Mental disorders

Chapter 8

Anxiety disorders

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Introduction

Anxiety disorders as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association, 2013) “include disorders that share features of excessive fear and anxiety and related behavioral disturbance. Fear is the emotional response to real or perceived imminent threat, whereas anxiety is the anticipation of future threat.” The fear or anxiety is not transient but persist, usually lasting six months or more. Within DSM-5 the chapter on anxiety disorders includes disorders that occur in childhood, namely separation anxiety disorders and selective mutism, but also specific phobias, social anxiety disorder (social phobia), panic disorder, agoraphobia, and generalized anxiety disorder. The focus of this chapter is to cover conditions that are commonly diagnosed in adult life and so come under sections F40 and F41 within the International Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10; World Health Organization, 1992), and include phobic anxiety disorders, panic disorders, and generalized anxiety disorder. Anxiety disorders do occur in people with ID but may be missed (Stavrakaki and Lunsky, 2007; Davis et al., 2008). Due to the limitations of DSM-5 and ICD-10 in diagnosing mental disorders in people with ID the Diagnostic Manual – Intellectual Disability (DM-ID; Fletcher et al., 2007) was developed in the USA and the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD) was developed in the UK to compliment the ICD-10 (DC-LD; Royal College of Psychiatrists, 2001). The use of an adapted diagnostic system can increase the rates of diagnosing anxiety and other mental disorders in people with ID (Cooper et al., 2007).

Anxiety disorders are estimated to occur in 2–17% people with ID (Reid et al, 2011), and it is generally accepted that rates of anxiety disorders are comparable to the wider population. The prevalence in the wider population for generalized anxiety disorder over a 12-month period is estimated to be 3.1%, and for agoraphobia 0.8% (Kessler et al., 2005), with a lifetime prevalence of 1.7% for agoraphobia in adolescents and adults (American Psychiatric Association, 2013). This compares to a point prevalence of 4% of anxiety disorders in a recent large-scale population study of people with ID in Glasgow, Scotland (Reid et al., 2011). Generalized anxiety disorder was the most common disorder at a rate of 1.7%, followed by agoraphobia at a prevalence of 0.7%. The participants in this study underwent a structured mental health assessment and the diagnosis was made.
using ICD-10 criteria. Another cross-sectional study of those with mild ID using ICD-10 criteria and in those with severe ID using the Diagnostic Assessment for the Severely Handicapped Scale found a prevalence rate of 2.2% for generalized anxiety disorder (Deb et al., 2001).

**History-taking and presentation**

People with ID may present with anxiety symptoms in an atypical way in terms of complaining of physical symptoms or presenting with a form of challenging behavior. It is important to recognize that developmental level may affect the presentation, and to be a disorder the fear or anxiety must be in excess or persist beyond what is expected for that developmental level. A full physical examination is required to identify any conditions that can be wrongly diagnosed as anxiety, such as thyroid disease or caffeine-induced anxiety disorder. For people with mild-to-moderate ID the history should be taken in the same way as for the wider population, which is by direct enquiry of their symptoms. For those with severe ID then additional observations from informants on behavior, such as sleep pattern, irritability, and aggression, is needed to aid diagnosis. There are no recommended investigations except those needed in the ruling out of medical conditions.

**Generalized anxiety disorder** presents as excessive anxiety, worry, and apprehension occurring for most days for six months (DM-ID; Fletcher et al., 2007). The person finds it difficult to control this worry and anxiety. The symptoms present as restlessness or feeling on edge, irritability, mind going blank, being easily fatigued, muscle tension, sleep difficulties, such as problems with getting off to sleep or remaining asleep, or having a restless night. Anxiety disorders also present with somatic or autonomic symptoms such as dry mouth, difficulty swallowing, sweating, shaking, chest pain, headache, fatigue, and urinary frequency. The behavioral response of anxiety is avoidance of situations, for example in those with agoraphobia, to be hypervigilant, to show a startle response, a reduced libido, and problems with concentrating. Anxiety can present as an episode such as panic disorder, be continuous in a generalized anxiety disorder, or in response to a specific stressful event such as moving to a new placement. Generalized anxiety disorder peaks in middle age and declines across the later years of life. There is no evidence to say this pattern is different for people with ID.

**Panic disorder** presents as a discrete period of intense fear or discomfort. In panic disorder, people have symptoms of palpitations in which the heart feels is racing and pounding. The person can be observed to be sweating, trembling, difficulty breathing, and may hyperventilate. The person may complain of chest pain, feeling dizzy, or look gray in color as if going to collapse. They can sometimes have feelings of unreality such as derealization, or being detached from oneself that is depersonalization, or fear that they are going to lose control. Symptoms of depersonalization and derealization may be difficult to detect in those with moderate-to-severe ID (Cooray et al., 2007). The person with ID may complain of a fear of dying or numbness sensations with observed chills or hot flushes. Extreme panic may result in aggression and destructive behavior with lashing out of arms and legs and head banging.

