

Chapter 3

Psychopathology in Older Age



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Introduction

Recent decades have seen life expectancy increase for those with intellectual and developmental disabilities (IDD). Advances in medical and social care have improved longevity, however with this increased life span comes greater exposure to age related conditions [1–3]. The prevalence of health issues and multimorbidity increases with age in both the general and IDD, populations, those with IDD showing both a higher prevalence overall but also at a younger age [4, 5].

It is estimated that by 2050, 22% of the global population will be aged 60 or over, therefore the burden of care is expected to reach unprecedented levels [6]. The World Health Organisation reports prevalence figures for depression, dementia and anxiety in older adults of 7%, 5% and 3.8% respectively. Overall, approximately 15% of

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older adults have a diagnosis of a mental health disorder [6]. Direct comparisons between the general population and those with IDD are difficult given the differences in demographics, life experience and diagnostic issues, however studies suggest a higher prevalence of mental ill-health in older persons with IDD, with reference to the general population [7–9]. The higher prevalence of mental health disorders in those with IDD has been attributed to many factors including; genetics, life events and level of disability [10]. Standard assessment tools used in the general population are often not applicable or valid for use in an IDD setting. Assessing for mental ill-health can be more challenging in those with IDD. The development of specific guides have aided the diagnostician in distinguishing a person's disability from their psychopathology [10, 11]. In generic mental health services a person with IDD, may require extra supports in consideration of their particular needs [12]. The guidance from the National Institute for Health and Care Excellence (NICE) (Department of Health, UK) on Mental Health Problems in People with Learning Disabilities [13] sets out a baseline assessment tool for use in these situations. Bertelli and colleagues [14] considered the diagnostic issues encountered when assessing persons with IDD, for mental health disorders. In their review they identified key considerations; identification of symptoms, behavioural equivalences, diagnostic criteria, setting, source of information, screening and diagnostic tools. Ultimately, they recommended an individualised approach to diagnosis given the heterogeneity of the group but made no specific recommendations with regard to ageing.

Diagnosing mental health disorders in people with IDD, poses a challenge. Recognised clusters of symptoms, which when taken together in the general population suggests a diagnosis, may present differently in those with IDD [14]. Eliciting psychopathology is further complicated as many general assessment tools are of limited use in those with compromised cognitive function.

In this chapter we will investigate the psychopathology of common mental health disorders as seen in the context of older adults with IDD. In addition, the concept of psychological wellbeing will be discussed; this aspect of health rarely explored in IDD literature.

Mental Health Disorders

Anxiety Disorders

Anxiety disorders include disorders that share features of excessive fear and anxiety and related behavioural disturbances. Fear is the emotional response to real or perceived imminent threat. In DSM 5, 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 [15]. The focus of anticipated danger may be internal or external [16].

In the general population, anxiety is among the most prevalent mental health disorder [17]. The prevalence of anxiety disorders in English speaking adults is high

with 12 month estimates of 18.1% [18]. In the general population the conservative estimates for the prevalence of anxiety disorders in older people varies between 0.7% and 5.9% [19]. Individuals with IDD have a higher risk for anxiety disorders [20]. The longitudinal Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) study from Ireland, using the Glasgow Anxiety Scale (GAS-LD) [21] reported that 15.1% of 291 older adult participants scored above the cut off for anxiety [9]. A large Dutch study assessed over 900 older adults with IDD for anxiety and depressive symptoms [22]. The authors reported that 16.3% of the study cohort scored positively for increased anxiety symptoms; this increase being significantly associated with female gender and mild/borderline disability.

People with IDD are diagnosed with the same diversity of anxiety disorders that have been documented in the general population [23, 24]. There are higher rates of anxiety disorders in the older IDD population than in the younger age groups [25, 26]. Depressive symptoms are frequently associated with anxiety making it challenging to determine which disorder is the primary diagnosis [27, 28]. Anxiety disorders with in IDD and the ageing IDD population can be difficult to diagnose due the numerous comorbidities such as mood disorders [29], other psychiatric disorders, behavioural presentation, physical illnesses and medical disorders.

