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The Experience of Being the Parent of an Adolescent with a Diagnosis of Depression

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Abstract Although there is a growing research literature exploring the experience of being the parent of an adolescent with mental health issues, there is little looking specifically at parents of adolescents suffering from depression. This is surprising given that adolescence is a period of development associated with significant risk for the onset of severe depression. The aim of our study was to qualitatively examine the experience of being the parent of an adolescent (aged 11-17) who had recently been referred to child and adolescent mental health services in the United Kingdom and diagnosed with moderate to severe depression. Semistructured interviews were conducted with 48 parents. A thematic analysis revealed four main themes: parents' 'lack of awareness' that their child was experiencing depression or that their child was experiencing any problem at all; the 'emotional turmoil' that parents were experiencing alongside that of their child; parents' feelings of 'helplessness'; and 'parenting in overdrive'. Overall, the findings of our study indicate that the strain and stress that can be experienced by parents of adolescents with a diagnosis of depression, at the outset of their child's treatment, is significant. Moreover, these parents' experiences are comparable to those of parents of adolescents diagnosed with such disorders as bipolar disorder, schizophrenia, or eating disorders.

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Introduction

The prevalence of mental health issues among children and adolescents is high, with 1 in 10 young people in the United Kingdom (UK) suffering from a diagnosed mental health disorder (Green et al. 2005). However, epidemiological studies have revealed that only a third of children and adolescents who are in need of treatment from mental health services actually receive treatment (e.g. Merikangas et al. 2011). For children and adolescents suffering from mental health issues, it is their parents who are likely to take on the primary responsibility for managing their symptoms at home, as well as managing their treatment attendance and adherence (Nock and Ferriter 2005). Therefore, the experiences of parents of children and adolescents with mental health issues of managing their child's symptoms, seeking help for their child, and potentially seeking help for themselves as their child's carer, arguably constitute an area of significant social concern.

In studies that have been conducted with parents of children and/or adolescents with mental health issues, researchers have used self-report measures to assess parents' help-seeking behaviour (e.g. Alegria et al. 2004), the levels of burden, strain, and stress experienced by these parents (e.g. Angold et al. 1998), and parents' levels of satisfaction with child and adolescent mental health services (CAMHS) (e.g. Bone et al. 2014). However, self-report measures can tell us little about the context and meaning behind parents' responses. Thus, a growing body of literature has also begun to qualitatively examine the experiences of parents of seeking help for, caring for, and

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parenting children and adolescents with mental health issues. This previous research has been conducted with samples of parents of children and adolescents suffering from a range of mental health issues, including eating disorders (e.g. Cottee-Lane et al. 2004), attention-deficit hyperactivity disorder (ADHD; e.g. Firmin and Phillips 2009), psychosis (e.g. McCann et al. 2011), self-harm (e.g. Oldershaw et al. 2008), bipolar disorder (e.g. Maskill et al. 2010), schizophrenia (e.g. Knock et al. 2011), obsessive compulsive disorder (OCD; e.g. Futh et al. 2012), or substance abuse (e.g. Choate 2011). Yet, there has been a dearth of research exclusively focusing on the experiences of parents of young people with one particular common mental health problem: depression.

Adolescence is a period of development associated with significant risk for the onset of severe depression (Stice et al. 2009). The 12-month prevalence of adolescent depression has been estimated to range from 2 to 8 % and estimates of the lifetime prevalence reach 20 % (Rice and Rawal 2011). This implies that a substantial minority of parents will likely have to face this disorder at some point during their child's adolescence. Moreover, as well as being one of the most common mental health problems experienced by children during adolescence, the incidence of major depression in adolescents is marked by a particularly protracted and recurrent course (Stice et al. 2009). Depressive symptoms that begin in adolescence have an increased likelihood of recurrence in adulthood, thus enhancing the risk of the individual experiencing impaired functioning in adult life (Dunn and Goodyer 2006), alongside the detrimental effects on young people's current psychological, social, and academic functioning that depression can have (Rice and Rawal 2011).

Studies that have been conducted specifically with samples of parents of adolescents with depression have examined the parenting behavior of these parents, often using observational methodological designs (e.g. Pineda et al. 2007; Sheeber et al. 1998), drawing on the evidence for the role of the quality of the family environment in the onset and maintenance of depression in adolescence (Kaslow et al. 1994). Studies have also examined, using self-report measures, the psychological well-being of these parents (e.g. Perloe et al. 2014), due to the associations that have been frequently found in the literature between parental mental health issues, particularly maternal depression, and poor psychological adjustment in adolescents (e.g. Murray et al. 2010). Yet, we know little about what it is actually like to be a parent of these young people, in parents' own words.

There is arguably good reason to address this dearth of research. Ultimately, it is parents who will bear much of the brunt of the negative impact that depression can have on young people's functioning, and it is parents, not clinicians, who will have to try and deal with their child's depressive symptoms on a daily basis (Sonuga-Barke and Balding 1993). However, despite the prevalence of depression in adolescence, to our knowledge, no published studies to date have exclusively focused on the parents of adolescents with depression to explore these parents' responses to their teenage child's depressive symptoms, the effects of their child's depression on their parental role, and these parents' support needs. Therefore, a qualitative study of the experiences of these parents at the start of their child's treatment at CAMHS, which explores how these parents' experiences compare to those of parents of adolescents with other mental health disorders, could crucially help to address this gap in the literature. Thus, the aim of our study was to examine the experience of being the parent of an adolescent who had recently been referred to CAMHS in the UK and diagnosed with moderate to severe depression. It should be noted that while we use the term 'parents' to refer to our sample, 80 % of our sample consisted of mothers.

