Autistic Subjectivities:

A critical narrative analysis of the stories of women who self-identified as autistic in adulthood

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A thesis submitted in partial fulfilment of the requirements of the University of the West of England, Bristol for the degree of Professional Doctorate in Counselling Psychology

Faculty of Health and Applied Sciences

July 2020

Abstract

Until recently, autism was assumed to be a predominantly male phenomenon, but a growing number of women are now identifying as autistic in adulthood after many years of unexplained difficulties in their everyday lives. The findings of the few studies in this area indicate that 'late diagnosed' autistic women commonly report a longstanding sense of 'difference', accompanied by efforts to conform to social norms and an increased vulnerability to mental health difficulties. To date, however, little attention has been paid to the potential implications for autistic women of dominant androcentric and deficit-focused constructions of autism. The present study employed a critical narrative methodology to explore this by examining the ways that discourses of autism are deployed and/or resisted within the autobiographical stories of women who identified as autistic in adulthood.

Narrative interviews were conducted with five women in order to explore the experiences that led to them identifying as autistic in adulthood, and the significance of this for their lives subsequently. The narrative analysis of the interview data was informed by critical realist and social constructionist perspectives, which view personal meaning making as socially mediated and culturally situated. It was found that dominant negative and androcentric discourses initially rendered autism unavailable to participants as a hermeneutic resource but that this changed when they discovered an alternative construction of autism which construes it as a valuable facet of human diversity. This neurodiversity discourse was deployed within the participants' narratives to construct an 'autistic identity' characterised by individuality and strengths, as well as vulnerabilities and difficulties as a consequence of being autistic in a world created by and for the non-autistic majority.

The participants' richly diverse personal stories demonstrate the potential for our knowledge about autism to be transformed by moving beyond current research preoccupations with homogenising behavioural and neurobiological characteristics. The current lack of awareness of female autism means that this is an important issue to be addressed within the training of counselling psychologists: the findings of the study highlight the need for such training to attend to the effects of gender on the

lived experience of being autistic, and to develop practitioners’ insight into the inequalities currently inherent in being autistic in a non-autistic world.

Acknowledgements

I would like to express my heartfelt gratitude to the women who participated in this study, and who were so generous in sharing their experiences with me. Your stories moved and inspired me, and I hope they do so for others too.

A big thank you to my supervisors Dr Helen Malson and Liz Maliphant (and not forgetting Dr Irmgard Tischner for the first year of this project), and also to Elicia Boulton for our long conversations about all matters autism and neurodiversity-related. Your support, suggestions, encouragement and belief in this project has meant a great deal to me.

Thank you too to family and friends who have been supportive and encouraging throughout what has sometimes seemed like a never-ending process, and who were always understanding about my long silences and absences.

Above all, an enormous thank you to my wonderful daughters, who have inspired, encouraged and entertained me throughout, and been so patient and understanding about the time and effort that this has taken: this thesis is dedicated to you.

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1. Introduction

1.1Background to the study

The focus of my study is women who came to identity as autistic in adulthood. For many years, they were all but absent from the research literature, reflecting a longstanding assumption that autism was characterised by overtly unusual social behaviours and interests that would typically be identified early in life by non-autistic 'experts' such as psychiatrists and paediatricians. This assumption is now being over-turned by the growing understanding that these behavioural characteristics were gleaned from studies with predominantly young male participants, and that autism in girls and women may be expressed rather differently (Krahn and Fenton, 2012; Kreiser and White, 2014): in particular, they appear more able (or are more motivated) than their male counterparts to conceal or compensate for the difficulties they experience in everyday life (Lai et al, 2011; Dean, Harwood and Kasari, 2017; Lai et al, 2017). As a result of this, the difficulties faced by autistic girls and women in coping with the social and sensory challenges of the 'neurotypical' world went unrecognised for many years by researchers and many clinicians (Gould and Ashton-Smith, 2011, Krahn and Fenton, 2012; Hearst, 2014; Attwood, 2015).

I embarked on my research project in 2015, when it had only recently been recognised that autism in girls and women had been largely overlooked by mainstream researchers and by clinicians (Gould and Ashton-Smith, 2011; Kopp and Gillberg, 2011; Lai et al, 2011; Rivet and Matson, 2011; Krahn and Fenton, 2012; Kreiser and White, 2014). This had prompted calls for research into sex-based differences in autism at the aetiological and behavioural levels (Lai, Lombardo, Auyeung, Chakrabarti and Baron-Cohen, 2015; Halladay et al, 2015) but my own interest in the area was informed by the counselling psychology profession's core values of empathic engagement with subjectivity and personal accounts, and commitment to social justice and diversity (British Psychological Society, 2005; Moller, 2011; Cutts, 2013). From this perspective, the historic neglect of female autism within mainstream research appeared to me to raise important questions about its implications for the lives of individual autistic women, who might reach adulthood without any way of making sense of why they find aspects of everyday life confusing or distressing. My view that this was a potentially important area from a social justice perspective was reinforced by the discovery that autistic individuals – and especially autistic women – are highly vulnerable to mental health difficulties (Croen et al, 2015); a common phenomenon amongst minority groups of various types (Cromby, Harper and Reavey, 2013; Botha and Frost, 2018).