Anxiety disorders are probably under-diagnosed in people with IDD [30] because of their limited ability to self-report anxiety, worry or fears [31]. The sources of information are usually carers, family and some of who may not be familiar with the individual and their behaviour, therefore leading to untreated anxiety. The diagnostic criteria for anxiety disorders in ICD-10 [32] and DSM-5 [15] are limited in people with IDD as both classifications rely heavily on the individual's subjective description of symptoms of anxiety. Therefore, the person would need to have adequate cognitive function and communication ability to describe their symptoms, both of which are probably compromised in people with IDD.

Making a diagnosis of anxiety disorders in this population is problematic, especially in those with moderate to severe disability. The literature in this population is limited. The Diagnostic Manual-Intellectual Disability [33] and the Diagnostic Criteria for Psychiatric Disorders for the Use with Adults with Learning Disabilities/Mental Retardation [11] were developed with proposed adaptations to both the DSM-5 and ICD-10 respectively to be used as guidelines/diagnostic criteria to facilitate making diagnoses of mental disorders in individuals with IDD. The use of an adapted diagnostic classification can increase the rates of diagnosing anxiety and other mental disorders in people with IDD [34].

Depression

Depression occurs more commonly in adults with IDD than other people without IDD [7, 9, 27]. Depression and anxiety may co-exist and/or perhaps share similar but overlapping developmental pathways. Depression is more challenging to

diagnose in individuals with communication difficulties and greater cognitive impairment due to the reliance of carer information [35]. Diagnosing depression in people in IDD may be complicated by an individual's medical history and side effects of medications that can obscure the clinical presentation [36, 37]. In DSM-5 [15] there are a few key developments:

1. Depressive disorders are now considered separately from bipolar and related disorders.
2. The additions of a new diagnostic category—disruptive mood dysregulation disorder.
3. When diagnosing major depressive episode it is no longer required to exclude bereavement

Two recent European studies reported data on depressive symptomatology in IDD cohorts. The IDS-TILDA study [9] reported that 10% of their study sample scored above the cut off of depressive symptoms using the Glasgow Depression Scale (GDS-ID) [38]. A higher prevalence of depressive symptomatology was presented by the Dutch Healthy Ageing and Intellectual Disabilities study group. They reported that 16.8% of their sample had increased depressive symptoms, this being associated with increasing age [22]. See Chap. 5 for a detailed review of depression in adults and ageing individuals with IDD.

Mania/Bipolar Disorder

First presentation of mania in later life in the general population is rare and usually part of a recurrent mood disorder that the individual has had previously in their life [39]. Following a literature review of the prevalence of psychiatric disorders in individuals with IDD, mania and bipolar disorders were rarely categorised [40]. A point prevalence of 2.5% in people with IDD has been reported [41] with a bipolar disorder being more likely to be diagnosed in persons with IDD, and more likely to be diagnosed in moderate to profound disability than those with mild disability [42]. However, a literature review on prevalence rates of mania and bipolar disorders in IDD suggest conflicting results, limited generalisability and lack of consensus.

Bipolar disorders may be missed in people with IDD due to the difference in their symptoms/clinical presentation to those in the general population. One reason is that the varying developmental status of persons with IDD may contribute to the differences in the clinical phenomenology observed. There are also numerous physical stressors such as delirium or the side effects of medication that can induce manic symptoms [43, 44]. A full physical assessment, including brain imaging, is required to rule out any underlying but modifiable cause.

An accurate assessment of psychopathology in IDD is challenging for various reasons, such as limited data and research in IDD and differences in clinical symptom presentation in IDD that is not captured in ICD-10 [32] or DSM-5 [15]. ICD-11 [45] is due to replace ICD-10 in 2022 when the complete manual will be published.

The introduction of a Bipolar II disorder classification will require the noted hypomania to be characterised by not only the presence of mood elation or irritability but also an increase in activity [46, 47].

