

Parental illness work across the attention deficit hyperactivity disorder diagnostic journey

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Abstract

The process of referral, assessment, and diagnosis of attention deficit hyperactivity disorder (ADHD) within the UK is often protracted. Given that parents are frequently the instigators of the diagnostic process, understanding the experience of parents is important. Drawing on findings from a longitudinal study, this article explores how the parental experience of the ADHD diagnostic journey includes three significant and distinct forms of ‘illness work’. Twenty-one semi-structured serial interviews were conducted over a 2-year period with seven parents of children on the ADHD diagnostic journey in North East England. We present three significant forms of parental illness work: (1) The ‘diagnostic quest’, parental work recognising and fighting for their children’s needs and selfhood, seeking diagnosis and engaging with systems, (2) ‘self-biographical illness work’, the personal parental biographical response to the diagnostic journey and (3) ‘child biographical illness work and recontextualizing the child’, parental biographical adjustment and recontextualisation of their children. We advance Rasmussen et al.’s (2021) model by demonstrating its usefulness in understanding how parents with a

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personal ADHD diagnosis experience biographical disruption or cohesion in response to their *children's* diagnosis. That a child's diagnosis leads parents with ADHD to experience a self-biographical cohesive or disruptive response is a unique and significant finding.

KEYWORDS

ADHD, attention deficit hyperactivity disorder, biographical disruption, illness narrative, illness work, parent

INTRODUCTION

Attention Deficit Hyperactivity Disorder (ADHD) is one of the most diagnosed childhood conditions (Barkley, 2015; Faraone et al., 2021), affecting an estimated 5%–7% of school aged children (Polanczyk et al., 2007) and 2.5% of adults (Faraone et al., 2021). Globally, ADHD is currently classified as a heterogeneous neurodevelopmental disorder (Sonuga-Barke & Thapar, 2021), where children demonstrate increased inattention, hyperactivity and impulsivity to levels negatively impactful on daily functioning (American Psychiatric Association [APA], 2013). The process of referral, assessment, and diagnosis within the UK is often protracted, fuelling a rising tide of criticism regarding the perceived failure of the ADHD diagnostic system in supporting parents and patients throughout the journey (Faraone et al., 2021; Young et al., 2020). Given that parents of children with potential ADHD are often the instigators of the diagnostic process (Honkasilta & Vehkakoski, 2019), understanding the experience of parents as their children traverse the ADHD diagnostic process is important. The parental experience of ADHD has been widely explored, with findings describing the parental experience of living with a child with ADHD as exhausting (Corcoran et al., 2017a), Corcoran et al., 2017b challenging (Ghosh et al., 2016) and a battle for justification (Carr-Fanning & McGuckin, 2018). Existing qualitative literature on the parental experience of ADHD is typically limited to studies in which parents are asked to reflect on their experience *after* their children have received a diagnosis (Cocoran et al., 2017a). These studies often explore the experience of *having* a child with ADHD (McIntyre & Hennessy, 2012) or explore the parental experience of their children's ADHD diagnosis *after* diagnosis has been given and integrated into everyday experience (Carr-Fanning & McGuckin, 2018; Ghosh et al., 2016). For many parents, the process of diagnosis is 'arduous' (McIntyre & Hennessy, 2012, p. 70), and experiences of distress, powerlessness and invalidation are commonplace (Carr-Fanning & McGuckin, 2018; Cocoran et al., 2017a). However, evidence suggests that a diagnosis of ADHD is perceived by parents as essential in supporting their children. A diagnosis is experienced as legitimising and validating of the difficulties and challenges faced by parents (Carr-Fanning & McGuckin, 2018), whilst also granting an increased sense of parental control (Klasen, 2000) by reinterpreting the child's behaviours and needs (Ringer et al., 2020). Evidence also suggests reductions in parental shame and blame following diagnosis, as a medical diagnosis allows children's difficulties to be reframed as symptoms of the condition and not parental failure (Ghosh et al., 2016; Singh, 2005).

While many of these studies explored the parental experience of diagnosis, none have studied the overall parental experience of the diagnostic journey itself, with authors calling for a longitudinal project to explore biographical work within 'society's institutional spheres' outside

of the family (Rasmussen et al., 2020, p. 7). The limited exploration of the parental experience pre-diagnosis, alongside a paucity of longitudinal projects on the parental experience of ADHD, provide a substantial theoretical gap within which this project is situated. This article develops understanding of the needs and experiences of parents whose children are travelling across the diagnostic journey of ADHD by exploring both pre- and post-diagnostic periods, in conjunction with the parental response to diagnosis.

The longitudinal study upon which this article is based explored how the experiences of parents across the ADHD diagnostic journey can be conceptualised as significant illness work (Corbin & Strauss, 1988). The study addressed a significant gap in the literature regarding the changing parental experience of the ADHD diagnostic journey and aimed to answer the following research questions.

1. What are the parental needs and experiences across the ADHD diagnostic journey?
2. How do these needs and experiences change across the journey?
3. How do parents make sense of the ADHD diagnostic journey?
4. What stories do parents tell regarding this journey?

The findings and conclusions are in keeping with similar studies investigating the experience of parents of autistic children (Singh, 2016), in which the illness work is divided into practical diagnostic work and biographical work. Our key findings suggest parents must engage on a 'diagnostic quest', upon which they recognise their children's additional needs, seek diagnosis, engage with the complexities and failings of the systems of health care, fight for their children's needs and selfhood to be understood and acquire educational and social resources. Parents were also found to engage in two distinct forms of biographical work: 'self-biographical illness work' and 'child biographical illness work and recontextualizing the child'. The former work prioritises the personal and individual biographical response of the parent. A spectrum model of biographical cohesion and disruption (Rasmussen et al., 2020) is used to understand the biographical impact in response to the ADHD diagnosis, the 'self-diagnostic' biographical response in parents with a diagnosis of ADHD themselves and the biographical response to the diagnostic journey itself. Parental biographical adjustment in the contextualisation of their children, alongside other child biographical work, is also evidenced. 'child biographical illness work and recontextualizing the child' demonstrates how a diagnosis of ADHD allows parents to recontextualise their children from a 'naughty typical child' to a 'normal atypical one' and explore their children's identity and personhood within the remit of disability language and neurodiversity.

