finances) Possible administrative engagement with community services Involvement can support therapeutic goals Therapy with and without supporters present enhances autonomy
Flexibility	Dynamic engagement strategies (e.g., therapy setting, involvement of others, small goals to foster self-belief and “buy-in”)

presenting problems (formulation of the case), (2) adaptations focused on improving cognitive and emotional skills, and (3) adaptations focused on effective communication strategies. These three aspects are discussed in more detail below.

Establishing Patient Skills

First and foremost, assessment of patients prior to commencing treatment is essential for determining their existing skills, to enable the clinician to structure and deliver therapy at an appropriate level. Neuropsychological assessment of intellectual and communication skills provides important background data on the patient's ability to communicate, comprehend, and problem-solve [21]. Memory assessment can be used to identify potential issues around retention of therapeutic exercises and discussions and inform the frequency and length of treatment sessions. Additional assessment of emotion recognition and social cognition, as well as understanding the cognitive regulation of emotions and behaviors, can provide important information about the ability of patients to comprehend and internalize issues being discussed, along with their level of insight and self-reflective capacity [4].

Determining the patient's developmental level and any relevant diagnoses are key assessment outcomes that frame the nature and delivery of psychological treatment. The developmental level can indicate patient readiness for treatment, particularly internal motivation and level of "psychological mindedness" to engage in self-reflection [22], and can be targeted as an outcome of treatment itself. As noted previously, in determining developmental level and possible diagnoses, clinicians should be aware of diagnostic overshadowing and how presentations of psychological distress may vary in ID populations [18, 20]. To assist with this, validation of diagnoses through discussion with other health practitioners, support services, and daily carers is vital [20]. The medical history, particularly relating to comorbidities, also provides important information; however, it should not be used as the *sole* factor in determining an individual's suitability for psychological treatment or support. Rather, all of the above sources of information are relevant to accurate case formulation that is best framed within a holistic, interdisciplinary patient-care approach [22]. In the first instance, the outcome of the assessment and indicators of developmental level may require a clinician to commence therapy with skills-based training to facilitate more complex, longer-term therapeutic goals [23].

Adaptations Addressing Cognitive and Emotional Skills

Researchers have investigated the emotion recognition skills of individuals with ID to determine their suitability for psychological therapy. Results show that on

emotion recognition tasks, people with ID are more able to identify an emotion than verbally express it [24] and 75 % of adults with ID can successfully link emotions to situations [23]. A cognitive mediation task has been developed to assess suitability for CBT in people with ID. This task requires patients to recognize the role of their beliefs in understanding the links between an event and the emotional consequences, a core concept in CBT [23]. Adults with ID have shown deficits on these tasks ranging from a 10 to 12 % overall pass rate when choosing the missing emotion given an event and belief, and a 10 to 25 % pass rate when choosing the belief given an event and emotion [23–25]. Unsurprisingly, language skills and intelligence measures have been associated with better performance on these tasks [23–26], and one study found the use of pictorial cues did not significantly improve task performance [26]. However, a recent training study on this task indicated that training can significantly improve the ability to correctly identify emotions, with some improvement also seen in belief identification for adults with ID [27]. While this has not been linked to therapeutic outcomes as yet, it does demonstrate an ability to learn and develop an understanding of the relationships between emotions, beliefs, and events in people with ID [27].

Scaffolding techniques constitute the primary adaptation for addressing limitations in cognitive and emotional skills in people with mild ID engaged in CBT. This involves a more directive therapeutic approach, where psychoeducation is used to help patients develop the necessary skills to understand the connections between their thoughts or beliefs and their emotions [21]. Scaffolding also involves reducing the complexity of therapy and may involve shorter sessions and “chunking” of therapeutic goals and techniques [28]. Repetition and reinforcement of concepts and goals can also help overcome these limitations.

A second adaptation involves identifying the strengths and limitations of the patient as a way of improving self-reflection. Identifying patient strengths, such as activities they enjoy, work, or friendships can help the therapist draw on these protective influences, providing useful examples and a context for homework and exercises that build on, or incorporate, these strengths. Identifying and encouraging areas of the patient’s life where self-management is evident can also be used as analogies to support and develop self-management in other areas, including less concrete issues like managing intrusive thoughts or controlling emotions [28]. Likewise, it is important to acknowledge and identify limitations and challenges faced by the patient and how the disability fits with this more balanced picture, to encourage acceptance of the disability, as well as positive self-perceptions and self-awareness [28]. In particular, qualitative research has shown that people with ID are capable of successfully identifying barriers to social inclusion and potential solutions to these barriers that are in line with current policies and therapeutic practices [29]. Since psychological therapies routinely involve patient identification of barriers to personal goals and problem-solving, these findings provide support for the suitability of people with ID to engage with, and benefit from, psychological therapy.

Communication Adaptations

The therapeutic relationship is paramount to the success of psychological therapy, and as such, communication abilities and the patient's "buy-in" have been a key focus for research. A study examining CBT session transcripts in 15 patients with borderline-mild ID found that the patients played an active role in directing the flow of sessions, and there was a balance of conversational power between the patient and therapist, indicative of collaborative dialogue [30]. A large number of direct questions by therapists were also noted, suggesting greater structuring or "scaffolding" by the therapist, as described above [22, 30, 31]. Importantly, while more scaffolding may be used to elucidate goals and facilitate cognitive processing, the use of probe questions or other nonverbal tools, such as observation and pictorial representations, are recommended not only to obtain greater detail and reflection from patients, but also to confirm understanding of questions, consistency of responses, and to check for acquiescence (indicative of a "desirability bias") [5, 20]. Reflections and nonverbal reinforcements can complement therapeutic discussions by helping to ensure the patient feels understood and to direct dialogue around the same topic while maintaining an active role and engagement of the patient [28, 30].