The recognition of the longstanding 'invisibility' of autistic girls and women has served to highlight the epistemological – as well as ethical - consequences of the inherent power imbalance within academic research that has led to the exclusion of autistic individuals from the processes of production of 'knowledge' about autism (Milton and Bracher, 2013; Yergeau, 2013; Milton, 2014; Pellicano, Dinsmore and Charman, 2014; O'Dell, Bertilsdotter Rosquist, Ortega, Brownlow and Orsini, 2016; Woods, Milton, Arnold and Graby, 2018). As a result of this, autistic voices and subjectivities have been marginalised for many years, thereby limiting and distorting 'knowledge' in this area, especially in relation to the experiences and perspectives of autistic girls and women. This has started to change in recent years, with the publication of a small but growing body of qualitative research with the aim of exploring female autism as a lived experience (see Baldwin and Costley, 2016; Bargiela, Steward and Mandy, 2016; Tierney, Burns and Kilbey, 2016; Kanfiszer, Davies and Collins, 2017; Webster and Garvis, 2017; Milner, McIntosh, Colvert and Happé, 2019; Leedham, Thompson, Smith and Freeth, 2020). In the current study, I seek to add to this body of research – which is largely characterised by thematic approaches to analysis - by exploring the individual narratives of five autistic women as expressions of socially mediated and culturally embedded subjectivity and lived experience (Somers,1994; Hammack and Toolis, 2015; McLean and Syed, 2015; Schiff, 2017).

1.2 A note on terminology

My study is informed by critical realist principles, with its position of ontological realism (albeit realism that is complex and systemic) accompanied by the explicit recognition that our *knowledge* about any form of reality is socially constructed, and therefore – of necessity – provisional and fallible (Fleetwood, 2014; Bhaskar, Danermark and Price, 2018; Wiltshire, 2018). In the case of autism, the process of knowledge production has long been shaped by an underlying assumption that –

whatever its underlying biological underpinnings may prove to be – it represents an ‘undesirable’ departure from the normative phenotype, rather than simply a difference (or, rather, constellation of differences). This is now starting to change with the growing influence of the neurodiversity movement, and its view of autism as a valuable, albeit minority, aspect of human diversity (Bagatell, 2010; Kapp, Gillespie-Lynch, Sherman and Hutman, 2012; Brownlow and O’Dell, 2013; Ortega, 2013; Den Houting, 2019): however, it remains the case at present that autism is formally classified as a ‘disorder’, and defined in terms of ‘deficits’, ‘impairments’ and so on (Chown and Leatherland, 2018). Underlying my study is the assumption that this dehumanising and medicalised construction of autism has implications in terms of how we think about and make sense of autism, including the ways that it is predominantly researched at present (Pellicano et al, 2014; Chown and Leatherland, 2018), and at the level of individual subjectivities (Foucault, 1977; White and Epston, 1990; Weedon, 1997; Sinclair, 2007; Burr, 2015; Gergen, 2015).

The terminology I use in my thesis is informed by this underlying assumption, and – unless I am quoting another author – I seek to make my allegiance to a neurodiversity-informed perspective on autism transparent by referring to *differences* (that is, from the majority non-autistic phenotype, or from cultural behavioural norms) rather than ‘deficits’ and so on. Furthermore, when I discuss ‘difficulties’ experienced by autistic individuals I understand such difficulties to occur largely because our social and physical[1] environments have been created by and for the non-autistic majority and can therefore be problematic or ‘disabling’ for others. I use the terms ‘non-autistic’ or ‘neurotypical’ interchangeably to refer to those who experience the world in ways that are considered to be characteristic of the majority phenotype (Chown, 2016).

Finally, when referring to individuals, I follow the preference expressed by the majority of participants in a survey-based study (Kenny et al, 2016) and by members of the autism community online (Brown, 2011; Sinclair, 2013; Kim, 2014) and use ‘identity first’ (e.g. autistic women) rather than ‘person first’ language, recognising concerns that the latter carries the implications that autism is an appendage that can be

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[1] That is, in the form of the built environment and public spaces, including schools, universities, workplaces, shops, social spaces and so on. At present, these are designed for those with a ‘typical’ capacity to process sound, light and other forms of sensory stimulation.

potentially removed (or indeed ‘cured’) rather than integral to the autistic individual’s selfhood. Nevertheless, individuals themselves may have different opinions and perspectives on the ‘language of autism’ and in this study I therefore started each interview by asking the participant how she prefers to refer to autism; I then used this preference in my interpretation of her story.

2. Literature Review

2.1 The creation of invisibility: a brief history of the neglect of female autism

One of the widely accepted facts about autism is that it is more commonly *diagnosed* in males then females (Fombonne, 2009; Loomes, Hull and Mandy, 2017). However, the 'diagnosis' of autism is a complex and contested issue (Chown and Leatherland, 2018). Although long viewed as a developmental phenomenon with a biological basis (Folstein and Rutter, 1977; DeLong, 1978; Volkmar and Reichow, 2013), research efforts are yet to identify any meaningful and reliable biomarkers or decisive environmental triggers (Modabbernia, Vethorst and Reichenberg, 2017; Eshraghi at al, 2018; McPartland et al, 2018; Fletcher-Watson and Happé, 2019). Similarly, within psychology, efforts to define autism in terms of cognitive functioning have led to a proliferation of theories, none of which appear to decisively account for its heterogeneity and complexity (Happé, Ronald and Plomin, 2006; Chown, 2016).

In the meantime, therefore, autism is classified and diagnosed largely in terms of observable behavioural characteristics (American Psychiatric Association, 2013; World Health Organization, 2016). Within the mainstream research literature, the potential fallibility and subjectivity of defining a human phenomenon in such terms is rarely acknowledged; instead the formal 'diagnostic criteria' of autism are typically assumed to be the inevitable behavioural consequences of underlying neurobiological differences (Happé, 1994; Morton and Frith, 1995). From a critical realist perspective, however, this is a striking example of an 'epistemic fallacy' of confusing social constructed *knowledge* with the reality that it purports to represent (Pilgrim, 2013; Wiltshire, 2018). Instead, the critical realist worldview highlights the importance of understanding the potential 'blind spots', biases and distortions that may permeate knowledge that is currently taken for granted, and the potential implications of this (Bhaskar et al, 2018). As I discuss below, a key consequence of the social production of knowledge about autism has been to render many autistic girls and women invisible to clinicians and researchers for many years; a lacuna in 'knowledge' that is only now starting to be addressed.