Illness work and ADHD

The notion of illness work has been developed and applied to many contexts since the coining of three main types of work by Corbin and Strauss (1985, p. 224). In the home, the process of managing chronic illness includes 'illness work' (work related directly to the illness such as diagnostic work and symptom management), 'everyday life work' (the typical roles and responsibilities of living everyday life such as cooking and cleaning) and 'biographical work' (developing and maintaining identity in the face of chronic illness) (Corbin & Strauss, 1988; Williams, 2000). The experiences of parents are 'entangled' in the biographies of their children (Bray et al., 2014) and childhood illness becomes 'parent work'. Childhood illness is likely to

have a direct impact on the parent additional to the typical 'labour' of care-giving (Kittay, 2011). Although it can be argued that all parents face these experiences, for those parenting a child with potentially disabling or chronic condition such as ADHD, these experiences are magnified. Given childcare is primarily the responsibility of mothers (Hayes, 1998), and western society often 'blames' mothers as 'responsible' for the existence of childhood disability (Runswick-Cole & Ryan, 2019, p. 203), a child's potential ADHD diagnosis represents not only parent work, but 'mother work'.

Biographical illness work

The disruptive impact of illness on individual narrative has a rich and complex history within sociological discussion (Bury, 1982; Charmaz, 1983; Corbin & Strauss, 1988; Williams, 2000). Much of the sociological literature exploring biographical disruption focuses on the impact on personal narratives of unexpected, chronic and deteriorating illnesses in otherwise healthy adults with established 'pre-illness identities' (Bray et al., 2014, p. 835). Over time, elaborations on this concept such as narrative reconstruction (Williams, 2000), biographical flow (Faircloth et al., 2004), biographical continuity (Ong et al., 2014) and biographical illumination (Tan, 2018) have developed in response to criticisms of a solely biographically *disruptive* perspective of illness experience.

However, there is a growing body of discussion arguing that biographical illness work provides an effective means to understand parental experiences of childhood diagnosis and illness (Rasmussen et al., 2020; Singh, 2016). As parents, and primarily mothers (Singh, 2004), are morally responsible for their children (Pejlert, 2001) and the parental experience is inter-linked with that of the child (Ghosh et al., 2016), it is reasonable to contend that childhood illness impacts parental narratives. As there is limited discussion of parental illness work within ADHD research, parental biographical work within autism research present an appropriate alternative. Singh (2016: 1114) framed the parental experience post-autism diagnosis as 'devastation' upon hearing that the diagnosis was lifelong, whilst others 'challenged the medical perception of their children'. Like ADHD, autism literature has shown that children are often misinterpreted as lazy and ill-mannered (Mogensen & Mason, 2015), creating deep-seated parental feelings of shame and guilt (Rasmussen et al., 2020). Rasmussen et al.'s paper exploring parental biographical narratives following childhood autism diagnosis (2020) introduced a biographical spectrum model, offering a framework from which to consider parental biographical response to childhood diagnosis. In this article, we explicitly bring the ADHD diagnostic journey into this spectrum framework of parental illness work to demonstrate how parents engage in three distinct forms of work; the diagnostic quest, self-biographical illness work and child biographical work and recontextualising the child.

METHODS AND ANALYSIS

The findings and arguments presented in this article are based on data collected while exploring the parental experience of the ADHD diagnostic journey. Using longitudinal serial interviews, the primary author conducted three interviews with each participant over a period of two years to explore parental experiences at the temporally significant time periods of *pre-diagnosis*, *diagnosis* and *post-diagnosis*, witnessing the meaningful changes that occur for parents as they

traverse the diagnostic journey. A purposive and convenience sampling strategy was employed to recruit seven parents of children being assessed for ADHD within a North East England NHS Child and Adolescent Mental Health Service [CAHMS] and two ADHD support networks. Although the inclusion criteria required only that the person to be a 'parent or caregiver', only one participant was a father, an issue typical within ADHD research dominated by the responses from mothers (Rowlands, 2016; Singh, 2003). As a research sample is defined by those who are 'prepared to be in it' (Smith & Osborn, 2015), it is notable that the majority of parental participants had some health care-related professional experience. The following table outlines relevant demographic data for the participants, including whether the participant has their own ADHD diagnosis:

This project utilised a narrative approach to explore the lived and storied needs and experiences of parents as they traverse across the ADHD diagnostic journey with their children. An adapted sociocultural narrative analysis methodology (Grbich, 2013; Jones & Mistry, 2019) was used to make sense of the construction and delivery of the parental narratives, as the content of parental narratives was synthesised and categorised into the three core findings discussed below. Rasmussen et al.'s (2020) biographical spectrum model was used analyse parental biographical responses to their children's diagnostic journey. Ethical approval was granted by Northumbria University's ethical review board and by Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust. The following section will discuss three overarching narrative forms evident across the longitudinal data: the diagnostic quest, self-biographical illness work and child biographical work and recontextualizing the child.