**Phobic anxiety disorders** can present as specific phobias in which the person has persistent fear of specific things, such as blood, having an injection, or animals. The individual may have phobia for a specific situation, such as going in an elevator, enclosed
places, or going on an aeroplane. In agoraphobia, people have anxiety around a place or situation usually outside the home, such as an open market place or traveling in a train, in which escape may be difficult. Agoraphobia can start in childhood but peaks in late adolescence and early adulthood.

Social phobia is fear of failing in social situations or performing in front of other people. Social phobias may happen when people are exposed to unfamiliar people or maybe scrutiny by others. The individual fears being negatively evaluated by others or being rejected or humiliated by others. They may express this fear or anxiety in those with severe ID through tantrums, freezing, or shrinking from social situations with unfamiliar people (Cooray et al., 2007).

Risk factors
Females have higher rates of anxiety disorders than men, and this possibly may be due to women being subjected to more stressful life events. Reports of childhood experiences of sexual and physical abuse are more common in panic disorder than in certain other anxiety disorders. A third of the risk of experiencing generalized anxiety disorder is genetic and overlaps with the risk for negative affectivity (American Psychiatric Association, 2013).

There are a number of reasons why people with ID might be vulnerable to developing anxiety disorders. This could be due people with ID having high rates of physical health problems, being more socially excluded, and being more at risk of experiencing adversity (Hassiotis et al., 2014). In the Glasgow Study, Reid et al. (2011) found not having daytime employment and a recent history of life events were associated with having an anxiety disorder but that previously being a long-term hospital resident was not linked with having an anxiety disorder in adults with ID. A life event such as a bereavement increases the risk for both anxiety and depressive symptoms in people with ID (Dodd et al., 2005; see also Chapter 9).

Some genetic conditions associated with ID such as tuberose sclerosis and Williams syndrome report anxiety to be common (Paschos et al., 2014). Anxiety is reported to occur frequently in people with autism and ID (Helverschou and Martinsen, 2011). Structural parts of the brain system, such as the amygdala and hippocampus, have been implicated in the development of the anxiety disorders, as have been neurotransmitters, such as serotonin and gamma-aminobutyric acid (GABA), which are also implicated in the brains of those with autism spectrum disorders (Romanczyk et al., 2006).

Diagnostic tools
There are a number of tools and instruments for identifying and diagnosing individuals with anxiety disorders in people with ID (Moss and Hurley, 2014).

These can include instruments that are based on interview with an informant to obtain the history, or tools can be used directly with the individual to elicit self-report symptoms.

Informant-based tools
The Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD; Moss et al., 1993) is a semi-structured interview of an informant that produces a psychiatric diagnosis using ICD-10 criteria. There are smaller, related measures, such as
the Mini PAS-ADD and the PAS-ADD Checklist. The PAS-ADD Checklist (Moss et al., 1998) serves as a screening tool to identify people with depressive or anxiety symptoms. The Mini PAS-ADD contains a subscale for anxiety and can be used by people who are not mental health specialists (Prosser et al., 1998).

The Diagnostic Assessment Schedule for the Severely Handicapped–II (DASH-II) was developed for those with severe and profound ID (Matson, 1995). The DASH-II has demonstrated good inter-rater reliability and validity and contains 13 subscales, which includes anxiety.

The Developmental Behavior Checklist (DBC) was initially developed for use with children and adolescents (Einfeld and Tonge, 2002), but now has an adult version (DBC-A) with 107 items. The DBC-A is designed to assess behavioral and emotional problems of adults with ID. This instrument has been widely used and has six subscales including anxiety.

Another tool with reported psychometric properties that has been used to assess anxiety is the Psychopathology Inventory for Mentally Retarded Adults (PIMRA; Aman et al., 1986). This is used to support making a diagnosis and, although it is able to recognize symptoms, it may overestimate rates of the disorder (Gustafsson and Sonnander, 2005). An earlier Swedish study of those with ID in contact with mental health services rates reported a prevalence rate of anxiety of 26.8% using the PIMRA (Gustafsson and Sonnander, 2004).

**Self-report tools**

The Glasgow Anxiety Scale for people with ID (GAS-ID; Mindham and Espie, 2003) is one of the only anxiety scales developed specifically for people with ID. It consists of 27 items broken down into 3 subscales: worries, physiology, and phobias. The GAS-ID has demonstrated good reliability and validity and is easy to administer in clinical practice.