Method

Participants

The Improving Mood with Psychoanalytic and Cognitive Therapies study (IMPACT; Goodyer et al. 2011) is a large randomized controlled trial (RCT) currently being conducted across England at three sites: North London, East Anglia, and Manchester. As part of the IMPACT trial, adolescents with depression have been randomized to receive one of three manualized treatment interventions: Cognitive-Behavioral Therapy, Short-Term Psychoanalytic Psychotherapy, or Specialist Clinical Care (a form of enhanced treatment as usual). A primary aim of the IMPACT trial is to compare the effectiveness of these three types of treatment for adolescent depression.

The IMPACT-My Experience study (IMPACT-ME; Midgley et al. 2014) is a qualitative, longitudinal study linked to the main IMPACT trial. As part of the IMPACT-ME study, the young people, their parents, and their therapists are interviewed before the young person's therapy starts (Time 1; baseline), at the end of their therapy (Time 2; 36 weeks after baseline), and 1 year later (Time 3). In our study, we drew on data from the Time 1 IMPACT-ME interviews with parents, which were conducted at the point of the adolescents' referral to CAMHS in North London and their recruitment into the IMPACT trial.

Forty-three interviews were conducted at Time 1 with parents of 43 adolescents, 27 girls (62.8 %) and 16 boys (37.2 %), aged 11.3–17.8 years old (M = 14.85, SD = 1.64), who were referred to selected National Health Service (NHS) CAMHS in North London between October 2011 and

January 2013, and diagnosed with moderate to severe depression. In terms of ethnicity, 27 young people described themselves as White British (62.8 %), four as Mixed: White and Black African (9.3 %), three as Black British (7.0 %), three as Any Other White Background (7.0 %), two as Any Other Ethnic Group (4.7 %), one as Mixed: White and Asian (2.3 %), one as Mixed: White and Black Caribbean (2.3 %), and one as Asian Bangladeshi (2.3 %). Ethnicity data was missing for one young person (2.3 %).

Thirty-five interviews were conducted with the young person's biological mother (81.4 %), three interviews were conducted with the young person's biological father (7.0 %), four interviews were conducted with the young person's biological mother and biological father (9.3 %), and one interview was conducted with the young person's biological mother and stepfather (2.3 %). The mothers' ages ranged from 32 - 56 years old (M = 43.87, SD = 6.68) and the fathers' ages ranged from 41 to 64 years old (M = 52.67, SD = 8.89). Age data was missing for 10 mothers (25.0 %) and two fathers (25.0 %).

Ethical approval was obtained from the Cambridge 2 Research Ethics Committee (REC Ref: 09/H0308/137). All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study. As part of this process, the young people and their parents were presented with a participant information sheet outlining the rationale for the research, the purpose of the study, and clarifying that their decision to participate (or not) in this additional study would in no way affect the treatment that they would be receiving as part of the main IMPACT trial. It was also made clear that selected excerpts from their interviews (fully anonymized) could be used in the writing up of the project. The young people and their parents who agreed to take part in the IMPACT-ME study were then asked to sign a consent form. University College London and Anna Freud Centre policies on data protection and confidentiality were followed, as well as local NHS Trust policies. To protect confidentiality and ensure that the interviews were fully anonymized, any identifiable details given by participants during their interviews were disguised in the interview transcripts. Participants have also been assigned pseudonyms.

Procedure

The young people who had been identified at referral by the selected CAMHS in North London as potentially eligible to participate in the IMPACT trial were contacted by telephone by the research assistants working on the trial to arrange a time to meet with them and their parents for their baseline assessments. The Time 1 IMPACT-ME interviews were then conducted by the research assistants with the young people and their parents separately as part of their baseline assessments, which also included a battery of standardized measures and a semistructured diagnostic interview, at a place convenient for the participants (in participants' homes or at the CAMHS). The parents also completed a demographics questionnaire during their baseline assessment. At the start of the participant's IMPACT-ME interview, the research assistant explained that they were interested in hearing about things in the participant's own words and that there were no right or wrong answers. The research assistants who conducted the Time 1 IMPACT-ME interviews had received training from the IMPACT-ME research team, led by the second author, in conducting qualitative, semistructured interviews and in using the interview schedules.

Measures

All of the adolescents met the Diagnostic and Statistical Manual (DSM-IV) criteria for moderate to severe depression (American Psychiatric Association 1994), as rated on the Kiddie-Schedule for Affective Disorders and Schizophrenia (K-SADS; Kaufman et al. 1997), a semistructured diagnostic interview. Exclusion criteria were generalized learning difficulties, a pervasive developmental disorder, pregnancy, and a primary diagnosis of bipolar Type I, schizophrenia, or an eating disorder. Exclusion criteria did not include drug and alcohol use because of the pragmatic nature of the IMPACT trial.

The Expectations of Therapy Semistructured Interview Schedule (Midgley et al. 2011) was developed for the IMPACT-ME study and draws on existing interview schedules designed to explore the process of change and recovery (Elliott et al. 2001), and ideas about cure (Philips et al. 2005). The parent interview schedule mirrored the young person interview schedule and covered three main areas: the difficulties that brought the young person into contact with CAMHS, how the parent makes sense of the young person's difficulties, and the parent's expectations of the young person's therapy. The use of a semistructured interview schedule ensured that while the researcher could guide the conversation, the data collected were still essentially participant driven. Thus, the interview schedule was considered flexible, rather than prescriptive. As the interviews were conducted as part of the parents' baseline assessments f or the main IMPACT trial, the parent interview schedule was designed for the interviews to take approximately 10-15 min. In reality, the Time 1 parent interviews ranged from 7 to 43 min in length.