FINDINGS: ILLNESS 'WORK' ACROSS THE PARENTAL ADHD DIAGNOSTIC JOURNEY

The diagnostic quest

A major form of illness work parents on the ADHD diagnostic journey engage with includes 'diagnosis work' (Corbin & Strauss, 1988), or work related to the process and challenges of seeking, fighting for, justifying, and receiving a diagnosis of ADHD. Diagnosis work requires significant effort from parents across the entirety of the diagnostic journey similar to the autism 'diagnostic quest' reported by Singh (2016). The beginnings of parental diagnostic work is captured in the phrase '*there was a problem*', as parents become aware of a potential '*problem*' akin to the lack of 'emotional ripeness' described by Plotkin-Amrami and Fried (2023, p. 15). Thus, begins an investigative process of monitoring and seeking confirmation. Increased parental engagement and involvement in education was common within the participant group, as ADHD symptom related academic difficulties required parents to communicate with teachers at increased rates, or to scaffold and support their children's education through increased emotional support, greater parental involvement with homework and greater degrees of 'at-home' education such as reading practice. Although this additional parental effort could appear to be evidence of parents simply supporting their children and may not seem immediately relevant to the diagnostic quest, on further inspection this process is often a form of strategic parenting work (Singh, 2016) used by parents to make others aware of the '*problem*' their children are facing. Cohen's (2009) claim that parental complaints about behaviour and impairment indicate an implicit suggestion that their children have/may have ADHD is of relevance. The requirement that their children's additional needs be seen within a medical

context, and not as evidence of poor parental ability as if often the case (Carr-Fanning & McGuckin, 2018), presents one aspect of the aforementioned diagnostic work.

Following on from the preliminary effort of recognising, monitoring and confirming their children's ADHD type behaviour, parents on the ADHD diagnostic journey are then forced to engage in a slew of challenges. The process of gaining access and inclusion onto a specific ADHD diagnostic pathway is itself significant illness work performed by these parents. Parents of children exhibiting the symptoms of ADHD described having their concerns rejected by schools, within families, and by medical professionals. Therefore, like Singh's (2016) parents of autistic children, the requirement to stand up to this rejection, fight for their concerns to be seen as legitimate by others and to find a medical professional willing to listen to these concerns constitutes a significant form of illness work. This work often exerts a physical and emotional toll on parents of children with ADHD, who describe a constant state of conflict and battle. Parents of children with suspected ADHD also described making expensive accommodations such as moving to 'better areas' or paying for private assessment. Furthermore, parents undergoing private assessment repeatedly expressed their regret, guilt and concern for those unable to pursue private assessment as they perceived private assessment as more thorough, effective and validating:

*My concern is the waiting list. I just can't wait. I feel like he's waited long enough, and we need to know now. I feel like I'm more **guaranteed a better service if I go privately**, I want **the best** for him, and I can't wait 2–3 years and not get the best quality. I feel private will be a better quality service... But on the other hand, going private I feel resentful. I shouldn't have to do this.*

(Pam Interview 1)

The belief that financial resources are beneficial in increasing the likelihood of receiving an ADHD diagnosis, whether objectively true or not, culminates in parents performing additional, often expensive, illness work such as paying for private assessment, moving home or paying for private tutelage.

Once their child has been accepted onto an ADHD assessment pathway, the work continues. The concept of '*the system*' emerged, relating to the many practical challenges faced by parents as they are required to engage in typical diagnostic work as outlined by Corbin and Strauss (1988), such as attending appointments, reading information leaflets and filling in questionnaires. For parents on the ADHD diagnostic journey this typical work was often narrated as judgemental and inflexible, purposefully ineffective and emotionally destructive. Parents engaging with health-care systems for their children are expected to attend appointments; however, parents of children with ADHD describe a lack of flexibility in appointment timings, and the perceived thoughtlessness of impractical appointment timings and locations for working parents can be conceived as additional illness work. For parents, it is not simply a matter of attending a health-care appointment. They must engage with further work by negotiating with employers for time off, requesting flexible working hours, reducing their overall working hours, or as one participant was required to do, leave employment entirely to support their children (Cocoran et al., 2017a). Chronic childhood illness, alongside limited employer support and unsupportive employer attitudes (George et al., 2008), has a major negative impact on parental employment (Kish et al., 2017). Our findings highlight how the parental work in traversing the ADHD diagnostic journey impacts on employment additional to the experience of having a child with a chronic condition.

Throughout the parental experiences and interaction with “*the system*” of health care, parents are required to ‘*prove*’ that they are not blameworthy for their children’s current difficulties by attending multi-week parenting courses and making practical changes at home prior to the completion of some clinical assessments. The implicit, and often explicit, communication that parents are in some way to blame for their children’s ADHD-related difficulties requires parents to perform as a ‘good parent’ by not presenting as overly emotional, or challenging the status quo beyond the acceptable, further adding to the perceived work burden. All mother participants described experiencing emotional pain and anxiety because of the difficulties that their children were facing, whilst also feeling that they cannot fully present this emotional anguish to professionals for fear of being perceived as ‘*overly emotional*’ or as ‘*anxious, histrionic mothers*’ [Pam, Interview 2]. The apparent necessity to hide or at least manage emotional pain throughout the diagnostic assessment of ADHD, to avoid being perceived as an unreliable source of information, is perhaps one of the more insidious forms of parental work throughout the diagnostic quest.

Post-diagnosis, the ‘diagnostic quest’ continues as participants sought ADHD-related information, academic and social support, financial assistance such as disability living allowance and advice on prospective treatment options. All parents described a desire to develop their ADHD knowledge, ‘filling in’ (Corbin & Strauss, 1988, p. 30) information gaps by reading literature or watching ADHD-related content online. Although parents of autistic children have been found to attend autism advocacy groups and parental support networks at this stage (Singh, 2016), parents of children with ADHD described little to no access to these types of supportive resources. Pam described the lack of peer-related support as ‘*isolating*’ and ‘*anxiety provoking*’ but hoped to begin a local ADHD support network of her own, adding significantly to her illness workload. Parents on the ADHD diagnostic journey proclaim an almost complete lack of support post-diagnosis, forcing them to proactively and assertively seek out what they ‘*could get*’. Although parents may not be the patient themselves, they must personify the ‘activated’ and ‘motivated’ patient (Entwhistle et al., 2018; Franklin et al., 2019, 14) to manage the collection of resources.

