

Correlates of Anxiety among Adults with Intellectual Disability: A Systematic Literature Review

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Abstract

Introduction: The aim of this systematic review was to synthesize the literature on the correlates and risk factors of anxiety among adults with ID.

Methods: Following the PRISMA guidelines, a systematic search of peer-reviewed literature was conducted across six major electronic databases. From an initial screening of 844 records, 13 studies were included for full-text review. Factors associated with anxiety were categorized utilizing the biopsychosocial model. Methodological quality was evaluated.

Results: Correlates of anxiety were identified at all levels of the biopsychosocial model, including psychological or psychiatric diagnoses, level of ID, gender, chronic health conditions, stressful life events, and social interactions. Modifiable correlates were discussed as potential targets for designing anxiety interventions for adults with ID.

Conclusion: Despite the increased recognition of the mental health needs of individuals with ID in recent years, this review highlighted a dearth of research investigating the risk factors of anxiety among this population.

Keywords

Intellectual disability; anxiety; stress; risk factor; correlate

Anxiety is defined as “the apprehensive anticipation of future danger or misfortune accompanied by a feeling of worry, distress, and/or somatic symptoms of tension” (*Diagnostic and Statistical Manual of Mental Disorders, 5th Ed.* [DSM]-5, American Psychiatric Association, 2013). Among the general population, anxiety disorders have a prevalence of approximately 19.1% (Harvard Medical School, 2007). Although data are inconsistent, it is widely believed that adults with intellectual disabilities (ID) have equal or greater prevalence of anxiety than the general population (Fletcher et al., 2016). In a recent review of data collected through the National Core Indicators Survey of adults with ID across the U.S., there was a reported range of 34% to 64% of respondents who met criteria for a dual diagnosis (i.e., mental illness and ID; Bradley et al., 2019). Among those dually diagnosed, the most prevalent mental health diagnoses are affective and anxiety disorders (Cooper et al.,

2007; Dykens, 2007; Tassé et al., 2016). Among adults with ID, estimates of the prevalence of anxiety symptoms range from 6% to 31% (Bailey & Andrews, 2003; Ballinger & Ballinger, 1991; Reiss, 1990), and more recent studies report estimated prevalence from <2% to 17% (Bailey, 2007; Reid et al., 2011). The wide range of prevalence estimates is due to the variable reporting of symptoms associated with anxiety versus a clinical diagnosis of an anxiety disorder, and the added difficulty of differential diagnosis (i.e., distinguishing anxiety from other mental health conditions) among this population (Bailey & Andrews, 2003; Fletcher et al., 2016). Anxiety disorders or the presence of anxiety symptomology are associated with symptomatic distress, as well as substantial impairments in overall health and functioning in psychosocial, physical, and cognitive domains (Rodriguez et al., 2005). These negative impacts on health and quality of life can sustain beyond immediate symptom offset (Stout et al., 2001)

The prevention and treatment of anxiety among individuals with ID requires urgent attention as individuals with ID are often found to have fewer resources available to support coping with anxiety symptoms (e.g., stress) than the general population (Scott & Haverkamp, 2018). Of the many individuals with ID with mental health needs, only 10–30% receive mental health interventions or supports (Dekker & Koot, 2003; Einfeld et al., 2006). Organizational barriers, lack of services, and problematic quality of services have been identified as primary barriers to receiving adequate mental health care in individuals with ID (Whittle et al., 2018). Moreover, critical gaps in clinical knowledge among healthcare providers and the lack of consensus for mental health service models for adults with ID have been noted (Whittle et al., 2018). To inform the development and refinement of services for reducing anxiety and its sequelae among adults with ID, it is critical to understand the factors related to anxiety among this population (Moss et al., 2000).

Risk factors associated with anxiety among the general population include age, female gender, stressful life events (in childhood and recent past), presence of physical disease, other mental health problems, and low socioeconomic level (Moreno-Peral et al., 2014). These risk factors reflect all levels of the biopsychosocial model, a model frequently employed in studies of health and disease that theorizes that health is influenced by biological, psychological, and social factors (Engel, 1977). This model contrasts the biomedical model of health, which suggests disease is explained as a deviation from normal function (Vögele, 2015). The biopsychosocial model has been increasingly applied to conceptualize and study the unique health needs of individuals with ID (Koritsas & Iacono, 2015; Sappok et al., 2019).

The substantial prevalence rates and potentially unique etiology of anxiety among adults with ID has led researchers to examine the correlates and factors associated with anxiety among this population. Ultimately, this research will

serve to identify optimal intervention targets to reduce anxiety among adults with ID. To date, however, this literature has not been synthesized. Therefore, the aim of this systematic review was to synthesize the literature on correlates and risk factors of anxiety in adults with ID to inform future research directions.