2.1.1 The origins of the gendering (and dehumanising) of autism

The focus on idiosyncratic behaviours as defining characteristics of autism has its roots in the seminal work of Kanner and of Asperger in the 1940s (Nadesan, 2005; Evans, 2013; Silberman, 2015; Donvan and Zucker, 2016). Respectively a US-based child psychiatrist and Germany-based paediatrician, they separately identified a similar constellation of behaviours amongst a small number of children referred to them: unusual social behaviours; a need for routine and difficulty with change; and a tendency to engage in repetitive or ritualistic behaviours, or in intense and unconventional interests (Kanner, 1943 and 1944; Wing, 1981; Asperger, 1991[2]). Previously, such children would have been given a diagnosis such as 'childhood schizophrenia', but both clinicians concluded that they had identified a distinctive phenomenon (Kanner, 1943; Asperger, 1991). Over time, this view was validated by epidemiological and twin studies (Folstein and Rutter, 1977; Volkmar and Reichow, 2013), and their vivid descriptions of behavioural eccentricities formed the foundation for the classifications of autism that have been enshrined in the various iterations of the diagnostic manuals of the American Psychiatric Association and World Health Organisation (Nadesan, 2005; Draaisma, 2009; Evans, 2013).

In the context of understanding how girls and women came to be overlooked by autism researchers, it is striking that the children described by Kanner and Asperger were almost exclusively male: just three of the eleven cases reported by Kanner were girls, and all of Asperger's were boys. Furthermore, Asperger claimed that "the autistic personality is an extreme variant of male intelligence", arguing that boys are intrinsically more skilled at logical thinking and "independent scientific intelligence" in contrast with girls' tendency to "draw more strongly on feelings and instincts" (Asperger, 1991, p.84-85). Asperger expressed these views in the 1940s, displaying no insight into the social and cultural contexts in which gendered qualities develop and

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[2] Originally published in German in 1944 in *Archiv für Psychiatrie und Nervenkrankeiten* (Frith, 1991).

are expressed. Thus, from the earliest days of its study, autism was inextricably associated with maleness.

Another key theme in these early descriptions of autistic children was their ‘otherness’, which Kanner characterised as “extreme autistic aloneness”: a way of being that “disregards, ignores, shuts out” the world around them (Kanner, 1943, p.242). From the outset of research into autism, therefore, autistic individuals were depicted in dehumanising terms as living ‘in a world of their own’, disengaged from everyday social interactions (Broderick and Ne’eman, 2008; Huws and Jones, 2010; Milton, 2014). It is a construction of autism that acted as the foundation for the longstanding exclusion of autistic people from knowledge production (Milton and Bracher, 2013; Yergeau, 2013; Milton, 2014), thus creating the wider context in which autistic individuals whose behaviours do not conform to the expectations of non-autistic designated ‘experts’ went unnoticed for many years.

2.1.2 Reifying the link between autism and maleness: the ‘extreme male brain’ theory of autism

Within psychology, research has been directed at exploring autism in terms of differences at the level of cognitive functioning as a presumed ‘bridge’ between its underlying genetic or epigenetic foundation and observable behavioural characteristics (Happé, 1994; Morton and Frith, 1995). For many years, the construction of autism in terms of ‘lack’ was reflected by an emphasis on explaining observed behavioural characteristics in terms of underlying *deficits* in specific aspects of cognitive functioning, in particular in relation to theory of mind (Baron-Cohen, Leslie and Frith, 1985), executive function (Hill, 2004) and central coherence (Happé and Frith, 2006). However, over time it was recognised that these deficit-focused models failed to address the relative strengths often associated with autism - such as a capacity to ‘hyper-focus’ on areas of interest - prompting efforts to develop more ‘balanced’ and expansive models of cognitive functioning (Murray, Lesser and Lawson, 2005; Krahn and Fenton, 2012; Chown, 2016; Murray, 2018). In terms of the pervasive gendering of autism, however, one such model has particular significance: the so-called ‘extreme male brain’ (‘EMB’) theory of autism (Baron-Cohen, 2002a).

The EMB theory was an extension of an earlier influential theory which hypothesised that a deficit in theory of mind is a defining characteristic of autism (Baron-Cohen, Leslie and Frith, 1985; Baron-Cohen, 1995): a model that had the significant drawback of only offering a possible explanation for the social differences associated with autism (Krahn and Fenton, 2012). This shortcoming was addressed in the EMB theory by the hypothesis that autism is characterised by a reduced capacity for empathy accompanied by good 'systemising' skills[3], and that the latter can manifest as the deep interests and preoccupations[4] that were first described by Asperger (1991). Asperger's descriptions highlighted the individuality of his young 'patients'' "specialised interests", such as collecting poisons, designing "spaceships" (in the 1940s) or displaying "rare maturity of taste in art" (Asperger, 1991, p.72). Within the EMB theory, however, such idiosyncrasies are replaced by examples of toys, interests and professions that are currently more commonly associated with boys and men: for example, playing with construction toys, computer programming and engineering (Baron-Cohen, 2002a and 2003).