Within this study, unless a child commenced on a medication regime, most parents describe being ‘*cast off*’ (Rachel, Interview 1) and ‘*set-adrift*’ (Pam, interview 2) as they are offered no alternative treatment or support. Those whose children are diagnosed with autism are offered a five-week autism awareness course, whilst ADHD parents must ‘*fend for themselves*’ (Cath, Interview 2). It has been argued that within typical illness encounters, self-management is ‘marginalised in favour of medical instruction’ (Ong et al., 2014, p. 232) as medical professionals dictate and prescribe the most effective treatment options (Stevensen et al., 2003). However, the apparent lack of non-medication-related support leads parents to work towards becoming an ‘*informed*’ parent who could challenge the system and self-manage their children. Post-diagnostic information has been declared by parents to be dissatisfying, overly technical, and non-specific to their child (Ahmed et al., 2014). Parental efforts towards becoming ‘*informed*’ evidences a form of evidence-based activism (Rabeharisoa et al., 2014), in which parents contest systemic and institutional problems with greater authority. Parents work towards becoming ‘*credentialed experts*’ as well as ‘*experientially informed*’ (Rabeharisoa et al., 2014, p. 119) to seek supportive solutions for their children and destabilise existing understandings and narratives of ADHD.

Within education, many parents feel they exist in a state of perpetual potential conflict as they battle for their children’s needs to be met. Similar to previous findings (Carr-Fanning & McGuckin, 2018), participants experienced a constant need to convince educational professionals of their children’s additional needs both pre- and post-diagnosis. Once an ADHD

diagnosis is confirmed, the work transitions from pursuing and legitimising their children's ADHD to fighting for effective academic provision. More than half of the parental participants gave examples of reading legal policy and legislation to seek effective school support, a process which Debbie [Interview two] points to as the reason for her '*emotional break down*' as she failed to cope with these overwhelming parenting demands. Parental 'evidence-based activism' (Rabeharisoa et al., 2014) at school was presented as particularly important towards the end of the diagnostic journey as, although some schools incorporated adjustments and learning interventions, these were rare. The diagnostic quest-related work does not dissolve once a diagnosis is given, it changes.

BIOGRAPHICAL ILLNESS WORK

Self-biographical illness work

'Self-Biographical Illness Work' encapsulates the work parents perform to maintain and define a stable personal biographical identity in response to the ADHD diagnostic journey. We argue that sociological discussion regarding chronic illnesses' impact on biography is useful in understanding the impact of the diagnostic journey itself on parental biographical narratives.

The impact of chronic illness on personal biographies has seen much sociological discussion since Bury's (1982) seminal work, including narrative reconstruction (Williams, 2000), biographical flow (Faircloth et al., 2004), biographical continuity (Ong et al., 2011) and biographical illumination (Tan, 2018). Although these theories were originally developed to understand the biographical impact of personal illness, they are increasingly being used to aid in our understanding of the impact of childhood illness on parental biographies (Bray et al., 2014; Rasmussen et al., 2020). However, these studies have typically explored the parental experience of ADHD and ASD diagnosis retrospectively. As timing, context, and circumstance play a role in the level of normalisation and problematisation of life altering events (Williams, 2000), retrospective stories are potentially altered by retelling of earlier experiences.

Perhaps the most expected form of parental self-biographical illness work was in response to diagnostic confirmation. Parents describe their children's ADHD diagnosis as legitimising, allowing them to re-establish their credibility as parents. ADHD diagnosis reduced feelings of guilt and shame, a conclusion echoed in other studies (Gwenan-Jones et al., 2015). Parents recontextualised their self-biography from that of a 'parent of a naughty child' to a 'parent of a child with additional needs and/or a medical condition'. Diagnosis allowed parents to reflect on experiences across the diagnostic journey damaging to their self-concept, such as being blamed for their children's behaviour, and positively reconstruct (Williams, 2000) their biography. The emotional impact of diagnosis is personified in the following excerpts:

People take you seriously, you're not just a neurotic mother.

[Pam Interview 2]

It was everything I wanted to hear so that I knew I wasn't going mad.

[Rachel Interview 1]

ADHD diagnosis allows some parents to positively reconstruct their personal narrative, echoing the biographical cohesion experienced by parents of autistic children discussed in

TABLE 1 Participant information.

Name	Age	Profession	Parental diagnosis?	Child's information
Sharon	41	CAHMS practitioner	Yes	Son (9)
Pam	39	Nurse	No	Son (8)
Rachel	43	Care worker	No	Daughter (12)
Debbie	45	Social worker	Yes	Daughter (16)
Jane	41	Healthcare Student	Yes	Daughter (9)
Cath	44	Nurse	Yes	Son (14)
Phil	46	Nurse	No	Son (6)

Rasmussen et al. (2020). For parents such as Cath and Phil, the biographical work took on a different form as they were confident of receiving an ADHD diagnosis due to their clinical experience. The self-biographical work was a confirmation and continuation of their expectations akin to Ong et al.'s (2011) biographical continuity.

Parental biographical work post-diagnosis was not always positive. For Debbie, confirmation of her daughter's diagnosis created two forms of biographical work. As Debbie's daughter had undergone an inconclusive ADHD assessment previously, the diagnosis led to an increase in feelings of shame and blame. Diagnosis was '*proof*' of her parental inadequacy, as she '*should have fought harder*' and '*not given up*' (Debbie: Interview 2) during the previous assessment. Debbie's post-diagnostic biographical work re-narrated her past behaviour as evidence of her '*failings*' as a mother, exemplifying biographical disruption post childhood diagnosis. This form of biographical disruption differs to that typically discussed within sociological literature, where disruption occurred following childhood diagnoses not previously considered (Rasmussen et al., 2020). Debbie's story indicates that childhood diagnosis can be biographically disruptive for parents who have previously pursued diagnosis unsuccessfully Table 1.

