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Beyond a diagnosis: The experience of depression among clinically-referred adolescents

Nick Midgley [a, b, *], Sally Parkinson [a], Josh Holmes [a], Emily Stapley [b, a], Virginia Eatough [c], Mary Target [b]

[a] Anna Freud Centre, 12 Maresfield Gardens, London, NW3 5SU, UK
[b] Research Dept of Clinical, Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB, UK
[c] Department of Psychological Sciences, Birkbeck College, University of London, Malet Street, London, WC1E 7HX, UK

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ABSTRACT

Policy-makers have identified an urgent need to improve our ability to detect and diagnose depression in adolescents. This study aims to explore the lived experience of depression in clinically referred adolescents. 77 adolescents, aged between 11 and 17 with moderate to severe depression, were interviewed as part of a randomised controlled trial, using the *Expectations of Therapy Interview*. Data were analysed qualitatively using framework analysis, with a focus on how the adolescents spoke about their depression. The study identified five themes: 1) Misery, despair and tears; 2) Anger and violence towards self and others; 3) A bleak view of everything; 4) Isolation and cutting off from the world; and 5) The impact on education. Researchers and policy-makers need to develop an understanding of depression grounded in the experiences of adolescents to improve detection and diagnosis of depression.

'I just feel lonely, like nobody understands what I'm going through'

Steven, 17.

Depression in children and adolescents is recognised as 'a broad and heterogeneous diagnostic grouping' (NICE, 2013), and policy makers in both Europe and the US have identified an urgent need to improve our ability to detect and diagnose, both among professionals in primary care and community settings, as well as by mental health professionals working in specialist child and adolescent mental health services (CAMHS).

Studies have demonstrated that most cases of depression in adolescence go undetected (Kessler, Avenevoli, & Ries Merikangas, 2001; Martinez, Reynolds, & Howe, 2006), leading policy makers to put an increasing focus on detection. For example, the National Institute for Health and Care Excellence (NICE), which provides guidance, quality standards and information services for public health and social care in the UK, identified the need for greater detection as early as 2005 (NICE, 2005), yet there is little evidence to date of significant improvements. This may be because of issues such as stigma regarding mental health, poor parent-child communication, and the lack of systematic early identification programmes or routine use of

* Corresponding author. Anna Freud Centre, 12 Maresfield Gardens, London, NW3 5SU, UK. Tel.: +44 20 7794 2313.
E-mail address: Nick.Midgley@annafreud.org (N. Midgley).

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screening tools within services (Rey, Grayson, Mojarrad, & Walter, 2002; Williams, O'Connor, Eder, & Whitlock, 2009). In addition, warning signs of depression, such as persistent change in mood, loss of interest and enjoyment in activities and rebellious behaviour, can sometimes be dismissed as 'teenage behaviour' (Dundon, 2006).

How depression should be understood in the context of 'normal' adolescent development has been a topic of debate for many years. Until the 1970s, episodes of depressive crisis were considered a usual part of adolescent development, and there was no recognised psychiatric diagnosis of child or adolescent depression in early versions of the Diagnostic and Statistical Manual (DSM). This changed with the publication of DSM-III in 1980 (APA, 1980), at a time when developmental psychologists such as Michael Rutter (1980) were establishing that most adolescents' lives were *not* characterised by the 'storm and stress' that some earlier theorists, such as Stanley Hall (1904), had assumed. Whilst recognising that the process of identity development in adolescence may well include typical feelings of self-doubt, loneliness and sadness, recent empirical studies have suggested that only about 2.8% of children under the age of 13, and 5.6% of those between 13 and 18, meet diagnostic criteria for a depressive disorder (Costello, Erkanli, & Angold, 2006) – with depression twice as common among girls than boys after the age of 13 (Birmaher et al., 2007).