To build rapport beyond scaffolded language, therapists need to provide space for patients to develop and promote self-efficacy, and the confidence to effect change in their own lives. Rapport helps motivate patients to establish and maintain engagement with the longer-term goals of therapy, which can be challenging for individuals of all intellectual abilities [22]. Linked to this is the need for flexibility in the delivery of therapy, for example, by engaging patients through short-term achievable goals to gain "buy-in" and bolster self-belief. Flexibility may also extend to changing therapeutic settings or individuals who attend sessions, for instance, from individual to group sessions, or running community-based workshops to ensure that the patient feel safes and at ease [21, 22, 28].

Related to this, therapists need to be prepared to work with other support services on a more administrative level if patients have insufficient opportunity to access and potentially engage with external services (known as experiential deprivation), or they are being exploited (e.g., with housing, financial, or employment situations) [20]. Ongoing lifestyle issues such as these may undermine therapeutic progress and/or prevent longer-term behavioral changes to improve self-regulation and quality of life. Involving external support services, and in particular caregivers, can be a beneficial therapeutic technique to support patient engagement with homework exercises and behavioral changes discussed in sessions [20, 21, 28]. In such situations, however, it is also important that the therapist's role is clearly defined for patients so they know their viewpoint and privacy is respected and fairly represented [28]. This process can be one of self-empowerment if patients are given the opportunity to self-manage life decisions in a safe environment, with the inclusion of caregivers or support service representatives with some discretion [22, 28]. Of note, therapists can also be the subject of strong attachments for patients and, as such,

appropriate peer-supervision and support for therapists is necessary to review and reflect on the maintenance of therapeutic boundaries [28].

Taken together, the above research indicates that while emotion recognition and collaborative dialogue abilities are present in people with ID, they face challenges with the more complex skills required for successful engagement in psychological therapy. This can be accounted for by (a) assessing patient skill levels prior to therapy and (b) developing any lacking skills (e.g., understanding the role of emotions and beliefs in interpreting situations) prior to engaging in goal-directed therapy. Of note, a review of treatment studies has shown that many adaptations are commonly used, in particular flexibility in approach, increased awareness of therapeutic attachment, and involvement of caregivers. Although equally important, disability acknowledgement and the use of directive methods have been less utilized [31]. While there is growing empirical support for the benefits of adapting psychological therapies, there is a need to continue improving our understanding in this area to develop strong resources to support clinicians in delivering efficacious evidence-based practice for adults with ID.

Effectiveness of Psychological Treatments in Adults with Intellectual Disabilities

Research into the effectiveness of psychological therapies in adults with ID has been summarized in a recent meta-analysis [2]. This employed a systematic review strategy, identifying 22 articles utilizing individual psychotherapy or group psychotherapy (18 of which used a CBT approach). For inclusion, an independent group design was required as a minimum standard of methodological rigor. Even so, a number of methodological issues were noted, including significant variation in the recruitment and type of participants, study designs, and outcome measures. This meta-analysis found a moderate effect size supporting the efficaciousness of psychological therapies in ID, with individual therapy shown to be more efficacious than group-based therapy. A breakdown by presenting problem revealed that psychological therapy, primarily CBT, was effective for depression (three studies) and anger (nine studies), but there was no evidence for an effect on interpersonal skills (two studies) [2].

Evidence for the effectiveness of psychological therapies, primarily CBT, in adults with ID has also been discussed in a number of independent reviews [1–4, 32–35]. A selection of general and systematic reviews are summarized in Table 10.2, which all show some evidence of the efficacy of psychological treatments using different types of therapeutic trials (controlled and uncontrolled), case studies, and case series. Although most authors have highlighted the lack of randomized controlled trials needed for a strong evidence base [2, 32, 33], the overall picture suggests that psychological therapies are appropriate, and beneficial, for the treatment of adults with ID. This raises the question: do people with E-ID experience similar mental health complaints as those in the ID population, and if so, could psychological therapies be similarly effectively applied?

Table 10.2 Findings from reviews of psychological interventions in adults with intellectual disabilities

Population	Reviewers	Intervention	Effectiveness
ID	Prout and Nowak-Drabik (2003) [1]	Psychotherapy	Moderately beneficial effect across a range of outcome measures, primarily behavior.
ID and Interpersonal functioning	Vereenghoe and Langdon (2013) [2]	Psychotherapy, CBT	No significant effect on meta-analysis.
ID and Offending behavior	Sturmey (2004) [3], Hatton (2002) [4]	CBT	Changes in attitudes towards offensive behavior, reduced offending-related cognitions, and reduced offending.
ID and Anger	Hamelin et al. (2013) [33], Hassiotis and Hall (2008) [32], Hatton (2002) [4], Nicoll et al. (2012) [34], Sturmey (2004) [3], Vereenoghe and Langdon (2013) [2]	CBT	Reduced anger and aggressive behaviors.
ID and Anxiety	Hatton (2002) [4]	CBT, relaxation	Reduced anxiety, improved cognitive performance.
ID and Depression	Sturmey (2004) [3], Vereenoghe and Langdon (2013) [2], Hatton (2002) [4]	CBT, CBT group therapy	Reduced depressive symptoms and negative thoughts. Increased positive self-perceptions.
ID and Psychosis	Hatton (2002) [4]	Behavioral therapy, CBT	Reduced displays of psychotic speech, management of hallucinations.
ID and PTSD	Mevissen and de Jongh (2010) [35]	CBT, Exposure Therapy, Imagery Rehearsal Therapy	Reduced distress and outbursts, reduced hypervigilance, reduced nightmares, and increased self-control.

Note: The above reviews cover a mixture of case studies, case series, and controlled and uncontrolled trials and are provided here as a brief summary of a representative selection of available reviews

Psychosocial Challenges in Adults with Comorbid Epilepsy and Intellectual Disabilities

To characterize the presenting problems of adults with E-ID, a systematic review of the available literature was conducted. At the time of this review, we could not find a systematic review of psychological challenges facing this population, which is an

important first step in identifying the issues faced by patients and thus prospective therapists. The aim of this systematic review was to characterize the psychological presentation of adults with E-ID and, in particular, to attempt to address two key research questions: (1) are there epilepsy-specific concerns in adults with E-ID? and (2) are epilepsy-specific concerns a key source of distress in adults with E-ID?