As the name indicates, a central tenet of the EMB theory is that the hypothesised 'hypo-empathising/hyper-systemising' phenotype is an exaggerated version of characteristics which are claimed to be innately more common in men than women (Baron-Cohen, 2002a and 2003). It is further hypothesised these supposedly innate differences result from differences in exposure to testosterone *in utero* (Baron-Cohen, Knickmeyer and Belmonte, 2005), but this claim lacks compelling research evidence (Grossi and Fine, 2012; Kung et al, 2016; Ferri, Abel and Brodkin, 2018). Indeed, the EMB theory has been subject to substantial criticism, not least for its failure to address the significance of the social and cultural contexts in which gendered behaviours and interests develop, and the corresponding potential for sex/gender-based desirability bias in participant responses to the self-report questionnaires (Baron-Cohen, Richler, Bisarya, Gurunathan and Wheelwright, 2003; Baron-Cohen and Wheelwright, 2004) on

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[3] 'Systemising is defined as: "'… the drive to analyse the variables in a system, to derive the underlying rules that govern the behaviour of a system. Systemising also refers to the drive to construct systems. Systemising allows you to predict the behaviour of a system, and to control it." (Baron-Cohen, 2002a, p.248).

[4] In terms of diagnostic criteria specified by the formal definition of autism, such interests and preoccupations can be viewed as evidence of "highly restricted, fixated interests that are abnormal in intensity or focus" (APA, 2013).

which its gendered claims are based (Fine, 2010; Jack, 2011; Grossi and Fine, 2012; Krahn and Fenton, 2012). Its basis in essentialised and dichotomised[5] sex/gender-based differences in cognitive functioning is also now being challenged by empirical findings from neuroscience, which indicate an extensive overlap between the distributions of females and males across a range of measures (Jordan-Young, 2010; Joel et al, 2015; Joel et al, 2018; Rippon, 2019). Despite these flaws, however, the EMB has had considerable influence on the way that 'knowledge' about autism is currently constructed, with Krahn and Fenton (2012, p.99) commenting: "Unfortunately, the very language used to describe [autism] is now laden with certain gender expectations." Unusually for a cognitive theory, its claims have been disseminated beyond the confines of academia (Baron-Cohen, 2003; Greenberg, Warrier, Allison and Baron-Cohen, 2018), which has arguably been facilitated by the gendered 'packaging' which gives it wider interest and appeal (Jack, 2011).

As well as reifying an association between autism and stereotypically 'male' social behaviours and interests, the EMB theory has had another powerful influence on knowledge production, in the form of the central claim that autism is associated with an 'empathy impairment' (Baron-Cohen, 2002a; Williams, 2010; McDonagh, 2013; Yergeau, 2013). This is grounded in a reductive and one-sided view of empathy which 'pathologises' the difficulties that autistic individuals commonly describe in making sense of the social behaviours and norms of the neurotypical majority and at the same time fails to acknowledge that non-autistic people appear equally unable to empathise with the experiences and subjectivities of autistic individuals (Hacking, 2009; Milton and Moon, 2012; Dinishak and Akhtar, 2013; Yergeau, 2013; Milton, 2014): a seemingly mutual difficulty in comprehension which Milton (2012) terms the 'double empathy problem'. In doing so, the EMB theory implicitly reinforces and perpetuates misleading and stigmatising assumptions that autism is inevitably characterised by a lack of social motivation and self-awareness (Huws and Jones, 2010; Yergeau, 2013; Limberg, 2016; John, Knott and Harvey, 2018; Jaswal and Akhtar, 2019).

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[5] Baron-Cohen acknowledges that some women have what he defines as a 'male' brain, and vice versa (with the 'female' brain being defined within the EMB theory as being characterised by a better-developed capacity for empathising than for 'systemising'). He also defines a 'balanced brain' phenotype in which the capacity for empathising and systemising is equally well-developed (Baron-Cohen, 2002a).

2.2 Removing the invisibility cloak: discovering female autism

The many years of male-focused autism research created an epistemic monolith in which autism was assumed to ‘look’ a certain way: that autistic individuals were socially awkward and lacking in self-awareness; more interested in numbers or objects than in other people; and usually male (Draaisma, 2009; Milton, 2014). Mainstream research thus appeared to provide ‘scientific’ gravitas to stereotypical portrayals of autism in popular culture, most famously in the form of the autistic ‘savant’ character Raymond Babbitt in the movie *Rain Man* (Johnson, 1988). More recently, the aloof ‘eccentric scientist’ trope which characterises the EMB theory (Baron-Cohen, 2003) has been embodied in the form of the character of Sheldon Cooper in the TV series *The Big Bang Theory* (Belyeu, 2007).

These gendered cultural representations of autism have been accompanied by the seemingly incontrovertible fact that autism is diagnosed more often in males than females (Shattuck et al, 2009; Russell, Steer and Golding, 2011, Rivet and Matson, 2011; Dworzynski, Ronald, Bolton and Happé, 2012): on average – three to four times[6] more often in males than in females according to prevalence studies (Fombonne, 2009; Loomes et al, 2017). However, behind this ‘headline’ sex ratio lies a curiosity in that it appears to vary according to whether autism is accompanied by intellectual disability (ID) or not (Werling and Geschwind, 2013); lower MTF ratios of around 1-2:1 are typically found in samples of autistic people with moderate to profound ID and higher – and more variable – MTF ratios amongst more intellectually able individuals (Fombonne, 2009; Brugha et al, 2009). Within the dominant biomedical paradigm, it was speculated that this is consistent with an unidentified biologically-based ‘female protective effect’ (FPE): empirical evidence for this claim, however, remains equivocal and inconsistent (Skuse, 2000; Szatmari et al, 2012; Robinson, Lichtenstein, Anckarsäter, Happé and Ronald, 2013; Jacquemont et al, 2014; Sandin et al, 2014; Lai et al, 2015; Werling and Geschwind, 2015).