Methods

Search Criteria

The search terms for this systematic review fell within three main categories: (1) Intellectual disability, (2) Anxiety, and (3) Risk factors and correlates. Each category included a group of similar terms or commonly used alternative terms. The Boolean operator “AND” was used between groups and “OR” was used within groups. Search strings are detailed in [Table 1](#). The search was conducted using the following databases: PubMed, PsycINFO, EBSCO: ERIC, MEDLINE, SCOPUS, and Web of Science. Database searches were refined to include journal articles that contained search terms within the title, abstract, and keywords (i.e., topic). No restrictions were placed on the time period of publication. Search results were exported to RefWorks ProQuest.

Eligibility Criteria & Study Selection

After exporting all search results, duplicates were automatically identified and removed. All remaining studies’ titles and abstracts were screened for eligibility based upon inclusion and exclusion criteria established by the authors. Studies were included for review if they were (a) quantitative studies that report on anxiety and its risk factors or correlates among adults with ID, (b) with a majority of participants (>75% of sample) reported as having ID, and (c) with a majority of participants (>75% of sample) aged 18 years or older. Studies excluded from review were (a) not in English, (b) not in a peer-reviewed journal, (c) not examining anxiety and its correlates or risk factors with quantitative methods, or (d) <75% of the sample were reported to have

Table 1. Search strings.

Intellectual Disability AND	Anxiety AND	Risk Factors & Correlates
OR	OR	OR
mental retardation	anxious	correlates
developmental disability	fear	risk factors
developmental disabilities	worry	determinants
	stress	associates
		causes
		predictors
		covariates
		contributors

a diagnosis of ID. Furthermore, if the studies included a majority of participants (>50% of sample) with ID *and* a co-occurring diagnosis of autism spectrum disorder, the studies were excluded since there are known positive correlations between autism spectrum disorder and anxiety (Gillott & Standen, 2007; Kim et al., 2000; Matson & Cervantes, 2013). Articles included after title and abstract screening underwent full text review based on inclusion and exclusion criteria. Articles meeting eligibility criteria were analyzed for the purpose of this review. An updated search was conducted to account for all articles published through the year 2020. The screening, review, and study selection process is outlined in Figure 1.