Data Analyses

All of the interviews were audio-recorded, transcribed verbatim, and then uploaded into NVivo Version 10, a computer-assisted qualitative data analysis software package (Bazeley and Jackson 2013). A thematic analysis of the interviews was then conducted to answer the following research question: what are the experiences of parents of adolescents who have recently been referred to CAMHS and diagnosed with depression? Thematic analysis can be used to identify and analyze themes in a qualitative dataset, which relate to the research question and represent "some level of patterned response or meaning" (p. 82) among participants (Braun and Clarke 2006). According to Braun and Clarke (2006), there are six key phases involved in conducting a thematic analysis: familiarizing yourself with your data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.

During the 'familiarizing yourself with your data' phase, each interview audio-recording was listened to several times by the first author while reading along with the transcript. This led to the 'generating initial codes' phase, during which potentially interesting and relevant features of each interview were coded systematically in NVivo by highlighting selections of text in each transcript and labelling them according to their content. This phase ended when a long list of codes had been recorded by the first author and all of the data or text that had been given the same code had been collated together in NVivo. In the next phase, 'searching for themes', similar codes (and their related data extracts) were sorted and combined in NVivo into potential main overarching themes and subthemes within these. During the subsequent 'reviewing themes' phase, all of the data extracts coded to and collated under each theme were read to check the relevance of each extract to each theme, as well as to check that there were enough data to support each theme, and that there were clear distinctions between themes (Braun and Clarke 2006). The first author also discussed and refined the potential main overarching themes and subthemes with the second and third authors at this stage. The entire dataset was then re-read by the first author to ensure that the themes accurately reflected the dataset as a whole and described the overall story of the data in relation to the experiences of the parents. Each main theme and subtheme was given a name and definition reflecting its content during the final 'defining and naming themes' phase.

A researcher independent to our study coded 20 % of the dataset (eight interviews) to enhance the reliability and transparency of the process of our analysis (Joffe and Bettega 2003; Joffe and Washer 2007). This revealed that in 80 % of cases the same codes were given to the same

excerpts, which led to further refinement of the definitions of each main theme and subtheme, as well as the content coded under each theme, where necessary.

Results

The results from the thematic analysis are presented in four sections below, which illustrate the four main themes and subthemes drawn from the dataset in relation to our study aim.

Lack of Awareness

Initial Confusion

Three-quarters of the parents described how they had noticed changes in their child's feelings and behavior prior to their referral to CAMHS. These changes included increases in their child's levels of anger, irritability, and moodiness, a loss of interest in doing anything or going anywhere, isolation and social withdrawal, increased levels of anxiety, increased sleep or a marked lack of sleep, and extreme tearfulness and sadness. These parents made explicit comparisons between 'my child now' and 'my child before', and voiced their perceptions that their child did not seem to be their usual self or did not seem to be behaving like a normal adolescent, "It's just not like her. It's just like having a stranger in the house" (Mr. Allen).

Despite the fact that the majority of the parents cited noticing these potentially concerning changes in their child's feelings and behavior prior to their referral to CAMHS, just two of these parents stated that they had felt that their child could be depressed. A quarter of the parents described instead how they had wondered whether their child could simply be experiencing a more extreme version of the typical mood swings that adolescence brings, that their child could just be going through a phase that they would grow out of, or that there might be something physically wrong with their child, such as low vitamin levels or a hormonal imbalance. For four of these parents, these ideas were reinforced by their local doctor, the general practitioner (GP).

... and we kept going to the GP, well I say "kept" but really about six times and each time they just kind of they were OK but they were passing it off as normal hormones and because she had all the medical tests done for hormone levels and all the vitamin levels to see if she was you know anemic or anything, you know possibly deficient or anything. (Mrs. Austin)

Consequently, a third of the parents acknowledged that they had only realized how bad things had become for their child, and how much of a negative impact these changes in their child's feelings and behavior had been having on their child's life, when their child broke down and told them. Likewise, six parents only realized the extent of their child's difficulties when a member of staff at their child's school got in touch with them and suggested that their child should be referred to CAMHS.

Out of the Blue

By contrast, a quarter of the parents had not noticed any changes in their child at all prior to being informed either by their child or by a member of staff at their child's school about their child's difficulties, "She went to someone in school and that person at school contacted me and said she'd been to her and that she was unhappy and that she'd been harming herself ... I didn't think there was anything wrong" (Ms. Wilson). Indeed, another parent was so convinced that her 15 year old daughter was simply being a "typical teenager" that she disagreed with the member of staff at her daughter's school who felt that she needed to be referred to CAMHS. Thus, for these parents the realization that there was anything wrong at all came as a complete shock.