Methods

Identification of Studies

We searched for studies describing impaired psychological well-being in adults (≥ 18 years) with E-ID. Our search was limited to available full-text, peer-reviewed journal articles written in English. We searched the PsycInfo and Medline databases using three search terms: (1) epilepsy OR seizure AND (2) intellectual disab* OR mental retardation OR intellectual handicap AND (3) psych* OR anxiety OR depress* OR mood. We also searched citing articles and reference lists of articles reaching the data extraction stage of the systematic review using the same screening process. This secondary search identified nine additional articles for inclusion.

Article Selection and Data Extraction

All studies available to the authors published up until October 2015 were included in the initial title screen ($n=328$). We first removed duplicates ($n=24$), leaving 304 articles for further review (see Fig. 10.1). For both title and abstract screening, we excluded case reports, articles about children and adolescents (i.e., <18 years), articles about other populations (primarily autism spectrum disorders and schizophrenia), or if an article did not meet all of these three search criteria (e.g., psychological complaints in people with epilepsy who have normal intelligence scores). Twenty-two articles reached full-text review, of which we excluded review articles without original data, articles that did not address all three search criteria, and articles that did not characterize an E-ID group. We then extracted the data from the eligible studies relating to the participants, their ID and epilepsy characteristics, the psychological outcome measures used, and the main findings of the study.

Results

In total, our search strategy resulted in 14 peer-reviewed empirical articles examining psychological complaints in people with E-ID (see Table 10.3). These 14 studies were published between 1989 and 2011, with only one of the studies (7%) conducted outside of the United Kingdom. The majority of studies (71%) sampled

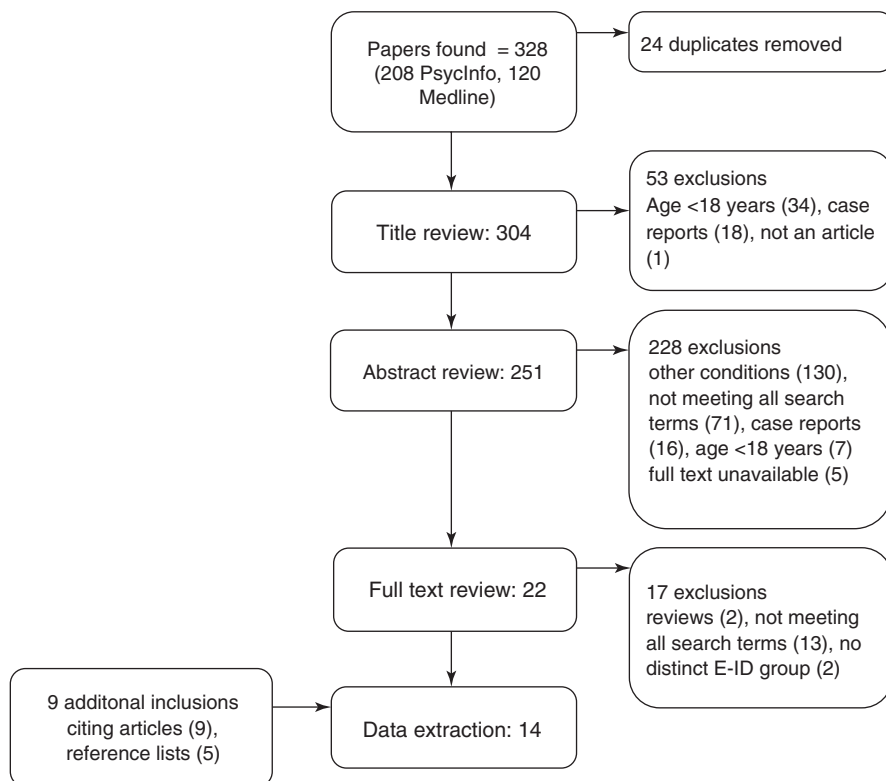


Fig. 10.1 Flow chart of the article review process

participants from available health services and registers, producing samples including both inpatient and community-based adults [36–46]. Two studies (14%) sampled participants from inpatient facilities [12, 47], and one study (7%) sampled participants from community-based adults with ID [48]. One study did not state the residential status of participants, but noted a similar prevalence of epilepsy in adults with ID who lived independently, with their family, or in residential care [49].

The full range of ID diagnoses were covered in the 14 studies, including borderline, mild, moderate, severe, and profound classifications. Overall, the majority of studies provided some level of description of the onset, type, and frequency of patient seizures; however, there was a noticeable lack of information relating to participant views of their epilepsy, particularly measures of the perceived impact of seizures, their sense of control, and their level of understanding of the epilepsy and its management. One study obtained carer reports for the perceived impact of epilepsy, with 41.5% of carers describing an impact of epilepsy most commonly on leisure activities, swimming, and employment [44].

Of the 14 studies, none used a non-ID epilepsy control group, while six (43%) recruited adults with E-ID and a matched ID control group [12, 38–40, 45, 47].

Table 10.3 Studies characterizing psychosocial issues in adults with epilepsy and intellectual disabilities