Schizophrenia

Schizophrenia and psychotic disorders are a group of disorders characterised by common symptoms below [48]:

- Hallucinations
- Delusions
- Disorganised thinking (speech)
- Disorganised or abnormal motor behaviours
- Negative symptoms (deficits of normal emotional responses or thought process)

In the IDD population it is diagnostically important to distinguish between psychotic symptoms and the general presentation of IDD. Non affective psychotic disorders occur more commonly in adults with IDD than in other adults in spite of the diagnostic difficulties in IDD [11]. Limited verbal communication, varying presentation, aggressive behaviour, negative symptoms and limited or lack of insight can make diagnosing these groups of disorders in people with IDD challenging. In the older adults with IDD making a diagnosis of these disorders is further complicated by comorbid medical disorders i.e. delirium, dementia, infections and hearing and visual impairments.

A Scottish epidemiological study of adults with IDD [41] found the point prevalence of all psychotic disorders varied between 2.6% and 4.4% depending on the diagnostic method. When using the DSM-IV-TR diagnostic criteria for schizophrenia to make the diagnosis, the point prevalence was 3.4%. Other researchers [49] looked at two cohorts with IDD; aged 38–43 and aged 44–58 using ICD-9 and found 5.2% of the 44–58 age group with IDD developed schizophrenia compared to 4.5% of the 38–43 aged cohort.

The diagnosis of schizophrenia and psychotic disorders with regard to age has been noted in the literature. The main issue is of the validity of a diagnosis of schizophrenia in older adults, and the possibility of an alternative pathophysiological process, such as neurodegeneration, underlying the illness presentation [50]. Although the typical age of onset of schizophrenia is in early adulthood, a substantial minority of patients, 20% in some studies [51] have onset of first episode after the age of 40 years. Debate about the significance of this later onset from a neurobiological perspective continues and generates changes on diagnosis criteria across DSM editions. For instance, in the DSM-III, new onset in a patient over the age of 45 years disallowed a diagnosis of schizophrenia, which was repealed in the ensuing DSM-III-R where the diagnosis could be made with the addition of a “late-onset” specifier [50]. The DSM-IV [52] and DSM-5 [15] do not contain a separate diagnosis for late onset schizophrenia.

The DSM-5 states that “late-onset cases can meet the diagnostic criteria for schizophrenia but it is not yet clear whether this is the same condition as schizophrenia diagnosed prior to mid-life” [15]. It refers to late-onset as being after age 40 years, but somewhat confusingly contrasts late-onset with onset ‘prior to mid-life’ (i.e. before age 55 years), leaving a 15-year period of uncertainty.

The International Late-onset Schizophrenia Group [53] published an international consensus statement. The authors concluded that late-onset schizophrenia (onset after age 40 years) appeared to bear a reasonably close resemblance to schizophrenia of earlier onset, whereas a very late-onset group (onset after age 60 years) was better classified as having a schizophrenia-like psychosis based on a convergence of clinical, epidemiological, neuroimaging and neuropsychological data, although there was no consensus on the age cut-offs for this distinction. Howard’s description of very late onset patients (after 60 years) stressed the high prevalence of sensory deficits especially long standing deafness, which is prevalent in the IDD population. Also when onset of psychosis is after age 60 years, formal thought disorder and negative symptoms are very rare but they are more likely to present with visual, tactile, olfactory hallucinations, persecutory delusions, third person, running commentary and accusatory and abusive auditory hallucinations.

The diagnosis of schizophrenia in adults with moderate and severe IDD continues to be problematic. The Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD) [11] states that for non-affective psychotic disorders it is not usually appropriate or valid to subclassify the disorders to the extent of ICD-10, as delusions and hallucinations are difficult to elicit in adults with IDD. In summary, a diagnosis of schizophrenia is made with a comprehensive assessment by an expert in the assessment and diagnosis of people with IDD and mental illness.