I always thought he was happy and one night I was working and he called me and asked me how soon I'm going to be home, so I said "I'm on my way now, is everything OK?" He said "No it's not," so I said "What's wrong?" And he said "Well I don't know." So I came home and I went to see him in his bedroom and he was sitting there crying his eyes out that he feels like a failure, that he's rubbish, and that he doesn't feel that it's worth living. (Mrs. Kowalski)

Emotional Turmoil

Worried and Anxious

Almost two-thirds of the parents described the worry and anxiety that they felt about their child in relation to their negative feelings, difficult behaviors, and future, "He just wants to stay in his bedroom. It just worries me. I'm just really worried" (Ms. Tyler). Indeed, one parent stated that her "biggest fear" was that her daughter might have committed suicide by the following year. Two parents also voiced their concerns about the therapy that their child would be receiving at CAMHS. Specifically, Mrs Austin said that she was worried that her daughter might not be able to cope with the demands of therapy, and Ms Woods expressed her fear that therapy "... can sort of lead to a lifelong obsession with overindulging one's emotions. It becomes a crutch that they'll always need". Other parents also alluded to the stress and pressure that they felt under from having to try and deal on a daily basis with their child's difficulties.

Upset and Distressed

Similarly, almost two-thirds of the parents referred to how upsetting it was for them to see their child feeling like this, as well as to how "depressing" trying to deal with their child's difficulties could be for them, particularly when their child had been self-harming or expressing suicidal thoughts, "The thought of my beautiful child marking her body in that way just distresses me to beyond anything really. I can't even put into words how distressed I was over it" (Ms. Leonidas). Nearly a quarter of the parents were visibly distressed and tearful during their interviews.

Guilt and Self-Blame

A major source of upset and stress for half of the parents seemed to be their feelings of guilt and self-blame in relation to their child's issues. Six of these parents appeared to at least partly blame themselves for their child's difficulties because of the negative effects that their own depression or emotional issues could have had on their child. "I don't know whether you know it could actually be related to myself, I've suffered from panic attacks for 20 years and depression myself so maybe it's sort of like rubbing off on her" (Mrs. Lee).

However, the majority of the parents alluded to their concerns that perhaps the ways in which they had parented their child could be linked to their child's difficulties. These concerns ranged from wondering whether they could have been too short-tempered and angry with their child throughout their life, to wondering whether they had potentially been neglectful of their child. Thus, these parents seemed to be questioning their parenting abilities as a result of becoming aware of their child's difficulties.

I would have done a hell of a lot of shouting over the years. Frustrated shouting. I'm not sure if it would have been necessarily more than others or less than others, but I think it must have had a bad impact on Grace particularly, you know when I say shouting I'm talking about tidying, you know not being slobby, things like this, you know. I wouldn't have thought about it if the incident hadn't happened. (Mr. Thompson)

Appalled and Frustrated

By contrast, just under a quarter of the parents alluded to how appalled they were by their child's behavior. This

group mainly consisted of parents who were caring for young people whose depression seemed to have manifested itself primarily in the form of extreme anger. Several of these parents voiced their disgust and shock about the extent of their child's anger and sometimes abusive behaviour, "The emotional abuse he uses, the name-calling, the disrespect he shows towards me and the younger two, is appalling" (Ms. Sharma). Another parent also expressed her distaste toward her daughter's self-harm. Three parents acknowledged that they were actually scared of their child's anger and rage, and so could not cope with it anymore. Other parents also referred to the frustration that they felt in relation to trying to deal with aspects of their child's behavior. For instance, Mrs Cook described how "frustrating" she found her daughter being sick every night because of her anxiety, and how powerless she felt to stop it from happening.

Helplessness

Parents' feelings of helplessness and powerlessness were a further example of the emotional turmoil that many of them were experiencing. However, as just over threequarters of the parents referred to these feelings, it was clear that parental helplessness constituted a main theme in its own right, rather than a subtheme. These parents, often despairingly, explained how they had tried everything that they could think of to try and help their child to feel better but nothing that they did seemed to make any difference, "I can't deal with the fact that she feels so alone and there's nothing I can do to help her" (Ms. Shepherd). They described feeling "lost" and "in limbo", and wishing that they could help their child but not knowing how to, as their child's difficulties seemed to be "too deep" for them to be able to deal with. One of these parents questioned how things could have got to this point, where she and her partner had been so unable to deal with their daughter's behavior that they had had to seek professional help for her.

Three parents also described experiencing parenting dilemmas, such as being unsure anymore about how strict they could be with their child when their child did not want to do something, which under normal circumstances they would have to do, such as go to school, "I try being reasonably firm with boundaries, I try being a bit more lenient, a bit kinder. So I'm constantly sort of playing around trying to do the right thing, whatever that is" (Mrs. Adams). Indeed, almost half of the parents acknowledged their feelings of self-doubt about their parenting prowess and parenting practices that had arisen as a result of being unable to help their child, "I just don't know what to do and then I feel, I've said to my mum and dad, you know I feel like I'm a failure as a parent" (Ms. Barker). The parents' feelings of helplessness seemed to be being reinforced by four factors: finding it hard to understand their child's difficulties; a communication breakdown between the parent and their child; having to contend with other issues alongside trying to parent their depressed teenager; having to deal with their child's difficulties alone and without support.

Dealing with the Unknown

Half of the parents alluded to how difficult it was for them to understand what their child was feeling and experiencing. For some of these parents, this seemed to be because prior to their child's diagnosis at CAMHS, depression was an unknown entity, "I've never had depression myself so I can't really understand kind of what she's feeling" (Ms. Hall). For other parents, this difficulty seemed to stem from their confusion about what might be their child's depressive behavior and what might actually be normal adolescent behaviour, "... I don't know if that's a teenage thing or it's a depression thing" (Ms. Leonidas).