Study	Sample (n)	Source	ID characteristics	Epilepsy characteristics ^a	Focus	Measures	Outcomes
Espie et al. (1989) [47], UK	<i>E-ID</i> (15) Age: 28.7 (7.5) years Sex: 8 males <i>ID</i> (15 matched) Age: 27.9 (5.5) years Sex: 8 males	All inpatients	Both groups comprised mild (7%), moderate (13%), severe (47%) profound (33%)	<i>Seizure frequency</i> : 60% had ≤1 seizures a year, 40% had ≥12 seizures a year <i>Age at onset</i> : NS <i>Seizure type</i> : Complex partial seizure (73%), simple partial seizures (7%), generalized epilepsy (20%)	Psychosocial functions	ABS, PBS	<i>Problem behaviors</i> : E-ID group significantly more impaired in daily-living behaviors <i>Social behaviors</i> : No significant differences <i>Epilepsy factors</i> : Higher seizure frequency associated with greater behavioral disturbance
Deb and Hunter (1991) [38], [39] UK	<i>E-ID</i> (150) Age: 40 (13) years Sex: 77 males <i>ID</i> (150 matched) Age: 40 (13) yrs Sex: 77 males	Both groups comprised inpatients (100) and community-based (50)	Both groups comprised mild (33%), moderate (17%) severe (50%)	<i>Seizure frequency</i> : 61% “active”, ≥1 seizure in last year; 29% “inactive” (no seizures within last year) <i>Age at onset</i> : 1–9 years (56%), ≥9 years (21%), unknown (23%) <i>Seizure type</i> : Most commonly: generalized tonic-clonic (83%), absence (19%) and complex partial (14%). 56% had one seizure type	Problem behaviors (1991a), psychopathology (1991b)	PAAS (1991a,b), PSE (1991b)	<i>Problem behaviors</i> : No significant differences <i>Psychopathology</i> : E-ID had significantly less psychopathology than ID group

<p>Deb and Hunter (1991), [40] UK</p>	<p><i>E-ID</i> (75) Age and Sex: NS^b <i>ID</i>: (75 matched) Age and Sex: NS^b</p>	<p>Inpatients (76) and community-based (74) (group breakdown NS)</p>	<p>“Mildly to moderately mentally handicapped”^{ns} (p.831)</p>	<p><i>Seizure frequency</i>: NS^b <i>Age at onset</i>: NS^b <i>Seizure type</i>: NS^b</p>	<p>Personality disorders</p>	<p>SAP, T-L personality inventory</p>	<p><i>Abnormal personality</i>: No significant differences</p>
<p>Deb and Joyce (1999) [36], UK</p>	<p><i>E-ID</i> (143) Age: 40.7 (13.3) years Sex: 82 males</p>	<p>Inpatients (78) and community-based (65)</p>	<p>Borderline (4%), mild (13%), moderate (16%), severe (56%) (11% undetermined)</p>	<p><i>Seizure frequency</i>: in the preceding year 73% had ≥1 seizure, 27% no seizures, 5% undetermined <i>Age at onset</i>: Infancy (24%), 2–9 years (34%), 10–18 years (11%) >18years (13%), unknown (18%) <i>Seizure type</i>: Most commonly: generalized tonic-clonic (83%), complex partial (20%) and absence (15%). 36% had more than one type of seizure</p>	<p>Psychopathology, behavior problems</p>	<p>Case notes, consultation of patients and carers when possible</p>	<p><i>Problem behaviors</i>: Rates comparable to ID populations <i>Psychopathology</i>: Rates lower than ID populations, comparable to non-ID populations <i>Epilepsy factors</i>: No significant influence on behavioral problems or psychopathologies</p>

(continued)

Table 10.3 (continued)

Study	Sample (n)	Source	ID characteristics	Epilepsy characteristics ^a	Focus	Measures	Outcomes
Matson et al. (1999), [12] USA	<i>E-ID</i> (353) Age: 37.9 (14.2) years Sex: 50% male <i>ID</i> (353 matched) Age: 41.2 (11.2) years Sex: 55% male	All inpatients	<i>E-ID</i> : mild (0.3%), moderate (4%), severe (6.7%), profound (89%) <i>ID</i> : mild (1%), Moderate (4%), severe (6%) profound (89%)	<i>Seizure frequency</i> : 60% had seizure activity in the preceding year, 40% were seizure free for 2 years <i>Age at onset</i> : NS <i>Seizure type</i> : NS	Problem behaviors (<i>E-ID</i> only), psychosocial skills, psychopathology	QABF (<i>E-ID</i> only) and DASH-II, ABC, MESSIER, VABS	<i>Problem behaviors</i> : Profile of behavioral problems and antecedents in <i>E-ID</i> comparable to previous <i>ID</i> research. <i>E-ID</i> had less aberrant behaviors <i>Psychosocial skills</i> : <i>E-ID</i> group had less social, less adaptive skills than the <i>ID</i> group, <i>Psychopathology</i> : <i>E-ID</i> less than the <i>ID</i> group
Espie et al. (2003) [41], UK	<i>E-ID</i> (186) Age: 31 year (family residences) and 39 years (staffed residences) Sex: 108 males	Inpatients (14%) living with carers (45%), living with relatives (41%)	75% "had at least moderate intellectual disability" (p.1486)	<i>Seizure frequency</i> : Daily (22%), weekly (35%), monthly (31%), 12% less frequent (5 missing cases) <i>Age at onset</i> : Mean = 4.5years (birth-38years) <i>Epilepsy diagnosis</i> : Most common types: tonic-clonic (61%), complex partial (44%), myoclonic (10%) and absence (10%). 52% had more than one type of seizure	Psychopathology, problem behaviors	PAS-ADD, ABC	<i>Psychopathology</i> : 33% had psychopathology (comparable to <i>ID</i> and epilepsy samples, above general community sample) <i>Problem behaviors</i> : <i>E-ID</i> below adult norms <i>Epilepsy factors</i> : Seizure frequency and severity were significant predictors of psychopathology