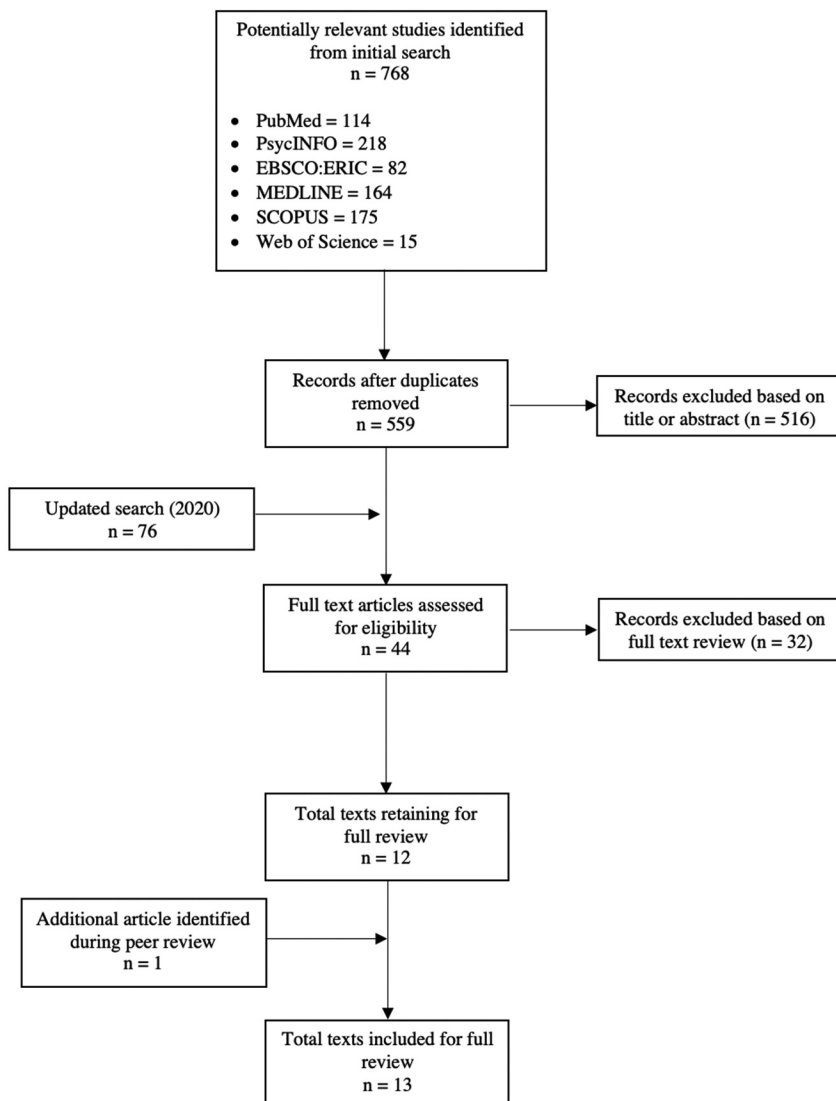


Figure 1. Flow chart of included studies.

Article Analysis

Analysis of the selected articles was conducted using data extraction methods outlined in Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework (Moher et al., 2009). A tool was developed to aid extraction of study characteristics including study design, population characteristics, measures, and correlates of anxiety (See Table 2). Two reviewers independently analyzed all included articles to extract necessary information. A third reviewer analyzed the level of agreement between the two reviewers for all included articles, and it was found to be 92.3% (132/143). Discrepancies between study codes (n = 11) were reviewed and classified as factual (n = 11). Factual errors were considered transcription errors where the correct answer was present in the study and either missed by the coder or inaccurately reported. Factual errors were corrected by the second author after revisiting the articles. No studies were classified as interpretative (i.e., errors where study information was inferred or not clear and required the coder to make an interpretation on the classification).

Quality Assessment

Internal validity of the included studies was evaluated with the National Institute of Health (NIH) Quality Assessment Tool for cohort and observational studies (National Institutes of Health, 2014). The tool, which employs

Table 2. Quality assessment tool for observational cohort and cross-sectional studies¹.

	Study Criteria*
Q1	Was the research question or objective in this paper clearly stated?
Q2	Was the study population clearly specified and defined?
Q3	Was the participation rate of eligible persons at least 50%?
Q4	Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?
Q5	Was a sample size justification, power description, or variance and effect estimates provided?
Q6	For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?
Q7	Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?
Q8	For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?
Q9	Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
Q10	Was the exposure(s) assessed more than once over time?
Q11	Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
Q12	Were the outcome assessors blinded to the exposure status of participants?
Q13	Was loss to follow-up after baseline 20% or less?
Q14	Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?

*Response Options: Yes (Y), No (N), Not Applicable (NA), Not Reported (NR), Cannot Determine (CD)

¹NIH National Heart, Lung, and Blood Institute. (2020). <https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools>.

fourteen quality indicators, allows authors to draw conclusions about the overall study quality rather than eliciting a single quality score (See [Table 3](#)). Quality indicators are scored with either “yes” (Y), “no” (N), “not applicable” (NA), “not reported” (NR), or “cannot determine” (CD). The tool’s fourteen quality indicators allow authors to weigh areas of bias and draw conclusions about the overall study quality, ranked as “good,” “fair,” or “poor.” NIH scoring guidance was reviewed by authors and the authors also established common scoring understanding for certain criterion. Two reviewers assessed the included studies to provide quality rating scores. A third reviewer evaluated the agreement between scores of quality assessment. There was 97.8% agreement between the quality ratings provided by both reviewers. Disagreements (4 of 182 ratings) were resolved by the third reviewer (See [Table 3](#)).

Results

Study Selection

The initial search of six databases yielded a total of 768 studies. Of those, 209 duplicates were removed. The remaining 559 studies were screened based on title and abstract and an additional 516 were removed. An updated search of the six databases was conducted for all articles published in the year 2020, which yielded an additional 76 articles. Of those, 75 were removed based on title and abstract review. A total of 44 articles were assessed based on a full text review and 32 were removed due to not meeting eligibility criteria. Of those removed, the primary reasons for exclusion were a lack of examining risk factors or correlates of anxiety utilizing quantitative methods (18/32), and a focus on a specific anxiety type (i.e., post-traumatic stress disorder, test anxiety, dental anxiety; 8/32). The final number of articles included for full review was 12. One additional article was identified during the manuscript peer-review stage, thus bringing the total number of articles to 13. [Figure 1](#) illustrates the search and selection process.

Study Characteristics

Study Design and Measures

Six studies were conducted in North America, of which five were conducted in the United States of America (Esbensen, [2016](#); Ezell et al., [2019](#); E. Glenn et al., [2003](#); Hartley & Maclean, [2009](#); Hsieh et al., [2020](#)) and one study was in Canada (Lunsky et al., [2009](#)). Six studies were conducted in Europe; three in the United Kingdom (S. Glenn et al., [2015](#); Reid et al., [2011](#); Startin et al., [2020](#)), two in the Netherlands (Hermans & Evenhuis, [2012](#); De Winter et al., [2015](#)), and one in Ireland (Bond et al., [2020](#)). One study was conducted in

Table 3. Quality assessment ratings.