A third of the parents spoke about how they had been trying to enhance their understanding by gathering information about their child's difficulties. Two of these parents described how they had looked up their child's symptoms on the internet. Three families expressed their hope that they would find out from their child's therapist about "why" their child had become depressed. However, the majority of these parents described how they had asked their child to explain what was going on, with varying degrees of success, "We've had this for years, 'Talk to me Clive, talk to me, make me understand'" (Ms. Ford).

A Communication Breakdown

Just over half of the parents stated that communication seemed to have broken down between them and their child, "She used to share quite a lot about how she was feeling but she doesn't do that anymore" (Ms. Hall). For some parents, this communication breakdown appeared to be the result of the young person refusing to or being unable to describe their feelings, "He don't talk to me. He won't. I'll sit there and I'll talk to him and he'll say, 'You don't understand, I'm depressed'" (Ms. Tyler). For others, it seemed to stem from the parents themselves finding it hard to speak to their children about their difficulties. For instance, Ms Kostopoulos described how she had found that she was unable to speak to her daughter about some of her issues because they centered, first, around her relationship with her dad (mum's ex-husband), which mum found it difficult to talk about, and second, around her anger with mum, "I think she does need somebody outside of me that she can talk to" (Ms. Kostopoulos).

Competing Demands

For just over a third of the parents, a further reason why they were feeling helpless appeared to stem from the fact that they also had their own issues to cope with, which in turn made it more difficult for them to deal with their child's problems. For the majority of these parents, these issues related to their finances and to their attempts to balance their work and home lives. Six parents spoke about the negative impact that the family's lack of money had been having on both them and their child, "I think the money situation in the house brings it down as well because when there is poverty, there is no happiness is there? He wants to go cinema or somewhere, there's not the money for it" (Mrs. Kowalski). One parent also described the tension that she faced between needing to work long hours to provide financially for her daughter and needing to be around at home enough to support her. Similarly, seven parents referred to the difficulty of having to try and deal with their child's issues at home alongside having to work to provide for their family, "I get stressed because I feel helpless, and because I work full-time as well, it's kind of hard trying to fit everything in and control everything" (Ms. Thomas).

Other parents referred to their own depression and emotional problems, which they had to contend with alongside trying to parent their depressed child. For instance, Mrs Pugh described how she had been taken to court and fined because her daughter had been missing so much school, even though she had tried to explain to the judge that her own depression made it harder for her to deal with her daughter crying and refusing to go to school every morning.

Lack of Support

A quarter of the parents also described how difficult they were finding trying to parent their depressed child by themselves, with little support from their child's other parent, their child's school, or health care professionals so far. This lack of support appeared to bolster these parents' feelings of helplessness, as they realized that not only were they struggling to help their child but they were struggling alone.

... honestly I am literally at the end of my tether because I mean I suffer from depression anyway and it's just like, I just feel like things are 20 times worse for me, you know his dad's aware of the situation and obviously he don't care because if he did he would have been involved in this. (Ms. Tyler)

One way in which some parents expressed this feeling of a lack of support was through their references to their

disagreements with their partners about how to handle what their child was going through. For instance, Mrs Brady described how, unlike her, her husband had not believed that there was anything seriously wrong with their daughter over the last few months, which had been a source of conflict between them as parents, "He says really she maybe needs a little kick up the ass and get going. But I try and say to him it's not that easy, you can't if you're feeling like that, you just can't shake it off" (Mrs. Brady).

Four parents also spoke about the lack of support in dealing with their child's difficulties that they had received from their child's school. Indeed, one parent recalled a meeting that she had had at her son's school during which a teacher had implied that it was her fault that her son was so unhappy. Finally, six parents alluded to the perceived lack of support that they had received so far from various health care professionals, such as GPs and social workers, in terms of managing their child's difficulties, "I mean it was like the doctor just didn't seem to hear what I was saying" (Ms. Walsh).

Thus, a third of the parents directly expressed a wish not only for their child to have therapy, but also for them as parents to be given some support from CAMHS to help them to cope with their child's difficulties at home, "... just like to know that I'm not on my own really" (Ms. Tyler). Some of these parents stated that they wanted to be given specific "strategies" to enable them to help their child and to deal with their child's difficult feelings and behaviors, "If someone could just turn round and say you know 'If you use this strategy, you're gonna have a happy son', you know, it's just, we feel lost" (Ms. Barker). Other parents expressed their wish to receive psychological help for themselves alongside their child to deal with their own emotional issues and to help them handle the stress of trying to parent their depressed teenager. Two parents also voiced their desire to be told by a professional about how they should be parenting their child now, for example, could they still enforce rules like going to school or eating with the rest of the family when their child has been feeling like this?

Yes so being involved to the extent that we know what we can do because I don't know, I feel like I can't do anything and as a mother it's the worst thing in the world that you can't help your child. So if I understood more about what is happening to him and what is the best way to deal with it ... (Mrs. Brewerton)

Parenting in Overdrive

Just over two-thirds of the parents referred to changes in the ways in which they had been parenting their child, as a result of their child's difficulties.

Providing 'Extra Parenting'

Half of the parents alluded to a feeling that they had to parent their child more now than they should need to at their child's age; an age at which their child should be growing more independent rather than becoming more dependent on them as parents, "I feel like I have to mother her more than when I look back at how I was when I was 16, 17" (Mrs. Austin). Indeed, for one of these parents, giving her son some 'extra parenting' was her way of trying to deal with his difficulties.