<p>Turkistani (2004) [42], UK</p>	<p><i>E-ID</i> (108) Age: 40.3 years Sex: 65 males <i>ID</i> (132) Age: 43.5 years Sex: 68 males</p>	<p><i>E-ID</i>: residential care (67%), family home (33%) <i>ID</i>: residential care (73%), family home (26%)</p>	<p><i>E-ID</i>: mild (9%), moderate (36%), severe (39%), profound (16%) <i>ID</i>: mild (13%), moderate (53%), severe (30%), profound (5%)</p>	<p><i>Seizure frequency</i>: 77% frequent seizures (>1 per month) <i>Age at onset</i>: <1 year (33%), 1–19 years (50%), >20 year (7%) and unknown (9%) <i>Seizure type</i>: generalized (15%), partial (1%), “unclassified” (1%), “mixed” (83%)</p>	<p>Psychopathology</p>	<p>Carer and family reports, case notes.</p>	<p><i>Psychopathology</i>: Trend for more psychopathology in the ID group than <i>E-ID</i> ($p=.07$) <i>Epilepsy factors</i>: No significant relationship between seizure frequency and psychopathology</p>
<p>McGrother et al. (2006) [49], UK</p>	<p><i>E-ID</i> (620) Age: mean NS Sex: 347 males <i>ID</i> (1773) Age: NS Sex: NS</p>	<p>NS</p>	<p>NS (<i>ID</i> defined as “moderate, severe, or profound developmental intellectual impairment”) (p.377)</p>	<p><i>Seizure frequency</i>: seizures reported occasionally or more often (77%) no current seizures (23%) <i>Age at onset</i>: NS <i>Seizure type</i>: NS</p>	<p>Problem behaviors, psychopathology</p>	<p>DAS and clinical interview.</p>	<p><i>Psychopathology</i>: <i>E-ID</i> associated with increased psychological symptoms <i>Problem behaviors</i>: <i>E-ID</i> more likely to have maladaptive behaviors, problems with daily-living skills and poorer understanding <i>Epilepsy factors</i>: Antiepileptic drug use associated with poorer understanding only</p>

(continued)

Table 10.3 (continued)

Study	Sample (n)	Source	ID characteristics	Epilepsy characteristics ^a	Focus	Measures	Outcomes
Ring et al. (2007), [48] UK	<i>E-ID-active</i> (110) Age: 39.6 years Sex: 54% male <i>E-ID-inactive</i> (65) Age: 41.2 Sex: 57% male	"The great majority of participants in the study lived with and were closely supported by family or paid carers" p.93	<i>E-ID-active</i> : mild (14%), moderate (15%), severe (65%), profound (6%) <i>E-ID-inactive</i> : mild (31%), moderate (20%), severe (46%), profound (3%)	<i>Seizure frequency</i> : In previous 3 months: 63% <i>E-ID-active</i> (≥ 1 seizure, mean = 11.4), 37% <i>E-ID-inactive</i> (no seizures) <i>Age at onset</i> : NS (duration for active <i>E-ID</i> s: 26.3 years, inactive <i>E-ID</i> s: 24.6 years) <i>Seizure type</i> : (all participants): idiopathic generalized epilepsy (40%), focal epilepsy (14%), other (2%), not established (44%)	Psychopathology	Clinical notes and interviews with service providers.	<i>Psychopathology</i> : 26% had a depressive disorder, 11% psychotic disorder, 18% challenging behavior, 8% self-injury (comparable to other work) <i>Epilepsy factors</i> : Psychosis and depression rates were higher in the <i>E-ID-inactive</i> group than the <i>E-ID-active</i> group
Pawar and Akuffo (2008) [43], UK	<i>E-ID</i> (53) Age: mean NS Sex: 30 male <i>ID</i> (124) Age: mean NS Sex: 65 male	<i>E-ID</i> : residential home (45%), supported living (15%), private home (38%) <i>ID</i> : residential home (47%), supported living (13%), private home (38%)	<i>E-ID</i> : mild (40%), moderate (26%), severe (30%), unspecified (4%) <i>ID</i> : mild (58%), moderate (31%), severe (11%)	<i>Seizure frequency</i> : NS <i>Age at onset</i> : NS <i>Epilepsy diagnosis</i> : NS	Problem behaviors, psychopathology	Case notes.	<i>Problem behaviors</i> : Less common in <i>E-ID</i> than <i>ID</i> (significance not reported) <i>Psychopathology</i> : More common in the <i>ID</i> group than the <i>E-ID</i> group (significance not reported)

<p>Matthews et al. (2007) [44], UK</p>	<p><i>E-ID</i> (58) Age: 39.6 (13.3) years Sex: 52% male <i>ID</i> (260) Age: 41.9 (15.3) years Sex: 42% male</p>	<p><i>E-ID</i>: staffed home (47%), family home (50%), independent (3%) <i>ID</i>: staffed home (44%), family home (44%), independent (12%)</p>	<p>NS</p>	<p><i>Seizure frequency</i>: median = 23 per year, no seizures (26.3%), 1–23 seizures (24.6%), 48–290 seizures (24.6%), 425–21,856 (24.6% – primarily absence seizures) <i>Age at onset</i>: 9.3 years (0–61) <i>Seizure type</i>: simple partial (0%), complex partial (14%), secondary generalized (17%), absences (16%), myoclonic (1%), clonic (6%), tonic (5%), tonic-clonic (38%), atonic (2%), unclassified (2%), 57% had one seizure type, 36% had two types and 17% had three types</p>	<p>Psychopathology, social skills</p>	<p>ABS, ABC, DAS, PIMRA.</p>	<p><i>Problem behaviors</i>: <i>E-ID</i> less adaptive behavior skills and more aberrant behaviors. <i>E-ID</i> comparable to <i>ID</i> when controlling for disability <i>Psychopathology</i>: No significant differences <i>Social skill impairments</i>: <i>E-ID</i> greater impairment. <i>E-ID</i> comparable to <i>ID</i> when controlling for disability <i>Epilepsy factors</i>: Less adaptive behavior associated with earlier epilepsy onset</p>
<p>Turky et al. (2011), [45] UK</p>	<p><i>E-ID</i> (45) Age: 34.7 (10.8) years Sex: 21 males <i>ID</i> (45 matched) Age: 45.2 (13.8) years Sex: 24 males</p>	<p><i>E-ID</i>: in care home (44%), with family carer (56%) <i>ID</i>: in care home (64%), with family carer (36%)</p>	<p><i>E-ID</i>: mild-moderate (47%), severe-profound (53%) <i>ID</i>: mild-moderate (47%), severe-profound (53%)</p>	<p><i>Seizure frequency</i>: Inclusion criteria of (>1 seizure in the 8 weeks prior to study recruitment <i>Age at onset</i>: NS <i>Seizure type</i>: Inclusion criteria of a diagnosis of either partial or primary generalized epilepsy</p>	<p>Psychopathology</p>	<p>ABS, mini PAS-ADD, interviews</p>	<p><i>Psychopathology</i>: <i>E-ID</i> group had a greater risk of developing psychiatric disorders than the <i>ID</i> group over a 1-year period</p>