Table 2 demonstrates the participant's biographical response to their children's diagnosis.

The second form of self-biographical illness work parents engage with can be conceptualised as 'ADHD self-diagnostic biographical work'. For parents with a personal ADHD diagnosis, their children's diagnostic journey created biographical moments within which the parents reconstruct their own ADHD narrative. Witnessing their children's ADHD related difficulties forced parents to consider ADHD's impact on their own lives, questioning: '*do I have these difficulties?*', '*if I had been diagnosed earlier would my life have been better?*' (Debbie, Interview 1) and '*am I disabled?*' (Cath, Interview 2). This illness work is similar to typical examples of biographical disruption (Bury, 1982) and reconstruction (Williams, 2000), as parental responses appear comparable to a personal diagnosis. Parents with ADHD describe dissonance between their personal ADHD narrative and their children's. Debbie and Sharon perceived their own ADHD in negative terms, presenting it as an antagonistic entity to be overcome. However, they described their children's ADHD as both beneficial and impairing. The reconstruction of a self-biography in which this dissonance became tenable exemplifies 'self-diagnostic biographical work'. Debbie and Sharon present their ADHD self-concept as an historical artefact, developed due to a lack of information on the diagnosis within a society experienced by older generations. 'Self-biographical illness work' allowed them to hold the seemingly contradictory positions of seeing their own ADHD as a disruptive force, whilst hoping their children see ADHD in a balanced way. Furthermore, given ADHD's high heritability (Barkley, 2015), this finding

TABLE 2 Biographical impact in response to ADHD diagnosis.

Parent	Biographical impact in response to ADHD diagnosis	Potential reason Why
Jane	Disruptive	The lack of a diagnosis appears disruptive given Jane's firm conviction that her daughter has ADHD
Debbie	Both disruptive and cohesive	Confirmation of a diagnosis proved Debbie's belief that her daughter has ADHD correct. However, it also evidences that she did not 'fight hard enough' in the final assessment.
Pam	Cohesive	The diagnosis recontextualised Pam's sons' difficulties by giving a justified medical reason for their existence.
Sharon	Both disruptive and cohesive	Sharon's healthcare background and personal diagnosis allowed her to draw upon her experience and feel confident in her conviction that her son has ADHD. However, the confirmation of a diagnosis also led to worry about the future given that she was "aware" of the potential risks.
Cath	Cohesive	Cath's healthcare background, her personal diagnosis, and eldest son's ADHD diagnosis allowed for a high degree of confidence in her belief that her son has ADHD
Rachel	Cohesive	The confirmation of a diagnosis was "everything" for mum as it allowed her to utilise medical understandings and discourse of ADHD to adjust her perception of her daughter.
Phil	Neither disruptive nor cohesive	Phil's high degree of confidence in his belief that his son has ADHD allowed for a more ambivalent approach to the diagnosis as it signified a minor barrier in his pursuit of treatment (medication)

presents an interesting area for future study. Table 3 outlines each parent's ADHD 'self-diagnostic' biographical response.

Exploring the diagnostic journey illuminated illness work uninterred in prior ADHD research studies. This work occurred in response to the diagnostic journey itself, as parents faced questions regarding their parenting capacity prior to diagnostic confirmation. Mothers in particular spoke of 'fingers pointed' at them, being blamed for their children's ADHD behaviours, and being questioned on whether they believed themselves to be '*overly neurotic*' or '*obsessively clingy*' (Pam, Interview 1). These questions invalidate parental concerns regarding ADHD, place the onus of responsibility on mother's perceived emotional and behavioural weaknesses and delegitimise requests for ADHD assessment. This onslaught requires mothers to perform self-biographical illness work, not in response to diagnosis, but to the illness journey. Confrontational interactions across education and health-care force parents to perform the practical 'diagnostic quest' alongside personal biographical work.

We propose that the self-biographical illness work, and the development of mothering self-identity fit within Rasmussen et al.'s (2020) parental biographical spectrum model. For parents such as Pam, interactions with 'The System' are biographically disruptive, as attacks on her parenting ability led her to question her mothering self-concept. Pam's [Interview one] emotional distress as she states that she '*thinks she is a good mum*' (after a healthcare professional questioned whether she is '*overly neurotic*'), evidences the disruptive impact of these experiences on parental biographies. Although the eventual diagnosis was a cohesive

TABLE 3 ADHD 'self-diagnostic' biographical response.

Parent	ADHD 'self-diagnostic' biographical response	Potential reason Why
Sharon	Disruptive	Her son's diagnosis led to a period of reflection in which Sharon lamented how ADHD has presented many difficulties and barriers in her own life. Sharon described how she would gladly take a pill which removed her own ADHD but would hate for her son to feel the same way.
Debbie	Disruptive	Debbie's daughter's diagnosis forced Debbie to reflect on her own self concept of ADHD and disability, reframing herself as " <i>less able</i> ". Debbie's framing of her own ADHD as her " <i>biggest nemesis</i> " meant that she was forced to confront this nemesis once her daughter was diagnosed.
Jane	Cohesive	Jane's daughter not getting a diagnosis was a matter of great frustration for Jane as she strongly associates with being neurodivergent and already having another daughter with ADHD. The lack of a diagnosis solidified Jane's belief in her own ADHD and the high likelihood that her daughter does have ADHD as she was able to explain this discrepancy as CAMHS' incompetence.
Cath	Cohesive	Cath strongly identifies herself and her family with the label of ADHD and neurodiversity/neurodivergence. Her son's diagnosis allowed for a comfortable integration and affirmation of her own ADHD related strengths and difficulties and further evidence of her " <i>neurodiverse family</i> ".

biographical experience for Pam, having to defend her mothering identity prior to diagnosis represents additional biographical work. For others, interactions with 'The System' led to self-described '*destruction*' and emotional breakdown. Debbie thought she was strong enough to manage these parental demands, but '*failed*' [Interview 3]. Her experience of revising her mothering self-concept from one prioritising strength to self-defined 'failure' represents disruptive parental self-biographical illness work.