Study	Clear research question	Clearly defined population	50% participation rate	Clear inclusion/exclusion criteria	Sample size justification	Exposure measured before outcome	Sufficient time frame	Different levels of exposure	Valid, reliable exposure measures	Exposure assessed over time	Valid, reliable outcome measures	Blind assessors	<20% loss to follow-up	Adjustments for confounders
Austin et al., 2018	Y	Y	CD	Y	N	N	N	Y	Y	N	Y	NA	NA	N
Bond et al., 2020	Y	Y	NR	Y	N	N	NA	Y	Y	N	Y	NA	NA	Y
De Winter et al., 2015	Y	Y	N	Y	N	N	N	N	Y	N	Y	NA	NA	Y
Esbensen, 2016	Y	Y	NR	Y	N	N	N	Y	Y	N	Y	Y	NA	N
Ezell et al., 2019	Y	Y	NR	Y	N	N	N	Y	Y	N	Y	NR	NA	Y
E. Glenn et al., 2003	Y	Y	Y	Y	N	N	NA	Y	Y	N	Y	Y	NA	N
S. Glenn et al., 2015	Y	Y	CD	Y	N	N	NA	Y	Y	N	Y	N	NA	N
Hartley & Maclean, 2009	Y	Y	CD	Y	N	N	NA	Y	Y	N	Y	N	NA	Y
Hermans & Evenhuis, 2012	Y	Y	NR	N	N	N	NA	Y	Y	N	Y	N	NA	Y
Hsieh et al., 2020	Y	N	CD	N	N	N	N	Y	N	Y	N	N	NA	N
Lunsky et al., 2009	Y	Y	Y	Y	N	N	NA	NA	Y	N	N	N	NA	N
Reid et al., 2011	Y	Y	Y	Y	N	N	NA	Y	Y	N	Y	N	NA	N
Startin et al., 2020	Y	Y	NR	Y	N	N	NA	NA	N	N	N	N	NA	Y

Australia (Austin et al., 2018). Twelve of the studies utilized a cross-sectional design, while one employed a longitudinal design (Hsieh et al., 2020). Eleven of the thirteen studies used validated measures to assess anxiety and seven studies employed measures that have been specifically validated for use with individuals with ID. Of the seven studies utilizing measures validated for use with individuals with ID, five studies used the Glasgow Anxiety Scale for people with ID (GAS-ID; Austin et al., 2018; Bond et al., 2020; Hartley & Maclean, 2009; Hermans & Evenhuis, 2012; De Winter et al., 2015) and two studies used the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD; Esbensen, 2016; Reid et al., 2011). Study characteristics are presented in Table 4.

Sample Characteristics

Study sample sizes ranged from 31 (Ezell et al., 2019) to 1023 participants (Reid et al., 2011). The mean age of the sample participants ranged from 18.8 years (Ezell et al., 2019) to 61.1 years (Hermans & Evenhuis, 2012; De Winter et al., 2015). Eight of the studies included approximately 50% male participants (Austin et al., 2018; E. Glenn et al., 2003; S. Glenn et al., 2015; Hartley & Maclean, 2009; Hermans & Evenhuis, 2012; Reid et al., 2011; Startin et al., 2020; De Winter et al., 2015), three studies included greater than 55% male participants (Hsieh et al., 2020; Lunskey et al., 2009; Esbensen, 2016), one study included less than 50% male participants (Bond et al., 2020), and one study included 100% male participants (Ezell et al., 2019). In all but two studies (Ezell et al., 2019; Reid et al., 2011), conditions were reported for participants and included depression, dementia, psychiatric diagnoses, Down's syndrome, autism spectrum disorder, cerebral palsy, attention deficit hyperactive disorder, schizophrenia, and bipolar disorder. Four studies did not report participants' level of ID (Ezell et al., 2019; S. Glenn et al., 2015; Hsieh et al., 2020; Lunskey et al., 2009). One study reported participants' level of ID as mild (Hartley & Maclean, 2009). The remaining eight studies all reported a combination of all levels of ID among participants, including mild, moderate, and/or severe.

Correlates of Anxiety

The correlates of anxiety were categorized using the biopsychosocial model (Engel, 1977). Correlates of anxiety among adults with ID were found at all levels of biopsychosocial model (See Table 4).