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[6] [6] For many years, 4:1 was the accepted headline MTF ratio (Fombonne, 2009) but a more recent meta-analysis found that – while the mean MTF ratio was 4:1 overall – the ratio reduced to about 3:1 when only those studies deemed to be of higher quality were included (Loomes et al, 2017).

In recent years, an alternative – or additional – explanation to the wholly biologically-based FPE has become increasingly influential: that for many years, autism in cognitively able girls and women has simply been under-identified and overlooked by clinicians and researchers because it does not conform to prevailing assumptions about what autism 'looks like' (Gould and Ashton-Smith, 2011; Kopp and Gillberg, 2011; Rivet and Matson, 2011; Russell, Steer and Goulding, 2011; Dworzynski, Ronald, Bolton and Happé, 2012; Zwaigenbaum et al, 2012; Krahn and Fenton, 2012; Bargiela et al, 2016; Loomes et al, 2017). In particular, as discussed below, it seems that autistic girls and women are more likely to develop strategies to help them fit in socially with the non-autistic majority (Gould and Ashton-Smith, 2011; Attwood, 2015; Tierney et al, 2016; Bargiela et al, 2016; Dean et al, 2017; Hull et al, 2019). Furthermore, if they have deep or 'intense' interests or passions, they are often in areas that are culturally normative for their gender – literature, animals, a particular TV show, other people and so on – rather than those stereotypically associated with autism, not least as a consequence of the androcentric EMB theory (Gould and Ashton-Smith, 2011; Jack, 2011; Attwood, 2015). This highlights the need to re-conceptualise autism as a socially and culturally-situated lived experience (Jack, 2011), rather than implicitly assuming that autistic individuals are wholly 'exempt' from societal influences (Happé, 1994; Morton and Frith, 1995).

2.2.1 Learning to camouflage: female autism during the school years

Within the framework of the EMB theory, autistic children have long been stereotyped as more interested in their 'special interests' - in areas like numbers, cars, computers and such like - than in making friends with other children: writing before the phenomenon of autistic camouflaging had been acknowledged in the research literature, Baron-Cohen (2002b, p.187) asserted that autistic children "[show] relatively little interest in what social groups are doing, or in being a part of them". Indeed, an observational study of the social interactions of primary school age children found that autistic boys often played alone (Dean et al, 2017), seemingly providing a degree of support for this claim. The study provided no insight into whether the boys' apparent social isolation was a matter of choice or had been enforced over time by peers; however, there is some evidence (based on self-reporting) that autistic boys may tend to be less socially motivated than their non-autistic peers (Head, McGillivray and Stokes, 2014; Sedgwick, Hill, Yates, Pickering and Pellicano, 2016; Sedgwick, Hill and Pellicano, 2019).

While such findings appear to provide some support for the stereotypical view of autism encountered in the EMB theory, the same studies suggest that the social motivation and experiences of autistic girls during the school years may be very different to those of autistic boys: that their social motivation is, in fact, similar to that of their non-autistic peers (Head et al, 2014; Sedgwick et al, 2016; Sedgwick et al, 2019). Furthermore, Dean et al's (2017) study found that – unlike the observed social isolation of autistic boys – autistic girls tended to be engaged with social groups, albeit often on the periphery rather than fully integrated (Dean et al, 2017). An earlier study provided interesting insight into the potential social implications of having more contact with non-autistic peers: for example, they are likely to be exposed to social 'sanctions' (such as eye-rolling, mocking or being ignored) from non-autistic girls when they fail to adhere to group norms (Dean, Fox Adams and Kasari, 2013). Such findings are consistent with those of a rare qualitative study of the experiences of adolescent autistic girls, who described their strong desire for friendships and their considerable efforts to fit in socially (Tierney, Burns and Kilbey, 2016). Despite their efforts, however, the girls reported that they experienced frequent rejection and misunderstandings in social situations: experiences that were variously described as distressing, stressful and anxiety-provoking. The researchers reported that the girls appeared to feel at the "mercy of more powerful others […] those who understood social rules." (Tierney et al, 2016, p.77).

For me, reading the studies of Tierney et al and Dean and colleagues (Dean et al, 2013; Dean et al, 2017) brought back vivid memories of being at school, with its gendered 'rules' and social hierarchies, and the pressures – implicit or otherwise – to fit in with one's peers (Wiseman, 2002): experiences that are evidently all the more complex for autistic girls who struggle to make sense of non-autistic girls' social behaviours (Tierney et al, 2016). The research findings suggest that school provides autistic girls with an intensive and often harsh 'education' in normative social expectations, with non-autistic girls providing a "normalising gaze" (Foucault, 1977, p.184) by means of which gendered behaviours are policed and enforced. At the same time, the motivation for friendships reported by autistic girls (Sedgwick et al, 2016; Tierney et al, 2016; Sedgewick et al, 2019) suggests that they are willing to endure this in an attempt to find social acceptance.

The efforts of autistic girls to fit in socially with their peers means that their social behaviours are less likely to appear unusual to teachers and parents: a factor which Dean et al (2017) suggests contributes to their longstanding ‘invisibility’. Furthermore, studies indicate that – as is the case for girls generally (Sroufe and Rutter, 1984; Zahn-Waxler, Shirtcliff and Marceau, 2008) – autistic girls tend to internalise any distress they experience, and are therefore less likely than autistic boys to display the type of externalising behaviours which are typically deemed problematic in a school setting (Timimi at al, 2010; Mandy et al, 2012; Solomon, Miller, Taylor, Hinshaw and Carter, 2012; Hiller, Young and Weber, 2014): yet another way in which their difficulties are less ‘visible’ to those around them.