However, for mothers who experience fewer direct attacks on their mothering identity, pre-diagnostic journeys can be biographically cohesive. Cath, whose professional ADHD expertise allowed her to position herself as 'informed', experienced minimal blame from health-care professionals. Professionals' readily accepted her expertise and use of medical language, but Cath also confidently challenged bad health-care practice. Cath could reinforce her mothering biographical self-concept and maintain her identity as a knowledgeable, informed professional mother. Table 4 highlights parental biographical responses to the diagnostic journey.

Child biographical work and recontextualising the child

A further form of biographical illness work relates to how parents contextualise and view their children in response to the diagnostic journey. Recontextualising the child is often necessary for parents whose "self-understanding and the possibilities for understanding and supporting their

TABLE 4 Biographical impact in response to diagnostic journey.

Biographical impact in response to diagnostic		
Parent	journey	Potential reason Why
Jane	Disruptive	<p>Jane explored how “The System” has let both her and her daughter down by not meeting her daughters needs by diagnosis ADHD. Jane presents the diagnosis of ADHD as the primary way she could access support for her daughter. She regularly expounds that society is the ‘problem’ and that “The System” does not allowed for her children to flourish.</p> <p>Jane regularly presents herself as the “Informed mother” who is more knowledgeable than the professionals responsible throughout the diagnostic journey. Jane’s story is one dominated by narratives of ‘fighting’ and “The System” as she experiences significant disruption to her own and her daughters’ narratives due to the significant challenges faced when pursuing a diagnosis.</p>
Debbie	Both cohesive and disruptive	<p>Debbie’s ‘quest’ for a diagnosis was a quest for cohesion. Previous inconclusive ADHD assessments and multiple experiences of being shamed and blamed as a mother throughout the diagnostic journey were significantly biographically disruptive. Whereas the diagnosis of ADHD was a cohesive experience, the disruption of her own biography as a mother was primarily due to Debbie’s negative interactions with “The System” when seeking diagnosis.</p> <p>Debbie always expected the diagnosis of ADHD, in part due to her own diagnosis and the diagnosis of her son. However, although the diagnosis of ADHD was a cohesive and expected experience for Debbie’s view of her daughter, the additional diagnoses of dyslexia and autism were felt to be biographically disruptive as she did not expect them. The focus on ADHD led to a “<i>blindsiding</i>” disruption when confronted with an autism diagnosis.</p>
Sharon	Both disruptive and cohesive	<p>Sharon expected her son to be diagnosed with ADHD, declaring that her previous experience working within CAHMS allowed her to ‘know what to expect’. This was a biographically cohesive experience for mum given her expectations. However, during the diagnostic journey professionals also considered a diagnosis of autism, which was experienced as significantly biographically disruptive to mum as she saw autism as a “<i>less hopeful</i>” diagnosis.</p> <p>This unexpected additional diagnosis, alongside school reports demonstrating her son’s significant difficulties were emotionally upsetting for Sharon and felt to be evidence of her being a “<i>bad mum</i>”, causing disruption.</p>
Cath	Cohesive	<p>Cath’s “Informed and Insider” position allowed her to consistently subvert “The System” to achieve the outcomes she desired. Although Cath experienced difficulties and ‘fights’ throughout the journey she was confident in her ability to overcome these by utilising her professional experience. Cath’s conceptualisations of her family as a “<i>weight and wonderful neurodiverse family</i>” allowed for a seamless integration of her son’s ADHD diagnosis into the overall narrative. Although not illuminating a process as it was for pam, the journey itself was cohesive and relatively problem free for Cath when compared with others’ experiences.</p>

TABLE 4 (Continued)

Biographical impact in response to diagnostic		Potential reason Why
Parent	journey	
Rachel	Both disruptive and cohesive	Rachel's overall story is one of great emotional difficulty, challenge, turbulence, and waiting. Although her daughters ADHD diagnosis was biographically cohesive, the journey itself was experienced as constant disruption and strife. Rachel experienced long waiting times with limited to no communication from CAHMS. The diagnostic process was often likened to being "lost at sea" as Rachel described limited support and communication from professionals and a perpetual state of anxiety and concern for her daughter. Rachels diagnostic journey was significantly disrupted by the Covid-19 pandemic and subsequent lockdown, as her daughter's assessment was postponed for over a year.
Phil	Neither cohesive nor disruptive	Potentially influenced by Phil's position as an "Informed father" and as the only father in the group, Phil's biographical experience of the ADHD diagnostic journey was unique within the sample. There was limited emotional confluent within Phil's story as the journey was presented as simply a series of goalposts and steps towards the expected outcome of his son's ADHD diagnosis and the commence of stimulant medication. The diagnostic journey was narrated as a necessary step towards phil getting support for his sons education. Although the diagnostic journey was presented as difficult and emotional due to systemic failures within the system, his healthcare experience allowed phil to prepare for and expect these difficulties in a way which did not disrupt his biographical position. The diagnosis of ADHD for his son was comfortably integrated into Phil's pre-existing narrative for his son but was not presented as particularly disruptive or cohesive.

children' (Rasmussen et al., 2020, 6) is "under assault" by diagnosis or illness (Bury, 1991, p. 453).