The Fear Survey of adults with Mental Retardation (FSAMR) is an instrument designed to measure current fears that are specific to people with ID given their experience. The FSAMR is administered verbally to the individual (Ramirez and Lukenbill, 2007) and includes 73 fear items from which fear frequency and intensity scores are calculated.

Other tools include the Beck Depression Inventory (BDI), which is widely used in clinical practice in the wider population and has been modified to be used with people with intellectual disability (Lindsey and Skene, 2007). The Hospital Anxiety and Depression Scale (HADS) has been used in assessing adults with ID, but needs adaptation of wording with further evaluation of the psychometric properties (Dagnan et al., 2008).

**Management and treatment**

The key first task is to undertake a multidisciplinary assessment. It is important not only to assess the presenting symptoms and behaviors but also how the person is functioning at home or in the day-service or at work and to review their current medication, including any evidence of substance misuse. It is important to obtain a history of current social supports, including their living situation, family relationships, and the level of support they are receiving. In addition, any other comorbid conditions that occur, such
as depression or dementia, need to be identified, as do any physical health problems. When anxiety is comorbid with depression then the first priority should be to treat the depression. Often people with generalized anxiety disorder have sleep disturbance, and it is important to advise them around regular sleep and wake times, taking physical exercise, and ensuring proper environment for sleep. Substance misuse needs to be assessed as a possible comorbid condition and within DSM-5 substance/medication-induced anxiety disorder is recognized as a specific condition. Anxiety disorders may occur in the context of autism spectrum disorders in adults with ID, but there are challenges in making the diagnosis (Hagopian and Jennett, 2008), and the physiological symptoms of anxiety may be more difficult to recognize in those with autism (Helverschou and Martinsen, 2011).

**Medication**

See also Chapter 13.

The first choice of antidepressant for anxiety disorders will often be a selective serotonin reuptake inhibitor (SSRI; for example, sertraline), and if the person's anxiety does not respond to one antidepressant then this can be changed to a different SSRI antidepressant, or one can be used from a different class of antidepressants, such as serotonin noradrenaline reuptake inhibitors (SNRI), as advised in guidelines from the UK’s National Collaborating Centre for Mental Health (2011). There is little evidence for the use of antipsychotics used on their own or in combination with an antidepressant for anxiety disorders (Pies, 2009). Benzodiazepines or antipsychotic drugs should not be offered for the treatment of anxiety disorders in a primary care setting but only be prescribed with specialist advice. The prescriber needs to show caution with anxiolytics in adults with ID as they may cause paradoxical excitement and disinhibition (King, 2007). Pregabalin can also be offered if the person cannot tolerate an antidepressant. The patient may not respond to a psychological intervention alone, so combining an antidepressant with cognitive-behavioral therapy (CBT) is recommended in national guidance as described below.

The National Institute of Clinical Excellence (NICE) guidelines from the Department of Health in England covering general anxiety disorder recommends a stepped-care model (National Institute of Clinical Excellence, 2011). The stepped-care model considers anxiety in increasing intensity in each of the steps, outlining the appropriate treatment, treatment location and support needed, and how services are organized to deliver the most effective interventions according to individual clinical presentation. Intervention is designed to “relieve symptoms, restore function and prevent relapse” (National Institute of Clinical Excellence, 2011) by targeting the triggers and factors that maintains the condition. The guidelines state that when assessing people with moderate to severe ID clinicians need to consult with the relevant specialist.

It is now generally accepted that people with ID can benefit from psychological treatments, although some still cast aspersions as to its effectiveness in this group (Hassiotis et al, 2011). Adaptation of CBT may be required on an individual basis depending on the individual’s level of ability with regards to language, communication, memory, and planning. For those with mild ID the same interventions apply as for the general population but may need to take into account the delivery and duration of the intervention (see also Chapter 15). In the early steps of treatment, NICE guidelines recommend the use of interventions, such as individual guided self-help (GSH) or
psychoeducational groups. All these treatments are based on the principles of CBT but involve minimal therapist contact. For severe anxiety, the options are individual high-intensity psychological interventions, such as CBT, or applied relaxation and/or drug treatment.

Improving Access to Psychological Therapies (IAPTs) teams have been created in the UK to provide psychological assessment and management of anxiety disorders. The reality is, however, that many IAPTs services still do not take referrals of people with ID (Burke 2014), even though UK policy advocates equal access to mental health services for this group. In some areas, specialist IAPTs teams for individuals with ID have been developed (Improving Access to Psychological Therapies teams, 2009).