Dementia

Dementia is more common in people with Down syndrome (DS) than in the general population mainly due to the presence of dementia of Alzheimer’s disease (DAT). A recent prospective longitudinal study reported that 97.4% of people with DS received a diagnosis of dementia [54]. Although there has been much research on the diagnosis and management of dementia in people with DS [55, 56], there has been less research on the psychopathology and the behavioural and psychological symptoms of dementia (BPSD) [57]. Dementia may mimic several other psychiatric disorders and the initial stages of the disease may present with depression, psychosis, behavioural changes or anxiety and it may be difficult to distinguish whether the illness represents a prodromal phase or a psychiatric or other illness [58]. Other researchers [59] have drawn attention to a frontal lobe presentation with apathy, loss of interest and change in personality presenting before cognitive decline.

Research on early symptoms of both cognitive and behavioural manifestations in a systematic review was recently published [58]. Whereas amnesic symptoms are

predominant in the general population, a more heterogenous presentation is noted in those with Down syndrome. In this cohort, the Behavioural and Psychological Symptoms of Dementia (BPSD) with particular difficulties in executive function appear early in the course of disease progression. Researchers [60] have looked at the association between BPSD and dementia in 224 adults over 45 years with Down syndrome and found associations between increased BPSD directed towards others and development of dementia as well as symptoms of sadness and anxiety. Changes such as restlessness aggression, repetitive speech and being uncooperative were reported in preclinical and early stages of DAT [61]. Emotional lability, lack of concern for others, stubbornness, disinhibition and impulsivity have been reported in people with DS prior to a diagnosis of dementia [62].

Several assessment procedures draw attention to differential diagnoses such as depression, grief and abuse as well as medical issues such as hypothyroidism, deafness, cataracts and sleep apnoea to name a few common disorders [63, 64]. For many people with DS, these illnesses may be comorbid, i.e., it is possible to have cataracts, hypothyroidism and dementia co-existing as a function of age. These lists, however, should not be prescriptively followed rather these conditions should be adequately treated before making a diagnosis of dementia. As dementia is a progressive illness, over time changes on cognitive tests and memory deterioration will advance even if mood and behaviour improve when adequately treated.

Particularly following a bereavement, the clinical picture of possible dementia can be an unclear one. Features of depression and anxiety can be present along with cognitive symptoms such as memory loss and poor attention span. Recent research [57] on BPSD and the development of a scale BPSD-DS (Behavioural and Psychological Symptoms of Dementia in Down syndrome) an informant interview administered to carers of 281 people with DS has shown an association with anxiety, depression, behavioural changes and the onset of dementia in people with DS. Since depression is common in people with DS a cautious approach to diagnosis is advised with treatment of the presenting issue and reassessment after treatment. Sleep wake cycle disorder and appetite changes may be seen as part of the prodromal phase of dementia and may exist by themselves or associated with other symptoms.

Due to the complicated neurochemistry of dementia and fluctuating levels of neurotransmitters there may be altered affective states (e.g., low mood, anxiety, irritability) and disrupted sleep-wake cycles as common features. There is often understandable anxiety around the diagnosis for the individual connected to having a life-changing diagnosis, loss of independence and increased reliance on carers for everyday tasks. The distress of the diagnosis and the implications for the individual and their family needs careful management and support as many people will be aware of friends and colleagues who have had the same illness.

Hallucinations and delusions may be a presenting feature of the illness and may be auditory, visual, tactile, olfactory and other [65]. Lewy Body variant should be considered particularly when associated with fluctuating cognitive symptoms, hallucinations and extrapyramidal features [66]. A recent study [57] did not find that hallucinations and delusions differentiated between people with DS with or without

dementia, however to describe a hallucination and delusion requires intact language ability and it may be difficult to elucidate these symptoms as dementia progresses. People with DS can be very sensitive to the side effects of antipsychotic medication, however the distress caused by the psychosis can be such that a balance has to be found between alleviating distress and side-effects of medication.

Behavioural changes that do not meet criteria for either a mood disorder or psychosis may also occur and may be difficult to treat due to the adverse side effects of medication. For instance, the increased risk of cerebrovascular accident with antipsychotics and the increased risk of falls and aspiration with any sedative medication. Many consensus guidelines do not advocate use outside stringent guidelines. Behaviours such as prolonged screaming, crying, self-injurious behaviour and verbal and physical aggression may not fit into a neat classification, but such symptoms indicate distress of either an emotional or physical nature. As with any indication of distress, infection, pain and discomfort, loss and loneliness and communication issues should be looked for, a behavioural analysis performed, and a full multidisciplinary approach to management adopted.