Biological. Seven of the studies reported biological correlates for anxiety among adults with ID. Four studies reported gender as a correlate of anxiety, with two studies reporting anxiety to be more likely among women (Hsieh et al., 2020; Lunskey et al., 2009) and one reporting anxiety to be more prevalent among men (Startin et al., 2020). The fourth article reported a positive and

Table 4. Study characteristics table.

Study Author (year)	Country	Study Design	Measure of anxiety	Validity of anxiety measure	Level of ID	Sample (N)	Mean Age (Years)	Sex (% male)	Risk factors for anxiety			
									Co-morbidities	Biological	Psychological	Social
Austin, K. L. et al. (2018)	Australia	Cross- sectional	Glasgow Anxiety Scale for people with ID	Validated tool for ID	Com (B, M, Mod)	55	21.67 SD = 3.24	51%	Depression		(-) insight Maladaptive coping Hopelessness Level of ID: (-) cognitive abilities	
Bond et al. (2020)	Ireland	Cross- sectional	GAS-ID	Validated tool for ID	Com (M, Mod, S)	291		41.58%	Depression	Chronic disease Poor health (self- reported)	Antidepressants Anxiolytics Trouble sleeping (-) enthusiasm (-) IADL	Loneliness
De Winter et al. (2015)	The Netherlands	Cross- sectional	Anxiety, Depression, And Mood Scale (ADAMS); GAS-ID; Hospital Anxiety and Depression Scale, Anxiety Subscale (HADS-A)	Validated tools (GAS-ID validated for ID)	Com (B, M, Mod, S)	990	61.1 SD = 8.2	51.3%	Depression	Diabetes	Level of ID: (+) cognitive abilities Depression	
Esbensen (2016)	USA	Cross- sectional	Psychiatric Assessment Schedule for Adults with DD (PAS-ADD)	Validated tool for ID	Com (M, Mod, S)	75	51.1 SD = 6.0	65.3%	Dementia	Older age	Depression Behavioral sleep disturbances	

(Continued)

Table 4. (Continued).

Study Author (year)	Country	Study Design	Measure of anxiety	Validity of anxiety measure	Level of ID	Sample (N)	Mean Age (Years)	Sex (% male)	Co-morbidities	Risk factors for anxiety		
										Biological	Psychological	Social
Ezell et al. (2019)	USA	Cross- sectional	Children's Interview for Psychiatric Symptoms- Parent Version (P-ChIPS); DSM- V	Validated tool	NR	31	18.8 SD = 2.1	100%	NR	No significant relationships found		
E. Glenn et al. (2003)	USA	Cross- sectional	Beck Anxiety Inventory	Validated tool	Com (B, M, Mod)	46	36.41 SD = 9.19	54%	Depression		Depression	
S. Glenn et al. (2015)	UK	Cross- sectional	'Strengths and difficulties' questionnaire	Validated method	NR	125	30.42 SD = 7.0	49.6%	Psychiatric diagnoses		Psychiatric diagnosis Repetitive behaviors Psychiatric diagnosis	
Hartley and Maclean (2009)	USA	Cross- sectional	Glasgow Anxiety Scale for people with ID	Validated tool for ID	M	114	40.33 SD = 12.52	52.6%	Psychiatric diagnoses		Stressful social interactions	
Hermans and Evenhuis (2012)	The Netherlands	Cross- sectional	Anxiety, Depression, And Mood Scale (ADAMS); GAS-ID; Hospital Anxiety and Depression Scale, Anxiety Subscale (HADS-A)	Validated tools (GAS-ID validated for ID)	Com (B, M, Mod, S)	990	61.1 SD = 8.2	51.3%	Depression	Gender Chronic diseases	Depressive symptoms Level of ID: (+) cognitive abilities Smoking (-) IADL	Life events (-) freq. of social contacts

(Continued)

Table 4. (Continued).

Study Author (year)	Country	Study Design	Measure of anxiety diagnosis	Validity of anxiety measure	Level of ID	Sample (N)	Mean Age (Years) SD = 13.61	Sex (% male)	Risk factors for anxiety			
									Co-morbidities	Biological	Psychological	Social
Hsieh et al. (2020)	USA	Longitudinal	Self-reported diagnosis	Not valid	NR	758	35.96 SD = 13.61	57%	Depression, DS, ASD, CP	Older age Gender (F) Hearing impairment Chronic health conditions Gender (F)	ASD Smoking	Stressful life events
Lunskey et al. (2009)	Canada	Cross- sectional	Staff-reported DSM-IV classification	Not valid	NR	369	46.16	65.9%	Psychiatric diagnoses			
Reid et al. (2011)	Scotland, UK	Cross- sectional	Psychiatric Assessment Schedule for Adults with DD (PAS-ADD), Present Psychiatric State for Adults with Learning Disabilities	Validated tools for ID	Com (B, M, Mod, S)	1023	43.94	54.9%	NR		Level of ID: (+) cognitive abilities	Unemployment Life events Communication needs
Startin et al. (2020)	England & Wales, UK	Cross- sectional	Informant report of clinical diagnoses in medical history	Not valid	Com	602		52.2%	ADHD, Schizophrenia, Bipolar Disorder, Depression	Gender (M)		