2.2.2 Camouflaging into adulthood: the experiences of ‘late diagnosed’ autistic women

Bearing in mind the reported social motivation of autistic girls, and their ‘intensive’ and gendered social experiences during the school years, it is unsurprising that research indicates that – by adulthood – they tend to display better social skills than their male peers (Lai et al, 2011) and to be more likely to engage in ‘camouflaging’ behaviours (Hull et al, 2017; Lai et al, 2017; Lai et al, 2019; Livingston, Shah and Happé, 2019; Mandy, 2019; Hull et al, 2020). The growing awareness of the prevalence of camouflaging amongst autistic women has highlighted the inadequacy of seeking to evaluate autism largely in terms of observable behaviours, and has led to a shift towards qualitative research which engages with personal experiences and perspectives (Baldwin and Costley, 2016[7]; Bargiela et al, 2016[8]; Milner et al, 2019[9]), including studies which focus on those whose autism was only identified in adulthood

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[7] Australian survey-based study; n=82, mean age 32.7 (age range 18-64) (Baldwin and Costley, 2016).

[8] Thematic (framework) analysis; n=14, mean age 26.7 (age range 22-30). Participants had been diagnosed at age 18+ (Bargiela et al, 2016).

[9] Thematic analysis of four group discussions and seven individual interviews. N= 22 (18 autistic girls/women and 4 mothers of autistic girls). Age range of participants in the autism group = 11-55 (Milner et al, 2019).

(Kanfiszer et al, 2017[10]; Webster and Garvis, 2017[11]; Stagg and Belcher, 2019[12]; Leedham et al, 2020[13]). The latter group – 'late diagnosed' women – are of particular interest in terms of understanding why autism may go unnoticed for many years, and the implications of this for the lives and wellbeing of autistic individuals.

A common theme within existing studies is the experience of 'feeling different' to other women, accompanied by descriptions of making considerable efforts to conceal self-perceived differences and to fit in socially (Milner et al, 2019): of "pretending to be 'normal'" (Bargiela et al, 2016, p.3287; Leedham et al, 2020, p.138). These adaptive strategies – now widely termed 'camouflaging' in the research literature – variously include behaviours such as mimicking the social behaviours of others; using learnt phrases or 'scripts' for interactions; suppressing 'stimming' behaviours in social situations; adopting a 'persona' for socialising and so on (Bargiela et al, 2016; Hull et al, 2017; Leedham et al, 2020). Unfortunately, these attempts to conform to social norms come at a potentially high cost for personal wellbeing: such behaviours are typically described as stressful, exhausting and anxiety provoking, and may be experienced as damaging for one's sense of self (Bargiela et al, 2016; Hull et al, 2017; Kanfiszer et al, 2017; Cage and Troxell-Whitman, 2019; Mandy, 2019; Milner et al, 2019).

An additional area of concern highlighted by Bargiela et al's (2016) study was the high incidence of sexual abuse[14] reported by the participants, which had often taken place in the context of a relationship. It has been suggested (by a female autistic author) that the difficulties that autistic women experience in inferring the motives of non-autistic others, alongside their desire for social acceptance, may render them particularly vulnerable to abuse and exploitation (Holliday-Willey, 2018) and the

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[10] Thematic (narrative) analysis; n=7 (age range 20 to 59; no mean provided). Participants had been diagnosed at age 18+ (Kanfiszer et al, 2017).

[11] Australian thematic (narrative) analysis; n10 (age range 28 to 55; no mean provided). Participants had been diagnosed at age 18+ (Webster and Garvis, 2017).

[12] Thematic analysis; n=9 (5 female participants). Age range 52-54; all participants had been diagnosed as autistic within preceding two years (Stagg and Belcher, 2019).

[13] IPA-based study; n=11; mean age 50.8 (age range 43 to 64). Participants had been diagnosed at age 40+ (Leedham et al, 2020).

[14] Further evidence of an increased vulnerability to sexual abuse was subsequently provided by a large scale Swedish study (n=4500) which found that autism in girls were associated with a nearly threefold greater incidence of sexual abuse by the age of eighteen, compared with non-autistic girls (Gotby, Lichtenstein, Langstrom and Petterson, 2018).

participants' references to their experiences of abuse in Bargiela et al's (2016) study were consistent with this view.

Diagnosis (and mis-diagnosis)

The lack of awareness amongst professionals of the differences in female 'presentations' of autism means that the road to obtaining an autism assessment can be a difficult one for women. Hughes (2015) conducted an online survey enquiring about the diagnoses that autistic girls and women had received prior to being diagnosed as autistic: nearly thirty were reported, including personality disorders, bipolar disorder, obsessive compulsive disorder (OCD) and social anxiety. Some of these diagnoses may have reflected 'genuine' co-occurring mental health difficulties, for which the long-term stress of being an autistic woman in the 'neurotypical world' is likely to have been a contributory or causal factor (Botha and Frost, 2018; Zener, 2019). Others, however, are likely to have stemmed from a misinterpretation of features associated with autism, such as 'repetitive behaviours' being construed as symptoms of obsessive compulsive disorder (OCD), or social difficulties being misinterpreted as evidence of a 'personality disorder' or social anxiety (Gould and Ashton-Smith, 2011; Bargiela et al, 2016; Chown, 2016; Au-Yeung et al, 2019; Milner et al, 2019; Zener, 2019; Leedham et al, 2020).