The importance placed on diagnosis exemplifies how parents see diagnosis as a tool in understanding their children and a means to effective support. Diagnosis explains their children's atypical behaviour, allowing Debbie [Interview 1] to learn "*what is making her (daughter) tick*" and re-evaluate her daughter from "*scatty ditsy girl*" to a child with 'additional needs'. Hamed et al. (2015) state that ADHD diagnosis allows one to become a 'person who has a problem', not a 'problem person'. Given participants were typically aware of their children's differences at an early age, the concept of biographical flow is of relevance, as those already aware of health issues may more readily accept additional health concerns (Faircloth et al., 2004). Five parents held firm convictions of an early 'problem' and a strong belief that their children had ADHD prior to diagnosis. Such parents experienced limited disruption in how they conceptualised their children post-diagnosis, describing a flowing cohesive experience as the diagnosis confirmed pre-existing illness narratives. Parents with limited pre-diagnostic conviction of their children's ADHD, found diagnosis to be biographically illuminating (Tan, 2018). The diagnosis created an enriching and empowering recontextualizing of their

children, allowing reconstruction of their children from the distressing ‘abnormal neurotypical child’ to the preferable ‘normal neurodivergent child’.

Additionally, parents imagine and construct new futures for their now medically diagnosed children. Parents (optimistically) describe diagnosis as important in allowing educators to understand their children better (reflecting school-based studies which demonstrate how teachers recontextualise ADHD behaviours post-diagnosis [Moore et al., 2017; Rogalin & Nencini, 2015]). However, these imagined futures generated additional fears as diagnosis created a conduit through which their children could be stigmatised and discriminated against. The construction of these new futures, alongside potential dilemmas such as disclosing their diagnosis to others, demonstrates further child recontextualisation work relatively unexplored within the wider ADHD literature.

Disability, difference, and personhood

Child biographical illness work is also apparent when parents engage with disability narratives. Across the diagnostic journey, parental oscillation between medical and social models of disability and ADHD, and the search for a balanced multi-modal view of their children, revealed further work. A medical model of ADHD is described by parents as undeniably useful for accessing treatment, improving understanding and reducing blame post-diagnosis. However, a solely medical model proved problematic for parents who wished to celebrate their children’s individuality and personhood beyond illness classification. Parents rejected the presentation of **all** their children’s differences as medical symptomology, opting for conceptualisations where difficulties are acknowledged and difference is celebrated. Illness and disability ‘negotiations’ are becoming increasingly common in the face of “medical claims to knowledge” which “sit uneasily with patient demands for co-operation” and individualism (Barnes & Mercer, 2010, p. 58). Initially, parents unanimously rejected disability language and/or viewing their children as disabled.

*I don't view him as **having** a disability.*

[Pam, interview 2]

I don't want to use the word 'disabled'.

[Debbie, Interview 3]

However, total rejection of disability language proves untenable for parents wishing to utilise the benefits associated with medical models of ADHD, leading to tentative acceptance of disability language and search for a balanced disability perspective.

It is a disability in some ways, they do need help. The stigma puts you off it.

[Cath, Interview 3]

Parents describe feeling compelled to accept the evidenced and lived reality of neurocognitive difficulties faced by their children. They also describe the practical challenges of rejecting disability language, especially when required to “*tick the box*” [Pam, interview 3] confirming their child ‘has a disability’ when applying for educational and social support. Navigating these contrary epistemological conceptualisations of ADHD and disability requires

parents to engage in a 'balancing act' of illness work. Parents seek an understanding of their children which utilises the benefits associated with a medical model, whilst including social and strength-based perspectives of neurodiversity.

The longitudinal nature of our study enabled observation of this illness work across the diagnostic journey. Preference towards models of neurodiversity/neuro-atypicality demonstrates parental desire for their children to exist outside of the individualising perspective of medical disability (Turowetz, 2015), and seek "neurobiological citizenship" (Brownlow & O'Dell, 2013, p. 106). Inconsistencies in language regarding ADHD creates additional work for parents when conceptualising their children. Examples include describing ADHD as neuro-developmental disorder (APA, 2013), impairment, disease, disability, illness or injury (Ortega, 2009), medical problem (Conrad, 2007), cognitive disability or learning difficulty (Lassinantti & Almqvist, 2021), superpower (Lench, Levine, & Whalen, 2013) or simply a difference. Parents argued the neurodiversity paradigm most comfortably allowed for positive conceptualisations of their children to flourish, contribute to society and seek neurobiological citizenship (Brownlow & O'Dell, 2013). One parent coined the term '*DIFFability*' in an attempt to capture the *difference* and *ability* of her children. Typically used illness vocabulary appears inadequate and unsuitable for parents of ADHD children. Nonetheless, biomedical understandings of ADHD prove beneficial in the parental process of recontextualisation of self and child, and alternative models of disability (Shakespeare, 2014) could inform future research on understanding these parental preferences.

The final form of child biographical work concerns medication practices. Parents on the diagnostic journey must consider and discuss stimulant medication given its status as an efficacious and conventional ADHD treatment (Faraone et al., 2021). There was considerable discussion within parental narratives towards medication use pre- and post-diagnosis, with most expecting to commence medication as soon as possible (unlike parents in Brinkman et al. (2009, 584) who saw medication as a 'last resort').