(continued)

Table 10.3 (continued)

Study	Sample (n)	Source	ID characteristics	Epilepsy characteristics ^a	Focus	Measures	Outcomes
Arshad et al. (2011) [46] UK	<i>E-ID</i> (156) Age: mean NS Sex: 87 males <i>ID</i> (596) Age: mean NS Sex: 369 males	<i>E-ID</i> : supported (34.6%), residential (10.9%), family home (48.7%), independent (5.8%) <i>ID</i> : supported (34.2%), residential (5.9%), family home (46.8%), independent (13.1%)	<i>E-ID</i> : mild (44%), moderate (23%), severe (33%) <i>ID</i> : mild (69%), moderate (22%), severe (9%)	Seizure frequency: NS Age at onset: NS Seizure type: generalized (82%), localized (18%)	Psychopathology	Clinical interviews	<i>P-psychopathology</i> : <i>E-ID</i> group more likely to have no psychiatric disorder compared to the <i>ID</i> group

Note: NS not stated, ABS adaptive behavior scale, PBS The Psychosocial Behavior Scale, PAAS profile of abilities and adjustment schedule, PSE present state examination, SAP standardized assessment of personality, QABF questions about behavioral functional, DASH-II diagnostic assessment for the severely handicapped-II, ABC aberrant behavior checklist, MESSIER matson evaluation of social skills in individuals with severe retardation, VABS The vineland adaptive behavior scales interview form, PAS-ADD psychiatric assessment schedule for adults with developmental disabilities, DAS disability assessment schedule, PIMRA psychopathology instrument for mentally retarded adults

^aThe authors acknowledge some diagnostic terms are not accurate in modern diagnostic terminology

^bAn unspecified subsample of individuals described in Deb and Hunter [38]

Five studies (36 %) were prevalence based, recruiting adults with ID and identifying epilepsy as a subgroup within this cohort. Prevalence rates ranged from 18 to 45 %, [42–44, 46, 49] with one prevalence study doing additional analyses using matched subgroups of E-ID and ID participants [44]. Two studies (14 %) compared E-ID populations to previously published data and clinical norms [36, 41], while one study compared adults with ID who had active epilepsy (defined as having seizures within the preceding 3 months) to those with inactive epilepsy [48]. Three main domains were covered across these studies, including (1) psychopathology, (2) problem behaviors, and (3) interactions with epilepsy-specific factors. The findings across these domains are summarized below.

Psychopathology in Adults with E-ID

In studies using a matched ID control group, psychiatric symptoms in the E-ID group were found to be significantly lower [12, 39], or comparable to, levels in the ID group [44]. As an exception, one matched control study found higher rates of depression and unspecified disorders (e.g., dementia) in the E-ID group in addition to a significantly higher risk of developing a psychiatric disorder than the ID group over a 1-year period [45]. This study specifically recruited individuals with “active” epilepsy, noting that previous work [38, 44] had a large proportion of participants with “nonactive” epilepsy, pointing to the importance of accounting for seizure frequency when considering psychopathology. In addition to the matched control group studies, there were five prevalence studies addressing questions of psychopathology in this population. Four found that rates of psychiatric illnesses and/or symptoms in the E-ID subgroup were comparable to or lower than [42, 43, 46] the nonepilepsy ID cohort. In contrast, the presence of epilepsy was associated with increased psychological symptoms, particularly mood swings, in one of these population studies [49].

Finally, in the two studies comparing rates of psychopathology in E-ID samples to preexisting data, one reported rates of diagnosed psychiatric illness (12.6 %) comparable with the general population, but lower than expected in an ID population [36]. The second study found rates of possible disorder presence (33 %) comparable to another published ID cohort [41]. Overall, research to date suggests that while there is a risk of psychopathology in adults with E-ID, the rates of psychiatric symptoms in this population are generally comparable with (or lower than) those in adults with ID.

Problem Behaviors in Adults with E-ID

Consistent with the psychopathology findings, studies comparing an E-ID group to published data or clinical norms for adults with ID have found no difference [12, 36] or lower rates of problem behaviors in the E-ID group [41]. In prevalence studies

and studies using matched controls, however, there are mixed findings. Four studies addressed challenging or maladaptive behaviors, with two studies (50%) finding lower rates in the E-ID group [12, 43], one (25%) finding no difference between groups [38], and one (25%) indicating individuals with E-ID were significantly more likely to have severe or frequent behavioral problems [49]. For social skills, one study found no significant differences despite a trend for the E-ID group to have poorer social skills [47], while a larger study found lower levels of social skills in the E-ID group [12]. This may reflect comparatively low power in the first study ($n=15$ per group), resulting in the nonsignificant trend for impaired social skills, compared to the second study ($n=353$ per group). Finally, in the domain of daily-living skills, there was general agreement between three studies that people with E-ID have poorer daily-living and adaptive skills than people with ID [12, 47, 49]. Interestingly, a prevalence study found that while the E-ID group showed more maladaptive behaviors, reduced social skills, and less adaptive behaviors overall, when participants were matched for disability level, there were no differences between the groups on these factors [44]. This suggests that behavioral problems are not uncommon in adults with E-ID, although existing studies may be biased toward the severe end of the behavioral impairment spectrum, as many have been conducted with all, or a large proportion of, inpatients [12, 38, 47]. Whether the same behavioral impairments, particularly with regard to daily-living skills and social abilities, are impaired to the same degree in community-based adults with E-ID requires further investigation.