In addition to the potential for misdiagnosis, participants in Bargiela et al's (2016) study described difficulties in being referred for an autism assessment due to a lack of awareness about female autism amongst general practitioners. Once referred for an assessment, another challenge reported by some autistic women is being able to *stop* camouflaging in order that they can demonstrate 'autistic behaviours' in a way currently expected by many autism 'experts' (Milner et al, 2019).

In general, existing studies typically depict the experience of being diagnosed as autistic in largely positive terms as a means of making sense of previously inexplicable difficulties and a pervasive sense of 'difference', thereby providing a 'lens' through which life and identity can be reappraised: in turn, this is often associated with an increase in self-acceptance and – for some – connection with other autistic individuals (Bargiela et al, 2016; Kanfiszer et al, 2017; Milner et al, ,2019; Leedham et al, 2020).

However, Leedham et al (2020, p.139) reported that in some cases this could be preceded by a period of “grieving and adjusting”, citing a participant who recalled experiencing sadness and self-doubt as she wondered “’am I just anything other than these symptoms?’”. The reference to ‘symptoms’ is consistent with the dominant – and overwhelmingly negative – discursive construction of autism, which in turn may have negative implications for an individual’s ‘autistic identity’ and emotional wellbeing as I discuss below (Kapp, Gillespie-Lynch, Sherman and Hutman, 2013; Cooper, Smith and Russell, 2017; Cage, Di Monaco and Newell, 2018).

2.2.3 Female autism and mental health difficulties

In general, autism is associated with a considerably elevated risk of mental health difficulties compared with the non-autistic majority (Huke, Turk, Saiedi, Kent and Morgan, 2013; Mandy and Tchanturia, 2015; Cassidy, Bradley, Shaw and Baron-Cohen, 2018; Au-Yeung et al, 2019; Brugha, 2019; Camm-Crosbie, Bradley, Shaw, Baron-Cohen and Cassidy, 2019; South et al, 2019). For example, a US population-based study (n=1507; non-autistic controls n=15,070) reported rates of 34% and 36% respectively for depression and anxiety amongst autistic women and 22% and 26% for autistic men: for the non-autistic controls (mixed sex results reported) the rates for depression and anxiety were 10% and 9% respectively (Croen et al, 2015). Furthermore, preliminary results from a yet to be published UK-based study suggest that as many as one in twenty individuals who are seen in adult mental health services are autistic (compared with an estimate of one in a hundred in the population as a whole) (Brugha, 2019).

Botha and Frost (2018) propose that the minority stress model offers a helpful framework for understanding the elevated risk of mental health difficulties amongst autistic individuals. First developed in relation to the mental health vulnerabilities found amongst sexual minority groups, this model addresses the effects on personal wellbeing of the “hostile and stressful” social environments that result from pervasive stigma, prejudice and discrimination towards minorities (Meyer, 2003, p.674): as such, it offers a useful ‘corrective’ to the current tendency to locate mental health difficulties ‘within’ the individual and to overlook the social and systemic contexts in which distress develops (Smail, 2005; Prilleltensky, Prilleltensky and Voorhees, 2009; Verhaeghe, 2012; Cromby et al, 2013; Pilgrim, 2015; Johnstone and Boyle, 2018). As

Botha and Frost (2018) argue, it is a particularly valuable perspective in the context of autism and mental health: it highlights the potential effects of stigmatising stereotypes and attitudes towards autism (Huws and Jones, 2010; John, Knott and Harvey, 2018) not only in terms of the ways that autistic individuals are viewed and treated by others, but also the potential effects on their mental health of being aware of – and internalising - such attitudes. Indeed, a qualitative study (n=12, with 4 female participants) of autistic individuals' views on autism stereotypes found that their perception is that such stereotypes are highly negative and homogenising, and that they are likely to contribute to the marginalisation and bullying of autistic people (Treweek, Wood, Martin and Freeth, 2019).

For psychologists and therapists with an interest in the social and systemic context of mental health, the claims of the minority stress model are uncontentious and are borne out by the experiences that we hear described by our clients. In terms of offering an evidence-based challenge to the medical model of mental health (Onyett, 2007; Johnstone and Boyle, 2018), however, it is helpful that Botha and Frost (2018) accompanied their theorising with a survey-based study (n=111, with 82 female participants) which found a significant association between self-reported psychological distress and a range of potential stressors, such as internalised stigma, experiences of discrimination in everyday life and concealment of autistic status from others. Similarly, Cage, Di Monaco and Newell (2018[15]) found associations between a lack of autism-related personal acceptance, perceptions of societal autism acceptance and higher levels of self-reported depression, while Cooper, Smith and Russell (2017[16]) found that levels of self-reported anxiety and depression amongst autistic individuals were mediated by personal and autism-related self-esteem, leading them to suggest that a "positive autism social identity" may have a protective effect for personal wellbeing (Cooper et al, 2017, p. 844).