According to the 5th edition of DSM (APA, 2013), a diagnosis of major depressive disorder in young people depends on signs of a pervasive shift towards sadness, irritability, loss of interest or loss of pleasure over a minimum of a two week period. To meet diagnostic threshold, these symptoms need to be markedly different from how the young person usually is, and to be leading to clear impairment in the young person's life. There is also an increasing recognition that children and adolescents suffering from depression are also likely to have a range of other difficulties, with levels of co-morbidity rated as between 50 and 80% (Birmaher et al., 2007). Depressed adolescents are most likely to also suffer from some form of anxiety disorder, but may also present with disruptive disorders, substance abuse and emerging personality disorder. Although there are relatively high rates of recovery from depressive episodes (which last on average between 7 and 9 months in young people), there is also a very high level of relapse, with as many as 70% of young people who experience depression having a further episode of depression within 5 years (Richmond & Rosen, 2005). The long-term consequences of depression in adolescence are also striking, with an increased risk of self-harm, suicide, depression, physical illness, substance misuse, and interpersonal problems in adulthood (Weissman et al., 1999).

Despite our increasing knowledge about the prevalence and course of adolescent depression, it is widely recognised that the nature of adolescent depression is still not sufficiently understood, with the psychiatric concept of 'depressive disorders' covering a heterogeneous range of difficulties. Young people suffering from depression themselves can often feel that no one understands them, as illustrated by the quotation at the start of this paper. Lachal et al. (2012) note that the Diagnostic and Statistical Manual (DSM) criteria for depression do not make reference to subjective experience, despite this being central to depression. We therefore need to develop an understanding of depression that is grounded in young people's experiences; without this, there is a danger that it will continue to be under-diagnosed, misdiagnosed or left untreated (Cicchetti & Toth, 1998; Lachal et al., 2012).

Due to the relatively recent recognition of child and adolescent depression as a psychiatric phenomenon, Studies only began to explore the idea that features of adolescent depression may differ from adult depression since the 1980's (Crowe, Ward, Dunnachie, & Roberts, 2006). On the basis of a series of studies, DSM-IV-TR concluded that the core symptoms of a major depressive episode are the same for children and adolescents, whilst recognising that certain symptoms may be more or less prominent at different ages (American Psychiatric Association, 2000). Most significantly, 'irritability' has been identified since DSM-III as one of the core characteristics of depression in adolescence, alongside low mood (American Psychiatric Association, 1980). A 2009 review article in *Psychiatry* concluded that depressed adolescents are 'less likely than adults to explicitly complain of feeling depressed and unlikely to exhibit melancholic symptoms', whilst being 'more likely than adults to exhibit mood lability or irritability and display indirect or behavioural manifestations of disturbed mood' (Cook, Peterson, & Sheldon, 2009, p.19).

Despite these conclusions, a number of questions remain unanswered about the nature of depression in adolescence. Crowe and colleagues, in a study from New Zealand, concluded that both the manifestation and the prominence of symptoms may differ between adolescents and adults, with irritability and decreased concentration being the most frequently reported symptoms in adolescents, followed by social withdrawal, fatigue, psychomotor retardation, depressed mood, hopelessness and helplessness, and insomnia (Crowe et al., 2006). Among characteristics not included within the diagnostic features of depression, social withdrawal was the most common symptom among boys, and loneliness among girls. The finding that irritability was more often reported than low mood confirmed the findings of earlier studies (e.g. Mueller & Orvaschel, 1997), and it was noted that the significance of irritability increased with the severity of depression. Yet, despite the apparent centrality of irritability to adolescent depression, Stringaris and colleagues noted that empirical data on the prevalence and correlates of irritability in depressed youth is lacking, and little is known about whether irritability is associated with outcomes (Stringaris, Maughan, Copeland, Costello, & Angold, 2013). Irritability and isolation seem to be important aspects the nature of depression in adolescents. Other issues that seem most pertinent for adolescents include problems with sleep, difficulties at school and with peers, and self-harm.

The studies reported above are limited by the fact that they used standardised measures of depression which predetermine which features they can report on. Although these measures have usually gone through a process of development that includes focus groups and input from young people, the measures often start as adaptations of tools widely used in adult literature, which may carry over certain 'adultomorphic' ideas of young people as 'miniature adults' into the definitions of adolescent depression. Giving young service users a voice in describing their experience of depression can help to improve