There are a number of psychological interventions available to treat anxiety and, according to the severity of individual clinical presentations, psychological interventions are split into high- and low-intensity interventions. Low-intensity interventions are embedded in the stepped-care approach and are used in cases of mild to moderate anxiety. This type of intervention is delivered usually within primary care settings, but can be seen in use in secondary and tertiary settings where anxiety coexists with other mental illness. Low-intensity interventions normally use cognitive-behavioral therapy and rely on helping the person understand their condition and to teach strategies aimed at self-management. This is in the form of non-facilitated help where the person is directed to appropriate self-help materials according to their needs. This differs from GSH, which is facilitated by a healthcare professional who guides, monitors and supports the person in treatment. The systematic review of non-facilitated help reported a “significant moderate effect” size for anxiety scores and rates of relapse when compared to non-active controls for generalized anxiety disorder (National Institute of Clinical Excellence, 2011). The NICE review on GSH reported on four RCTs with some improvement in the treatment groups, but the evidence was of insufficient quality to draw any inferences from (National Institute of Clinical Excellence, 2011). However, there is no evidence reported in these reviews relating to individuals with ID.

High-intensity interventions are used to treat moderate to severe forms of anxiety, including phobias and generalized anxiety disorder, and for those who have not responded to treatment using low-intensity interventions. High-intensity interventions include applied relaxation, where the person manages their anxiety whilst exposed to the situation which triggers anxiety, and a number of psychotherapeutic approaches. Of these, CBT is the most common and, working with a therapist, the individual works on set goals that are informed by a shared formulation relating to the presented problem. The NICE systematic review of 12 RCTs reported significant improvements in response and remission rates (indicated by a 75% response rate using a validated anxiety measure) in treating anxiety for those receiving CBT compared to waiting-list controls. There is not the same strength of evidence for the use of CBT for anxiety disorders in populations of people with ID. The best evidence evaluating psychological interventions in populations of people with ID has come from systematic and general reviews (Hatton, 2002; Hassiotis and Hall, 2008; Brown et al., 2011), but with little evidence on how interventions work and are delivered (Wilner, 2005). Hassiotis et al. (2011) has developed a manual of CBT for individuals with ID that covers the treatment of common mental disorders in an attempt to define and standardize what is a modified approach. This manual is freely available at www.ucl.ac.uk/psychiatry/cbt. There is less evidence on the clinical
effectiveness of low-level psychological interventions in people with ID and what is available is mostly anecdotal.

In recent years there has been an increasing interest in the use of GSH (Chaplin et al., 2012, 2013; Chester et al., 2013). This has included publication of the SAINT, which is the first GSH manual and resources publicly available to have been developed specifically for people with ID (Chaplin et al., 2014). Single-case experimental design (SCED) in four phases (A–B–A–B) has been used to trial the SAINT. Twelve participants completed all 4 phases with 9 (75%) demonstrating decreased symptom scores in both intervention phases for depression and 3 (25%) for anxiety. Two of the participants and a control replicated the SCED over a longer period with the intention to see if positive results could be replicated. All 3 of the participants showed a decrease in anxiety symptoms in both intervention phases and 2 (66.6%) had decreased depression scores. Overall, those with a history of affective disorders \( (N = 8) \) showed the most consistent improvement (Chaplin, 2014).

**Conclusions**

It appears that individuals with ID are not evidently at increased risk of anxiety disorders compared to the general population. However, the limited studies have reported variable prevalence rates depending on diagnostic system used and the population under study. When anxiety symptoms occur in people with ID they are often not recognized by health professionals to be a condition that needs further assessment and treatment (Hassiotis et al., 2014). The NICE guidelines (National Institute of Clinical Excellence, 2011) from the UK provide evidence of the stepped-care approach to the assessment and treatment of anxiety disorders. However, there is limited evidence of the effectiveness of these approaches for individuals with ID who experience barriers when trying to access the psychological treatments available. There are still those that question the ability of people with ID to engage in such treatments, but in the last few years resources for both CBT and GSH specifically developed for people with ID have become available (Hassiotis et al., 2011; Chaplin et al., 2014). There needs to be a focus on supporting people with ID and carers to recognize when they have anxiety, so they can access interventions with emerging evidence of effectiveness (Hassiotis et al., 2011) and have more control over their mental and physical well-being (Burke, 2014; Taggart and Cousins, 2014). Future research is needed on the application of these adapted treatment manuals in different clinical settings with evaluation of their effectiveness in combination with psychopharmacological treatments in adults with ID.

**Key summary points**

- Anxiety disorders are estimated to occur in 2–17% of adults with ID, and these rates are comparable to the wider population.
- Life events, such as bereavement, increase the risk of anxiety disorders in adults with ID.
- There are an increasing number of self-report tools and measures that have been developed specifically for the diagnosis of anxiety disorders in adults with ID.
- There are treatments that have been developed in recent years for adults with ID and anxiety disorders including manualized approaches to CBT and GSH.
References