Contribution of Epilepsy Specific Factors to the Psychosocial Well-being of Adults with E-ID

In the psychopathology domain, only one study used a predictive model to investigate whether epilepsy factors predicted psychiatric illness rates. In this study, seizure frequency, seizure severity, and loss of consciousness were all significant predictors of possible psychiatric illness [41]. In contrast, three other studies investigated epilepsy factors by comparing subgroups of their E-ID participants. These studies found higher rates of psychiatric illness in individuals with epileptiform changes on electroencephalogram (EEG) [36], no difference in psychiatric illness for different seizure types [36, 42], and comparable or lower rates of psychiatric illness for people with “active/frequent” seizures compared to “nonactive/infrequent” seizures [36, 42, 48]. While these results seem to present a mixed picture, particularly with regard to the impact of seizure frequency on psychological well-being, the only predictive study suggests a clear relationship, with this study also recruiting individuals with more frequent seizures than the “active/frequent” groups in the other three studies. The disparity between studies relating to seizure frequency indicates a clear need for more research on this issue in the adult E-ID population to understand the impact of the full spectrum of seizure frequency on psychological well-being.

In the behavioral domain, no relationship has been found between maladaptive behaviors (e.g., aggression, irritability, stereotypic behaviors) and seizure frequency [36, 41]. However, maladaptive behaviors have been found to be more common in individuals with generalized tonic-clonic seizures than those without [36]. In addition, higher seizure frequency has been associated with poorer social skills [47], leading to the suggestion of a “dual disability” whereby adults with E-ID may develop fewer life skills, despite being similar to adults with ID in other respects. The stigma associated with seizures may also play a role in decreasing the social opportunities and growth of adults with E-ID. Difficulties with general adaptive behaviors (e.g., personal independence and daily-living skills) have been found to be associated with earlier seizure onset [44].

Overall, the somewhat inconsistent picture of how epilepsy impacts behavior and psychopathology in the ID population highlights the need for more rigorous research into the interplay of epilepsy, ID, and psychological factors. This could include identifying possible mediators or moderators of the relationships between patient understanding of their health and well-being, seizure characteristics, and emotional state. Future research should begin to characterize the experience of mental health difficulties within the E-ID population, capturing patient perspectives, insight, and how this interacts with other health factors (e.g., ID and epilepsy factors). In particular, research using non-ID epilepsy control groups as well as ID control groups will help tease apart the differential contribution of these factors. Research should also canvass a broader cultural context, employ more rigorous demographic and psychological measurement tools, and utilize more stringent exclusion and inclusion criteria relating to ID and epilepsy variables to improve the quality of research in this field.

Psychological Treatments in Adults with Epilepsy and Intellectual Disabilities

Although impaired psychological well-being does not appear to be any more prevalent in E-ID compared to ID populations, nonetheless it remains an established issue of concern. Recommendations relating to the assessment and management of adults with E-ID have recognized the importance of including health practitioners with expertise in the fields of psychology and psychiatry. In particular, the 2009 *Consensus Guidelines into the Management of Epilepsy in Adults with an Intellectual Disability* states that confirmed neuropsychiatric comorbidities “should be thoroughly treated optimizing both nonpharmacological and pharmacological therapies” [41]. In addition, clinical psychiatric and psychological assessments are recommended to (a) determine if problem behaviors are manifestations of treatable psychiatric conditions (e.g., depression) and (b) identify the causes or antecedents of challenging behaviors and offer appropriate therapeutic advice [50]. Furthermore, the 2011 *International Consensus Clinical Practice Statements for the Treatment of Neuropsychiatric Conditions*

Associated with Epilepsy addressed the assessment and management of psychiatric disorders in children with E-ID [51]. These guidelines offer some important principles that may be relevant to adults with E-ID, including (1) consideration of permanent cognitive impairments versus state-dependent impairments, which may arise from the epilepsy or antiepileptic medications; (2) recognizing state-dependent cognitive impairments or learning disabilities, which can be easily missed but treatable with resultant improvement in cognitive functioning; and (3) prevention of permanent impairments associated with status epilepticus via prompt treatment, with any loss of skills urgently investigated [51].

Based on the need for psychologically based treatment strategies in E-ID, a systematic review was conducted to determine the evidence base for psychological therapies in the adult E-ID population. In particular, we aimed to identify research on the effectiveness of psychological therapies (e.g., CBT, psychotherapy) in adults with E-ID.

Methods

Identification of Studies

We searched for studies describing psychological treatments in adults (≥ 18 years) with E-ID. Our search was limited to available full-text, peer-reviewed journal articles written in English. As before, we searched the PsycInfo and Medline databases for empirical studies using four search terms: (1) epilepsy OR seizure AND (2) intellectual disab* OR mental retardation OR intellectual handicap AND (3) psyc* OR cognit* OR behav* AND (4) treatment.

Article Selection

All studies available to the authors published up until October 2015 were included in the initial title screen ($n=134$). We first removed duplicates ($n=3$), leaving 131 articles for further review (see Fig. 10.2). For the title and abstract screening, we excluded articles about children and adolescents (i.e., <18 years), articles about other populations (primarily autism spectrum disorders) and articles that did not meet all of the search criteria (e.g., articles focused on ID only, or that included E-ID but no treatment data). Five articles reached full-text review, of which we excluded review articles without original data, articles that did not address all components of the search criteria, and articles that did not have control groups for treatment effect comparisons (e.g., case studies). We also searched citing articles and reference lists using the above process, which did not produce any additional articles.