... it would be me that would have to be kind of making sure he got out of bed and it would be me that would be sort of having dialogue with his teachers when they'd emailed me and said "Look his coursework's late", and so suddenly then I'd go into overdrive, and make sure that what needed to be done was getting done and the problem is once you start doing that, you're almost overcompensating, so the stuff that your child should be doing, you are almost doing that for them. (Ms. James)

Similarly, other parents gave specific examples to show how much energy they had been putting into trying to deal with their child's difficulties. For instance, Mrs Allen described how every weekend she had been making a conscious effort to take her 16 year old daughter out to stop her from staying in her bedroom all weekend, and Mrs Baxter stated that it had been taking her "two hours" every morning to try and get her 13 year old son out of bed and ready for school.

Impact on the Family

For some parents, this perceived need to give extra parenting to their depressed teenager had a knock-on effect on their parenting of their other children, as it meant that they did not have as much parenting energy or time to spend with them, "I can't read to her in the evening, there's a lot going on with Tom" (Mrs. Baxter). These parents, in particular, tended to describe how "exhausting" and "draining" they were currently finding life as a parent. Ten parents also referred to how they and their other family members had had to change their own routines and lifestyles to adapt to the young person's difficulties, "We have to sort of plan things differently so that he is not alone ... he's so sad sometimes I don't want him to feel like we're going off and abandoning him" (Mrs. Brewerton). Indeed, Mrs Creedon described how although her daughter was now old enough for her parents to leave her at home while they went out for the evening or away for the weekend, they were so worried about leaving her alone when she was feeling so unhappy that they had had to put their social lives "on hold" for now.

Walking on Eggshells

Other parents also alluded to this shift in their parenting behavior by implying that they had started deliberately avoiding confrontation with their child, out of a fear of upsetting their child even more.

I'm just aware of trying not to have too many arguments with her, or you know I need to make sure I'm justified in telling her off, or you know like for example when there was a big upset last week, I was really aware of getting really upset with her and making her upset and getting angry with her. (Ms. Leonidas)

In relation to this, a third of the parents described how they had been being more lenient with their child than they usually would be over them doing things like household chores or homework, "Some of the normal rules have slipped a bit, so I'm letting her get away with things that I wouldn't have before probably" (Mrs. Creedon). Thus, several of the parents directly acknowledged the need that they now felt to take extra care when interacting with their child and almost tiptoe around them just in case they somehow made their child's difficulties worse; a feeling described by five parents as "walking on eggshells".

Discussion

Our study was based on 43 semistructured interviews conducted with 48 parents (the majority of whom were mothers) of adolescents in the UK who had recently been diagnosed with moderate to severe depression. The aim of our study was to examine the participants' experiences of being parents of these adolescents at the point at which they had been referred to a mental health service, but had not yet received any treatment. Four main themes were found: 'lack of awareness'; 'emotional turmoil'; 'helplessness'; 'parenting in overdrive'. In this section we review the key findings and discuss how these parents' experiences compare to those of parents of adolescents with other mental health disorders, as reported in previous studies.

The first main theme in our study, 'lack of awareness', supports the findings of previous qualitative studies with parents of adolescents suffering from a range of mental health issues, which show that prior to their child's diagnosis, parents describe recognizing their child's suffering but not necessarily realizing that this suffering is a mental illness (e.g. Bradby et al. 2007). Logan and King (2002) reported that 79 % of their sample of 44 parents of adolescents with depression did not endorse any symptoms of depression in a diagnostic interview. Thus, Highet et al.

(2005) have suggested that schools, community, and health care organizations could be in a strong position to educate families in the community about the symptoms of depression. Indeed, given the fact that some of the parents in our study were informed by a member of staff at their child's school about the extent of their child's difficulties, this could imply that schools in particular may be key sites for recognition of depression in adolescents. Moreover, two of the parents in our study described searching for information about their child's symptoms using the internet, which could imply that potentially clinicians and schools might also have an important role in pointing parents towards helpful online resources with information about mental health issues in young people.

On the other hand, our finding that other parents did not have any idea that their child had been experiencing any problems at all prior to their diagnosis of depression has not been frequently echoed in previous research. This could be because, unlike our study, previous qualitative studies in this area have not tended to focus exclusively on the experiences of parents of adolescents with a diagnosis of depression. It can be argued that some of the symptoms of adolescent depression might be particularly difficult for parents to distinguish from normal adolescent behavior. This is because the symptoms of adolescent depression can include, for example, increased irritability, anger, or hostility, hypersomnia or insomnia, and reckless behavior (American Psychiatric Association 2013); all of which to some extent are commonly associated with adolescence generally (Dundon 2006). Indeed, Karp and Tanarugsachock (2000) found that the parents of adolescents with mental health issues interviewed in their study appeared to find it especially hard to understand their children's difficult behaviors. It can also be argued that it might be easier for adolescents, compared to young children, to hide their distress from their parents, particularly when this distress is the internalized distress characteristic of emotional problems. Potentially school counsellors are in a position to explicitly offer to talk with young people about how to let people, such as teachers and parents, know if they are experiencing emotional distress and need help.

The second main theme in our study, 'emotional turmoil', has been frequently echoed in previous studies qualitatively exploring the experiences of parents of young people with mental health issues (e.g. Byrne et al. 2008), or measuring the levels of burden that these parents can experience (e.g. Barksdale et al. 2009). Establishing the level of emotional burden that can be experienced by parents of adolescents with a diagnosis of depression at the point of their child's referral to CAMHS is important, given the potential implications of this for the clinicians who will be working with these adolescents. Parents might require help themselves to resolve the distressing feelings and emotions associated with their child's difficulties, potentially through individual psychotherapy of their own if their level of emotional distress is worryingly high (Marsh and Johnson 1997). This might be particularly important given that in a longitudinal study of 164 families, Early et al. (2002) reported on the bidirectional nature of the relationship between parent and child psychological well-being. Specifically, Early et al. (2002) found that child functioning significantly affected parental well-being and, in turn, child functioning also worsened in the face of lower parental well-being.