Parents must consider whether medication fits within their conceptualisation of ADHD, given their engagement with social and/or neurodiversity models. Tension exists between the desire to see ADHD as neurodiverse difference and commencement of medication aimed at reducing problematic symptomology and improving academic performance. Parents worry about the stigma associated with stimulant medication, a concern well-founded (Cocoran et al., 2017b; Koro-Ljungberg & Bussing, 2009; Mueller et al., 2012). Three parents attempted to reframe ADHD medication discourse, presenting the re-establishing of dopamine balance via stimulants as a *medical* treatment akin to insulin for diabetes. This position prioritises a medical model of ADHD, with parents accepting a treatable biological deficit in their child's ability to function at a normative standard. These counter-stigma medication narratives featured in the accounts of parents with health-care backgrounds were absent from the narratives of parents with non-health-care backgrounds, echoing Birdsey and Joseph's (2021) claim that parents utilise medical expertise to develop treatment perspectives. Being medically 'informed' allowed for deeper engagement in this work, as parents draw upon medical language to reframe medication from social control against deviancy (Conrad, 1992) to agency over illness (Stewart, 2017).

Given arguments that ADHD medication represents a method of social control and 'drugging' of unwanted behaviours (Conrad, 1992; Conrad & Potter, 2000), framing stimulants as synonymous with medication for physical illnesses allows children to be conceptualised as 'typically ill', not deviant. This relatively unexplored form of parental illness work is of interest given the changing public discourse on ADHD medication. Parents commonly acknowledge

that symptom improvement outweighs medication's potential 'cost' (Wong et al., 2018), with many declaring medication is crucial to managing ADHD (Brinkman et al., 2009). Comstock (2015, 15) concurs, arguing that ADHD medication can no longer be viewed as merely 'prosthetic enhancement' (Conrad & Potter, 2000), but as a form of self-actualisation as ADHD adults 'self-invest' through medication to produce a 'self-disciplined and productive identity' (Comstock, 2015, p. 17).

We argue that parents on the diagnostic journey perform two distinct forms of medication related illness work: (1) The recontextualisation of ADHD medication from psychiatric drug to necessary physical treatment and (2) child biographical recontextualisation and identity adjustment in the face of medication.

CONCLUSIONS

This article is the first to prioritise an illness sociology perspective for parents of ADHD children both pre- and post-diagnosis. This study presents unique insights into the benefits of recruiting participants without a confirmed diagnosis, especially when analysing differences in parental anticipated pre-diagnostic biographical response and actual post-diagnostic response. The differences and similarities in pre- and post-diagnostic ADHD illness experience, and consequent effect on biography, require further study. The absence of parents from diverse minority groups is a limitation, as findings are unlikely to reflect the additional intersectional challenges faced pre- and post-diagnosis such as racial bias and the dual stigma of racial diversity and ADHD (Emmanuel et al., 2022; Paidipati et al., 2022), the experience of stigmatisation and victimisation of ADHD children of same-sex parents (Sullins, 2015) and the currently unknown and relatively unexplored (Conway et al., 2022) experiences of trans and non-binary parents.

We employed the concepts of parenting and biographical illness work utilised within autism studies (Rasmussen et al., 2020; Singh, 2016) and applied them in a novel manner to a UK-based ADHD context. We further these approaches by analysing the overarching diagnostic journey (without being limited to the post-diagnostic period), offering unique insights into how the diagnostic journey itself presents a variety of parental illness work. Understanding the parental ADHD experience (through the 'the diagnostic quest', 'self-biographical illness work', and 'child biographical work and recontextualizing the child') provides an important novel perspective on illness work and ADHD by demonstrating how different temporal points on the diagnostic journey, parental pre-existing ADHD and/or health-care knowledge and mothering identity contribute to the development of shared parental narratives of ADHD, themselves and their children. Although in a typical UK context, public discourse on ADHD often has a 'strong biomedical investment' alongside 'substantial, but subtle public scepticism' (Singh, 2018, p. 23), our findings included less scepticism regarding ADHD treatment and relatively nuanced conceptualisations of ADHD outside of the simple biomedical-social construction binary. Our sample, of which there was an over representation of health-care professionals, presents both a limitation in terms of transferability but also a unique insight into how parents with insider health-care knowledge may have unique illness work experiences regarding ADHD.

In conclusion, Rasmussen et al.'s (2020) biographical spectrum model is equally valid and theoretically relevant when applied to ADHD. Moreover, we advance the scope of the model by demonstrating its usefulness in understanding how parents with a personal ADHD diagnosis may experience a self-biographically disruptive or cohesive experience in response to their *children's* diagnosis. That a child's ADHD diagnosis leads parents with ADHD to experience a

self-biographical cohesive or disruptive experience (as if the parent had been diagnosed themselves) is a unique finding and significant contribution to our understanding of parental illness work generally, demonstrating that parental biographies are more closely 'entangled' with their children's than previously thought (Bray et al., 2014). This provides a fascinating area for further inquiry and may be transferable to other hereditary conditions where parent and child have the same diagnosis concurrently. The final development in relation to Rasmussen et al.'s (2020) model is its application outside of a solely diagnostic context. Table 4 reveals how the journey for parents can be biographically cohesive, disruptive, neither or both, and how the spectrum model is useful for analysing confirmation of diagnosis *and* diagnostic journeys. The successful application of a spectrum model of disruption and cohesion provides future researchers opportunities to explore how experiences outside of the diagnostic moment, such as invalidating conversations with professionals or the influence of parental conviction and belief in the presence of a problem, can impact parental biographical response.

AUTHOR CONTRIBUTIONS

Tom Nicholson: Conceptualization (lead); data curation (lead); formal analysis (lead); funding acquisition (equal); investigation (lead); methodology (lead); project administration (lead); supervision (supporting); validation (lead); writing – original draft (lead); writing – review & editing (equal). **Richard Lee:** Conceptualization (supporting); methodology (supporting); project administration (supporting); supervision (lead); validation (supporting); writing – original draft (supporting); writing – review & editing (equal).

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CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

In order to respect the confidentiality of research participants, consent was not sought to make available original transcripts. Therefore, the data cannot be made open.

ETHICS STATEMENT

Northumbria University Faculty of Health and Life Sciences Ethical Approval. NHS Integrated Research Application System [IRAS] Ethical Approval.

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