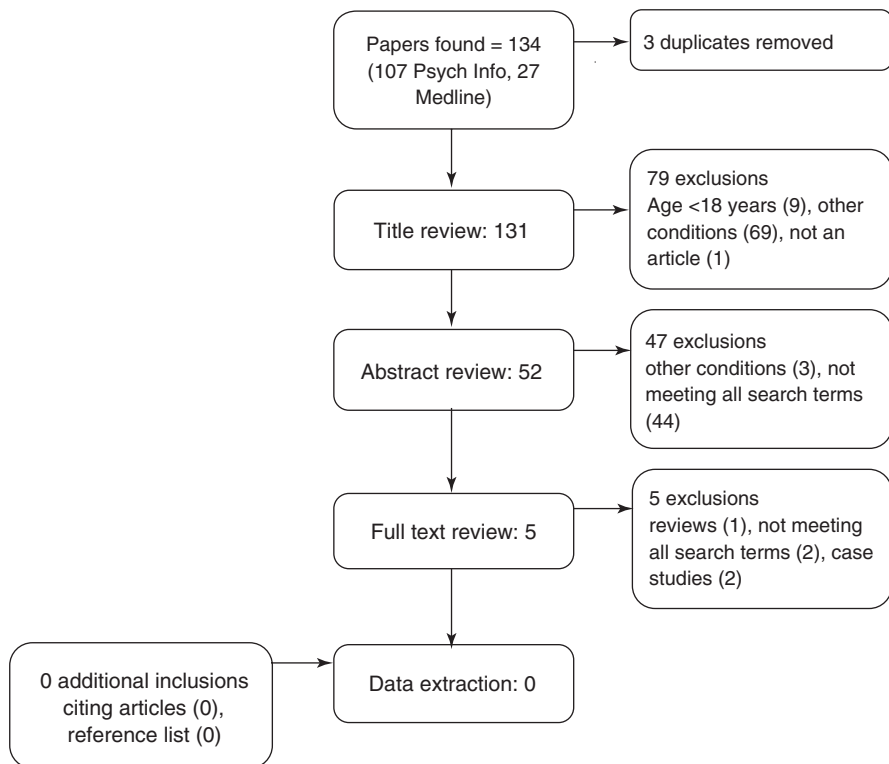


Fig. 10.2 Flow chart of the article review process

Results

This search strategy generated no peer-reviewed journal articles about psychological treatment for people with E-ID. Of concern, there were no methodologically robust treatment studies in the literature, a result also found in a recent Cochrane review of nonpharmacological interventions in this population [7]. In light of this, the two published case studies we identified are briefly described below, both of which presented complex patients engaging in behavioral therapies.

In the first case, a 27-year-old male (IQ=64) with multifocal epilepsy since the age of 3 underwent a resection of the anterior two-thirds of his corpus callosum, followed by biofeedback and behavioral self-regulation training, including relaxation exercises to help manage seizure frequency. Five weeks after surgery, baseline measures were taken, with therapy commencing 3 months postsurgery. Therapy consisted of a 3-week block of daily biofeedback exercises and behavioral therapy sessions, followed by an 8-week break with homework exercises and a further 3-week therapeutic block. Following therapy, the authors reported increased independence and social skills compared to baseline, as well as improved emotion regulation and reduced seizure frequency [52].

The second study presented the case of a 42-year-old male with drug-resistant epilepsy, profound ID, cerebral palsy, and additional health issues, who was experiencing psychogenic nonepileptic seizures (PNES) and maladaptive behaviors (sliding off chairs and falling down). Over an 18-month period, he received behavioral therapy focusing on the antecedents of his PNES and maladaptive behaviors. Therapy involved a three-step differential reinforcement of a behavioral process. For the PNES this involved: (1) a verbal cue of “no” (2) repeated verbal cues, eye contact to determine attention seeking, and gently shaking the patient’s arm or shoulder. If these first two steps were unsuccessful, staff used step (3) offering the patient a small food item that was reinforcing for him to cease the behavior. If the maladaptive behaviors stopped after step 1, the patient was helped up and no positive reinforcement (attention) given for 3 min, after which he received attention on approximately 10-min intervals, comprising verbal statements, eye contact, and gentle physical contact. This treatment was successful in reducing the frequency of the patient’s PNES and maladaptive behaviors, from a baseline of 7 days/month without a psychogenic seizure or maladaptive behavior to a maximum of 19 days/month during treatment [53].

These two case studies provide support for the benefits of behavioral therapy and/or psychological support in relation to seizure activity and quality of life, although the nature of case studies limits their generalizability.

Based on the effectiveness of psychological therapies in the ID population, and recent clinical guidelines recommending the exploration of psychological techniques to support the psychosocial well-being of the E-ID population, the lack of research in this area constitutes a serious concern, and empirical studies are urgently needed. The case studies summarized above hopefully provide the impetus for conducting future robust methodological work in this field.

Conclusions

This chapter has used literature on the psychological well-being and effectiveness of psychological treatment in adults with ID to create a framework to further our understanding of the psychological presentation of people with E-ID. Psychological treatments are increasingly recognized as beneficial in the management of adults with ID, particularly those with additional psychosocial challenges. In this chapter, we have established that adults with E-ID present with similar challenges to psychosocial well-being as adults with ID, while there is mixed evidence for epilepsy-specific concerns that may further impact psychological well-being. This suggests that the adapted psychological treatments, which have been effective in ID populations, may also be effective in improving the well-being of adults with E-ID.

In order to inform best-practice guidelines for the use of psychological management strategies in E-ID, there are two key questions requiring further research:

1. How significant are epilepsy-specific factors in people with E-ID, in terms of their impact on psychosocial functioning and quality of life?

2. Can the psychosocial issues identified in the E-ID population be effectively targeted by psychological treatments?

The presenting issues of adults with E-ID may be ameliorated using psychological treatments, particularly if therapy is adapted to be most effective in people with ID. To empirically assess this, however, rigorous randomized control trials and longitudinal multicenter studies are required, incorporating patient and carer perspectives.

Finally, there is a need to continue to evaluate service delivery models and to develop clinical guidelines to address the possible undertreatment of cognitive difficulties and psychopathologies in the E-ID population. Understanding the etiology and presentation of psychopathology and psychosocial issues will be highly beneficial for clinicians to develop evidence-based multidisciplinary treatments. In addition, clinically relevant measures assessing issues arising in people with E-ID, particularly measures sensitive to change over time, require development to monitor significant clinical changes that may accompany treatment. Research into these areas will not only inform clinical practice and bridge the gap between clinical knowledge and scientific evidence, but will also improve the psychosocial well-being of people living with E-ID.

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