A major source of emotional turmoil for many of the parents in our study appeared to be their feelings of guilt and self-blame in relation to their child's difficulties. This has been another prevalent theme in the literature (e.g. McDonald et al. 2007). Hoskins and Lam (2003) have proposed that mothers, in particular, of children with mental health issues may "assume an identity of dysfunction" (p. 165), as a result of the tendency in the field of psychology towards mother-blaming. However, Moses (2010) found that in a sample of 70 parents of adolescents currently receiving psychological treatment for various mental health issues, 22 % of the parents reported that their feelings of self-blame had in fact grown substantially less over time. This was because these parents had reasoned that, first, their ways of helping their child were "good enough" (p. 111), second, as their child grew older the parents felt that their child became more responsible for their own actions, and third, they had observed that their other children had not developed mental health issues (Moses 2010). Thus, from this one could speculate that potentially at the start of their child's journey through CAMHS, parental feelings of guilt and self-blame might be at their peak. Indeed, clinicians could have a crucial role in normalizing parents' feelings of guilt and self-blame, and in providing parents with information about the etiology of depression in adolescence (McDonald et al. 2007).

For many of the parents in our study, their distress also seemed to stem from their feelings of 'helplessness' (our third main theme), in terms of being unsure how to deal with their child's difficulties, which seemed to have gone beyond their capabilities to manage by themselves. In a study of the caregiving experiences of 25 parents of adolescents with mental health issues, Harden (2005) captured these parents' similar feelings of helplessness and powerlessness in a theme called 'parental deskilling'. Further resonating with many of the parents in our study, Corcoran et al. (2007) found that the parents of adolescents and adults with recent-onset psychosis in their sample reported that they had sought psychiatric help for their child only when they had tried everything that they could at home to manage their child's behavior, but nothing had seemed to work. Thus, this implies that clinicians could also have a

vital role in helping parents to manage their child's difficulties at home (Cottee-Lane et al. 2004), to make them feel empowered and address their concerns about their parenting abilities. Ultimately, a third of the parents in our study directly expressed a wish not only for their child to have therapy, but also for them as parents to be given some sort of support from CAMHS to cope with their child's difficulties. The similarity of the experiences of the parents in our study with those of parents of adolescents with other mental health disorders would also suggest that offering such support in 'mixed' groups of parents could be as meaningful to these parents as it would be to create support groups specifically for parents of depressed adolescents.

In terms of our fourth main theme, 'parenting in overdrive', many of the parents in our study alluded to the changes that had occurred in their parenting practices and in their own lives as a result of their child's difficulties. This could point towards the potential utility of family therapy for these families. Francis (2012a) introduced the concept of 'family trouble' to capture the upheaval that children's problems can lead to in the family as a whole, as well as in parents' own lives and sense of self. In line with our findings, Francis (2012a) found from interviews with 55 parents of children, adolescents, and adults with mental health problems, learning disabilities, or developmental disabilities, that parents' experiences included disruption to their daily routines and in their relationships with others due to the time-consuming nature of dealing with their child's difficulties and the stigma of being the parent of a child with such difficulties, and disruption to their "role performances as mothers and fathers" (p. 387), as their child's difficulties challenged their capacity to perform their normal parental roles.

McCann et al. (2011) concluded that by adapting their parenting practices and lives around their child's mental health issues, parents are adapting to their dual role as a parent and as a caregiver. Specifically, the parents in our study described feeling that they had been parenting their child more than they should need to at their child's age. Similarly, in a study of 10 parents' experiences of caring for adolescents with eating disorders, Svensson et al. (2013) found that these parents reported that they felt that they had begun parenting a toddler again, rather than an adolescent. The parents in our study also described being more lenient than usual with their child. By contrast, several of the parents of adolescents with anorexia nervosa in Cottee-Lane et al.'s (2004) study implied that they had been being particularly firm with their child to ensure that their child was eating, such as by enforcing rigid mealtime routines. Perhaps this is more of a feature of the experience of parenting an adolescent with an eating disorder, or potentially during the young person's treatment clinicians could help parents to feel less apprehensive about enforcing boundaries with their child.

Scholars such as Blum (2007), Francis (2012a, b), and Malacrida (2003) have highlighted the fact that parenting in today's society "is characterized by an ideology of intensive mothering" (Francis, 2012a, p. 374), in which parents, particularly mothers, are held entirely responsible by society for all areas of their children's lives and development. From interviews with 45 mothers raising children with 'invisible' disabilities, such as ADHD, Blum (2007) employed the term 'vigilante' to describe, first, the intensified monitoring of their child and their self that these mothers engaged in, and second, the advocacy of these mothers on behalf of their vulnerable child to obtain the support, services, and treatment necessary to ensure their child's success. Thus, in this context of intensive parenting where parents are held primarily responsible for their children's development, the fact that the parents in our study described experiencing emotional turmoil, helplessness at being unable to 'fix' their child's mental and behaviour problems themselves without the need of professional intervention, and a sense of parenting in overdrive, is entirely consistent with broader cultural discourses around parenting-and mothering in particular.