significant relationship between gender and anxiety symptoms but did not specify which gender (Hermans & Evenhuis, 2012). Four studies reported chronic health conditions (e.g., diabetes) as a correlate of anxiety (Bond et al., 2020; Hermans & Evenhuis, 2012; Hsieh et al., 2020; De Winter et al., 2015) and Hsieh et al. (2020) demonstrated having a hearing impairment to be associated with anxiety. Older age (Esbensen, 2016; Hsieh et al., 2020) was identified as a correlate of anxiety, as well. Finally, self-reported poor health condition was correlated with anxiety (Bond et al., 2020).

Psychological/Behavioral. Ten studies reported psychological or behavioral correlates for anxiety. Seven studies reported a comorbid psychological or psychiatric diagnosis as a correlate of anxiety (Bond et al., 2020; Esbensen, 2016; E. Glenn et al., 2003; S. Glenn et al., 2015; Hartley & Maclean, 2009; Hsieh et al., 2020; De Winter et al., 2015). Three studies specifically reported a diagnosis of depression as a correlate of anxiety (Esbensen, 2016; E. Glenn et al., 2003; De Winter et al., 2015) and one study reported depressive symptoms as a correlate (Hermans & Evenhuis, 2012). Autism spectrum disorder (ASD) was also a noted risk factor for anxiety among adults with ID in one study (Hsieh et al., 2020). Four studies reported level of ID as a correlate of anxiety, with higher levels of cognitive abilities (i.e., milder levels of ID) associated with a higher likelihood of anxiety or anxiety symptoms in three studies (Hermans & Evenhuis, 2012; Reid et al., 2011; De Winter et al., 2015) and lower levels of cognitive abilities associated with more symptoms of anxiety in one study (Austin et al., 2018). Smoking was identified as another factor associated with anxiety by two studies (Hermans & Evenhuis, 2012; Hsieh et al., 2020). Two studies also reported lower levels of independence in activities of daily living to be associated with anxiety (Bond et al., 2020; Hermans & Evenhuis, 2012). Two studies reported trouble sleeping and sleep disturbances as a factor associated with anxiety (Bond et al., 2020; Esbensen, 2016). Other psychological correlates reported included low levels of insight, maladaptive coping, hopelessness (Austin et al., 2018), low levels of enthusiasm, use of antidepressant and/or anxiolytic medication (Bond et al., 2020), and repetitive behaviors (S. Glenn et al., 2015). Of note, Ezell et al. (2019) examined ASD severity and nonverbal ability levels as potential correlates for anxiety among adults with ID yet found no significant relationships to exist in their sample.

Social. Five studies reported social correlates for anxiety. The presence of significant or stressful life events (e.g., change in job, loss of a loved one) correlated with anxiety in three studies (Hermans & Evenhuis, 2012; Hsieh et al., 2020; Reid et al., 2011). Two studies reported social interactions as a factor associated with anxiety: specifically stressful social interactions (Hartley & Maclean, 2009) and a lower frequency of social contacts

(Hermans & Evenhuis, 2012) were associated with greater levels of anxiety. Similarly, Bond et al. (2020) reported feelings of loneliness to be associated with anxiety. Furthermore, Reid et al. (2011) reported unemployment and communication needs as correlates of anxiety.