Dementia is a progressive degenerative disorder, psychiatric symptoms usually decrease and disappear in the late stages and there is a need for a palliative care approach at the end of life. In the vast majority of people with late stage dementia this will be a peaceful time, however for some people there can be emotional distress and anxiety and a collaborative approach with the palliative care team is advocated.

Positive Mental Health and Wellness

It has been noted that there is a higher prevalence of psychiatric conditions in older people with IDD. Whilst biological factors may provide an explanation for some mental illness, the reasons are diverse and psycho-social factors play an important and modifiable part [67]. Thus, for example, negative life experiences and rejection may be implicated in the development of mental illness [25, 68]. Furthermore, social isolation can lead to the absence of the social networks which may provide protective support [69]. This is in the face of significant adverse life events which can result in generalised symptoms of stress and depression [70]. These represent factors which may be addressed through the promotion of self-management and mentally healthy lifestyles.

People with IDD are more likely to experience more negative and multiple life events than those in the general population [71]. In Wave 3 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), 63% of respondents reported having experienced more than one such event in the previous 12 months, with nearly 20% reporting four or more [9]. The vast majority of these related to social changes (staff mobility, bereavements and new residents), and were associated with significant stress and mental ill health [68, 70].

The experience of stress and anxiety can influence an individual's vitality resulting in reduced energy. Whilst *vitality* is a pre-requisite for physical activity, the more encompassing *subjective vitality* may be a more holistic indicator of well-being, focusing on life meaning and energy for living. Indeed, it has been described as a phenomenological concept with a subjective 'sense of aliveness and energy' [72] and is suggested to have correlations with positive mental and bodily health [73]. Loss of such vitality often manifests as fatigue which, in turn, can result in reduced mobility, diminishing social contact, and impaired mental wellbeing [74]. Impaired vitality has been reported to be closely associated with depression in older people [75].

The Energy and Vitality Index (EVI) [76] was used to assess vitality in older people with an IDD [8]. It was noted that the scores from this cohort were similar to the results from a large scale study of the general population [77]. Ageing had little impact on the EVI scores with a slight decrease reported in older age groups.

Responses to psychiatric illness in the general population have increasingly become focused on individualised recovery-oriented approaches, which centre on the restoration of meaning in life, hope for the future and retrieval/reconstruction of self [78–80]. These may be achieved by re-establishing a locus of control (empowerment) in the person and thus supporting empowerment, in a supportive and connected context [80]. Such approaches have been somewhat radical requiring significant education and training of mental health practitioners, people with experience of mental health concerns and family members, and evidence has indicated that they are leading to positive change in people's lives [81]. This is particularly pertinent to people with IDD, many of whom have lived with the reality and stigma of mental illness and poor mental health throughout their lives and, for whom, access to recovery-oriented mental health services may have been limited [82]. The development of such approaches within IDD service provision may play an important part in addressing some part of the prevailing mental health problems that are so evident in the IDD population.

Conclusion

Successful ageing is a relatively new goal for individuals with IDD. Unfortunately, with increased longevity, more age-related morbidity has been reported. While the same mental health issues occur in those with IDD as in the general population; the presentation, associations and prevalence of these disorders differ, the most notable being the emergence of dementia in those with DS.

Diagnosticians should be aware of challenges which may present when engaging with people with IDD. Communication difficulties for the individual may interfere with their ability to verbalise symptoms, this results in placing more weight on biological features or collateral histories. Sensory loss can compound communication problems, and this may worsen with age. Education of carers to pick up on early signs of change such as altered adaptive function, increased irritability, sleep

disturbance or a change from baseline of the person they support should prompt further enquiry. Careful history taking which is mindful of the complex interplay of physical, environmental, behavioural and social factors will aid the clinician in reaching an accurate diagnosis and allow the formulation of a bespoke treatment plan.

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