It is important to note the following limitations of our study. A higher proportion of the parents in our sample were parents of adolescent girls, which likely reflects the fact that statistically girls are twice as likely as boys to develop depression during their teenage years (Rice and Rawal 2011). Nonetheless, the transferability of the findings of our study to samples composed of larger numbers of parents of adolescent boys should perhaps be treated with caution. Furthermore, epidemiological evidence suggests that many adolescents with depression do not get recognized or referred as depressed (Kessler et al. 2001; Martinez et al. 2006). Thus, taking a sample of referred young people in the UK in our study did not give us a representative sample of parents of depressed adolescents. Consequently, the extent to which the findings of our study can be applied to other populations of parents, such as parents whose child has been suffering from depression but who has not been referred to CAMHS, again is limited. This is because the experiences of these parents may be qualitatively different to the experiences of the parents in our study.

Moreover, taking a sample of parents of young people who had recently been referred to CAMHS meant that in our study we could only explore these parents' experiences at this particular point in time. The value of exploring parents' experiences at the start of their child's treatment at CAMHS lies in the potential implications of this for the clinicians who will be treating the young people, such as in terms of parents' support needs. However, our findings cannot tell us anything about the long-term experience of being a parent of a young person with a diagnosis of depression. Therefore, given the longitudinal design of the IMPACT-ME study, the next step will be to explore how these parents' experiences change over the course of their child's treatment. We also know little about how parents of adolescents with a diagnosis of depression experience CAMHS, both in terms of their own involvement and how they feel that it impacted on their child. Future research could additionally examine whether parents' experiences at the point of their child's referral to CAMHS might influence their child's subsequent engagement with treatment for their depression. For instance, could more highly distressed parents be more likely to support their child's adherence to treatment, compared to less distressed parents?

As the interviews with the parents in our study were conducted as part of the parents' baseline assessments in the main IMPACT trial, the semistructured interview schedule used for the parents' interviews was developed with the aim of exploring the parents' perspectives on their child's depression and their expectations of their child's therapy at CAMHS. Consequently, it did not focus solely on 'the experience of being a parent'. Nonetheless, it can be argued that in their interviews the parents were still being asked implicitly to think about their experiences of being a parent of an adolescent with a diagnosis of depression. Moreover, as the interview schedule was semistructured, rather than prescriptive, this gave the parents room to talk about their own experiences as they wished-and for many of them, the issue of how their child's depression impacted on their experiences as a parent was at the forefront.

It is also important to highlight that being part of the parents' baseline assessments for the main RCT meant that the interviews conducted with the parents were relatively short because of time restrictions. Thus, while each interview offered an insight into parents' experiences, one could argue that the constrained length of the interviews could have affected the depth and richness of the interview data that we collected. Nonetheless, it seems reasonable to propose that, given the comparability of the findings of our study to those of previous qualitative studies in which much longer interviews were conducted with parents of young people with mental health issues, it is perhaps unlikely that entirely different main themes would have been found in our study had the length of the interviews not been restricted by time constraints.

The majority of the parents interviewed in our study were mothers; only eight of the parents were fathers. Although this is relatively consistent with previous qualitative studies of parents of adolescents with mental health issues, the majority of which have arguably focused on the experiences of mothers who are often seen as children's primary caregivers (Fraser and Warr 2009), the extent to which our findings can be said to 'speak for' fathers of depressed adolescents is relatively limited. This is particularly pertinent in light of previous research in this area, which has highlighted the differential reactions of mothers and fathers to their child's mental health issues (e.g. Chesla 1991; Johansson et al. 2012). However, it is also important to note that some previous studies exploring the caregiving experiences of fathers of children with various mental health issues have reported finding similar themes in fathers' narratives to those reported in studies with mothers, with fathers likewise experiencing feelings of emotional turmoil in relation to their child's illness, as well as making adjustments to their lifestyles in order to meet the needs of their ill child (e.g. Fraser and Warr 2009; Wintersteen and Rasmussen 1997). The comparatively large proportion of mothers in our sample could be explained by the fact that mothers in our society are still responsible for the majority of routine parenting activities (Bianchi 2000), and so were more likely to be the parent responsible for bringing their child to seek professional help. Moreover, equal representation of mothers and fathers as participants was not sought in the IMPACT trial, as it was only expected that at least one of the young person's parents would be able to take part.

In this article, we have focused on the experiences of parents of adolescents with a diagnosis of depression at the point of their referral to CAMHS in the UK. Research has shown that depression is viewed by members of the general public in the UK as a mental illness with a relatively good prognosis for recovery, compared to schizophrenia or bipolar disorder (Furnham 2009). However, the findings of our study overall indicate, in line with previous research exploring the experiences of carers and family members of individuals with depression (Highet et al. 2004), that the stress and strain that can be experienced by parents of adolescents with a diagnosis of depression at the point of their child's referral to CAMHS in the UK is still significant. Indeed, the findings of our study are comparable to those of other qualitative studies that have detailed the emotional distress, feelings of helplessness, guilt, and selfdoubt, and disrupted parenting, social lives, and daily routines that parents of adolescents diagnosed with such mental health disorders as anorexia nervosa, schizophrenia, or bipolar disorder, can face. The findings of our study are also distinctive in that they show that some parents had not noticed any changes in their child's feelings and behaviors at all prior to their child's referral to CAMHS, and they highlight the lack of support and consequent support needs voiced by many of the parents at the start of their child's journey through CAMHS. Given the dearth of research focusing on the experiences of parents of adolescents with

a diagnosis of depression, as well as the prevalence of depression in adolescence, this is crucial.

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