Quality Indicators of Studies

Internal validity and potential bias of the studies was evaluated with the NIH Quality Assessment Tool for cohort and observational studies (National Institutes of Health, 2014). In general, the reviewed articles demonstrated good or fair quality. All thirteen of the articles included a clear research question, and all but one (Hsieh et al., 2020) had a clearly defined population. One article demonstrated fair quality due to the lack of clearly defined inclusion and exclusion criteria, the use of exposure and outcome measures that were not validated for use among adults with ID, and the absence of adjustments for confounding variables of interest (Hsieh et al., 2020). That said, Hsieh and colleagues were the only group to assess exposure over time employing a longitudinal study design and large sample size ($N = 758$). Several indicators were more heavily weighted given the aim of the systematic review to better understand risk factors and correlates of stress and anxiety among adults with ID. These indicators included Q9 (i.e., use of valid and reliable exposure measures), Q11 (i.e., use of valid and reliable outcome measures), and Q14 (i.e., adjustments for cofounders). Two articles did not use valid exposure measures for the target population (Hsieh et al., 2020; Startin et al., 2020) and three articles did not use valid and/or reliable outcome measures for anxiety (Hsieh et al., 2020; Lunskey et al., 2009; Startin et al., 2020). Six articles adjusted statistically for key potential confounding variables when analyzing the relationship between exposures and outcomes (Bond et al., 2020; Ezell et al., 2019; Hartley & Maclean, 2009; Hermans & Evenhuis, 2012; Startin et al., 2020; De Winter et al., 2015). See Tables 3 & 4 for a more detailed review of the quality review results. Certain indicators were not heavily weighted in drawing quality conclusions as they were less or not applicable to the cross-sectional nature of twelve of the thirteen studies, specifically the indicators Q6 (i.e., exposure measured prior to outcome), Q7 (i.e., sufficient timeframe), Q10 (i.e., exposure measured over time), and Q13 (i.e., <20% loss to follow-up), all of which received “No” or “Not Applicable” response ratings on all included studies.

Discussion

This is the first systematic review to synthesize the literature on the risk factors and correlates of anxiety among adults with ID. Despite the increased recognition of the mental health needs of individuals with ID in more recent years,

this review highlighted a dearth of research investigating the risk factors of anxiety among this population. However, it is promising that the majority (9 of 13) of included studies were published within the last decade, demonstrating increased attention on this topic. Reviewed studies were primarily cross-sectional in design (12 of 13) and were rated as fair to good based on quality assessment indicators. Among the reviewed articles, correlates of anxiety were found at all levels of the biopsychosocial model, highlighting the influence of biological, psychological/behavioral, and social factors on the wellbeing of individuals with ID. It is also important to note that among the range of factors associated with anxiety among this population, several factors are potentially modifiable and can serve as a focal point for future research on supporting the mental health needs of individuals with ID.

When considering the direction of future research and practice to support the mental health needs of individuals with ID, it is essential to decipher which associated factors are modifiable as these may serve as targets when designing interventions. Modifiable correlates of anxiety identified in the current review include low levels of insight, maladaptive coping, feelings of hopelessness, level of independence in activities of daily living, and frequency and quality of social interactions (Austin et al., 2018; Bond et al., 2020; Hartley & Maclean, 2009; Hermans & Evenhuis, 2012). Similar findings exist with regard to the modifiable risk and protective factors for anxiety among adults without ID (Blanco et al., 2014; Moreno-Peral et al., 2014; Zimmermann et al., 2020). In particular, negative appraisal of life events and avoidance are identified risk factors for anxiety among adults, while social support and coping are demonstrated protective factors (Zimmermann et al., 2020). While findings are consistent regarding factors with anxiety, it is important to recognize how these factors may differently impact individuals with ID. Individuals with ID have been reported to use more avoidant coping (i.e., avoid and disengage from emotions or situations) versus active coping (i.e., gain control over emotions or situations) when compared to peers in the general population (Hartley & MacLean, 2008). This maladaptive coping is especially common among stressful social interactions (Hartley & Maclean, 2009). Among adults with ID living in the community, individuals report their closest and most significant relationships are often with a member of their support staff (Giesbers et al., 2019; Verdonchot et al., 2009). People with ID are also less likely to engage in community groups, choosing more solitary leisure activities (Verdonchot et al., 2009). Each of these modifiable correlates can serve as targets of interventions (i.e., promotion of social inclusion; support and education around adaptive coping strategies) in future research to reduce anxiety among individuals with ID.

Non-modifiable correlates were also identified in the current review. Of the reviewed articles, ten studies reported on psychological correlates of

anxiety, with psychiatric or psychological diagnoses, such as dementia, bipolar disorder, and ASD, commonly reported as correlates of anxiety. This finding is consistent with the literature related to anxiety among adults without ID (Gillott & Standen, 2007; Grant et al., 2004; Kim et al., 2000; Matson & Cervantes, 2013; Rodriguez et al., 2005). Mental health conditions commonly co-occur, with complex interrelationships existing between diagnoses, functional impairments, and treatment (Rodriguez et al., 2005). In addition, milder levels of ID (i.e., higher level of cognitive functioning) was reported as a correlate of anxiety. This may be partially attributed to the fact that people with mild ID are increasingly likely to be living in community settings versus segregated facilities with more intensive levels of support in place (Verdonschot et al., 2009). Biological factors such as gender (i.e., more often associated with females, although one study reported an association among males) and chronic health conditions (e.g., diabetes) were also reported as being associated with anxiety among several of the articles. Notably, these non-modifiable factors associated with anxiety are the same among adults with ID and adults without ID (Blanco et al., 2014; Moreno-Peral et al., 2014).

Recommendations for Future Research

The current literature review highlighted the gaps that exist in our overall understanding of anxiety among adults with ID. First, there is a need to ascertain the prevalence of anxiety among the population of adults with ID. While there are studies on the estimated prevalence of anxiety in this population, the outdated nature of the data is highlighted by the fact that the commonly reported prevalence is based on data from over a decade ago (Harvard Medical School, 2007). Second, all but one of the included studies were cross-sectional in design, which limits the ability to make inferences about the temporal relationship between risk factors and outcomes. Therefore, this review primarily synthesized literature on correlates of anxiety, with only one study employing a longitudinal analysis and assessment of risk factors for anxiety (Hsieh et al., 2020). Future research using longitudinal, cohort, or clinical trial designs are recommended to gain insight into the directionality and temporality of the relationships observed. Furthermore, it is strongly suggested that more qualitative work is conducted to gain a richer insight into the experiences of anxiety among adults with ID. Third, only half of the included studies used measures of anxiety that have been validated for use among adults with ID. This limitation reflects not only on the quality of studies conducted related to mental health among adults with ID, but also the limitation of the field overall regarding the lack of available measures that have been validated for use among this population. Future research is needed to

increase availability of assessment tools that are appropriate and validated for use with adults with ID, both clinically and in research settings.

Recommendations for Practice

Among adults with ID, this review has identified several modifiable factors (i.e., factors that can be intervened upon, including level of insight, coping styles, and types of social interactions) associated with anxiety consistent with those observed among the general population of adults. However, it is important to recognize the unique life circumstances that frequently exist for individuals with ID in order to best understand the implications for anxiety symptomology and the design of supports and services. For example, individuals with ID are more likely to rely on support staff for social support and be more socially isolated than their peers without ID (Giesbers et al., 2019; Verdonschot et al., 2009). The lack of quality social interactions and/or the stressful nature of social interactions may present as a risk factor for anxiety that can be addressed through increased access and opportunity for meaningful social inclusion for individuals with ID. Individuals with ID are also more prone to utilizing maladaptive and avoidant coping strategies when faced with stressful situations and emotions. Oftentimes, studies related to anxiety for the population of adults with ID utilize cognitive behavior therapy (CBT; Cooney et al., 2017, 2018; Hronis et al., 2018). While results of recent studies utilizing CBT for adults with ID and anxiety are promising, CBT is resource-intensive, requiring extensive modifications for this population. Other interventions, such as behavioral activation therapy, guided self-help, and mindfulness-based programs, have demonstrated effectiveness in promoting positive mental health (i.e., reducing depressive symptoms, anger, and challenging behaviors) among adults with ID (Jahoda et al., 2015; Singh et al., 2007). While these interventions show promise for responding to the mental health needs of individuals with ID, they are not specifically designed for addressing anxiety. This demonstrates the need for designing coping interventions for adults with ID to improve their use of active coping strategies and thus reduce their risk for anxiety. Overall, the findings of this literature may be used to inform the development and implementation of interventions to reduce anxiety among adults with ID and advance the field with much needed evidence-based practices.

Limitations

There were several limitations to the current literature review. First, while data extraction was completed and reviewed by multiple authors, only the primary author compiled the searches. Second, only articles published in English were included for review; studies in other languages may have been overlooked.

Third, the review was limited to peer-reviewed articles; dissertations, theses, and non-peer reviewed works were excluded from review. Fourth, the focus of the literature review was on generalized anxiety and/or anxiety symptoms; studies focused on a specific anxiety type or subgroup (e.g., dental anxiety, post-traumatic stress disorder) were excluded from review. Finally, only quantitative articles were included for review; qualitative articles and reviews were excluded for consistency in data extraction and due to the scarcity of qualitative work conducted in this area.

Conclusion

While anxiety is a known common comorbid condition among adults with ID, this review highlighted the paucity of research on the risk factors for anxiety among this population. More encouragingly, this review demonstrated the increased attention to this topic in recent years, but there remains an urgent need to explore the temporal relationships between risk factors and outcomes, as well as appropriate and consistent measures of anxiety for individuals with ID. Correlates for anxiety were identified at all levels of the biopsychosocial model. Both modifiable and non-modifiable factors associated with anxiety were reported, several of which were found to be consistent with findings for adults without ID. However, shared etiology of anxiety between adults with and without ID does not guarantee that methods to reduce anxiety among adults without ID will transfer to adults with ID; research is urgently needed on this matter.

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