The findings of the few studies in this area highlight the need for further research to improve understanding and awareness of the ways that the mental health of autistic individuals may be negatively affected by their social environments and by wider

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[15] n=111, with 82 female participants

[16] n=539, with 272 autistic participants. 47% of autistic participants were female and 53% of non-autistic controls.

societal factors, including stigmatising attitudes and beliefs about autism (Huws and Jones, 2010; John et al, 2018; Treweek et al, 2019). In this respect, the current gendering of 'knowledge' about autism (Jack, 2011; Krahn and Fenton, 2012) may have specific implications for the identity and self-image of autistic girls and women. Furthermore, the experience of being autistic *and* female is accompanied by additional pressures in the form of specifically gendered expectations for 'feminine' social behaviours (Bargiela et al, 2016; Kanfiszer et al, 2017; Saxe, 2017; Milner et al, 2019). It is within this gendered societal context that autistic girls and women are especially likely to resort to camouflaging strategies in order to conform to social norms, with potentially negative effects for their emotional wellbeing and sense of self (Bargiela et al, 2016; Tierney et al, 2016; Kanfiszer et al, 2017; Hull et al, 2017; Lai et al, 2017; Cage et al, 2018; Cage and Troxell-Whitman, 2019; Milner et al, 2019; Leedham et al, 2020). In relation to this, it is of particular concern that a recent study found an association between self-reported camouflaging behaviours and suicidality (Cassidy et al, 2018). Furthermore, evidence that autistic girls may be at particular risk of sexual abuse before the age of eighteen (Ohlsson Gotby, Lichtenstein, Långström and Pettersson, 2018) highlights another (gendered) area of concern, bearing in mind that childhood sexual abuse is itself associated with an elevated risk of subsequent mental health difficulties (Hailes, Yu, Danese and Fazel, 2019).

2.3 Discursively constructing autism: 'disease', 'disability' or (gendered) difference?

Preliminary evidence that a "positive autism social identity" might have a protective effect for an individual's mental health (Cooper et al, 2017, p.844; Cage at al, 2018) highlights the importance of exploring the effects of current constructions of 'knowledge' about autism at the level of individual subjectivities (Elder-Vass, 2012; Marks and O'Mahoney, 2013; Bhaskar et al, 2018). From a critical realist perspective, constructing a 'positive autism identity' is not a simple matter of choice for an individual: instead, critical realism views personal identity and meaning-making as socially and culturally-situated (Elder-Vass, 2012; Maxwell, 2012; Marks and O'Mahoney, 2013; Bhaskar et al, 2018). As such, it shares with social constructionism the assumption that individual subjectivities are simultaneously influenced and constrained by social practices and interactions, and by available cultural resources such as discourses, narratives, stereotypes and so on (Foucault, 1977; Potter and Wetherell, 1987; White and Epston, 1990; Parker, 1992; Weedon, 1997; Maxwell, 2012; Marks and O'Mahoney, 2013; Burr, 2013; Gergen, 2015; Bhaskar et al, 2018; Johnstone and Boyle, 2018). From this perspective, it is therefore significant that dominant discourses and narratives of autism are – at present – overwhelmingly negative and dehumanising (Huws and Jones, 2010; Milton and Moon, 2012; Yergeau, 2013; Milton, 2014; O'Dell et al, 2016; Treweek et al, 2019) and are embedded in medicalised social practices, such as diagnosis by designated 'experts' (Foucault, 1972 and 1973).

From a critical realist perspective, the way that autism is currently classified as a 'disorder' (APA, 2013; WHO, 2016) is not a neutral reflection of objectively knowable reality (Pilgrim, 2015), and is instead a socially constructed and value-laden classification of behaviours that are deemed to be non-normative relative to (implicit) 'ideals' for social, communicative and other[17] behaviours (Brownlow, 2010a). Those behaviours could simply be referred to *differences* relative to the majority phenotype (or indeed to culturally sanctioned norms) but instead are variously described in pejorative terms as 'impairments', 'deficits' or 'symptoms': terms which are typically associated with 'disease'. The formal framing of autism in 'medicalised' language – the 'medical' discourse of autism – arguably has far-reaching implications for social and cultural practices, bearing in mind that it is likely to be assumed to be a transparent reflection of 'reality' (Pilgrim, 2015). For example, if autism is presumed to be a 'disease' (or akin to one), then it follows that it would be 'logical' to fund research aimed at understanding its genetic underpinning and environmental 'risk factors' (Pellicano et al, 2014; Chown and Leatherland, 2018): research which is typically aimed at 'fighting'[18] or eliminating feared conditions such as cancer (Broderick and Ne'eman, 2008). The inference of a 'disease' status is similarly evident in periodic

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[17] Including behaviours that are defined as "repetitive and restrictive" according to the diagnostic criteria for autism and unusual sensory experiences (APA, 2013).

[18] Indeed, this pugilistic stance was reified for many years in the United States in the form of the Combating Autism Act[18] of 2006) (Broderick and Ne'eman, 2008). This was renamed the Autism Collaboration, Accountability, Research, Education and Support (Autism CARES) Act in 2014, following lobbying by the autistic self-advocates (Ne'eman, 2016).

references in the mainstream media to an ‘epidemic’ of autism, and the fears that have been periodically expressed about an alleged (and long discredited) link between childhood vaccination, which saw autism implicitly positioned as a ‘fate worse than death’ (Dahl, 1986; O’Dell and Brownlow, 2005; Milton, 2014; Silberman, 2015). It also legitimises interventions aimed at ‘normalising’ behaviours which are deemed to be characteristic of autism (Milton and Moon, 2012).

The ’medical’ discourse of autism thus depicts it as an unquestionably problematic phenomenon – a departure from idealised normalcy and wellbeing – which ‘scientists’ should strive to ameliorate, if not eradicate (Chown and Leatherland, 2018). For many years, the main discursive alternative to this has been the ‘disability’ discourse of autism, which – in theoretical terms - can be seen as occupying the intersection between the medical and social models of disability (Oliver, 2009). Thus, while this discourse foregrounds the disabling effect of society and of built environments for autistic individuals (National Autistic Society, 2016a), it nonetheless deploys medicalised terminology – such as ‘condition’ - and implicitly locates problems of social understanding *within* the autistic individual, rather than being a mutual ‘mis-attunement’ between autistic and non-autistic subjectivities (Milton, 2012; Milton and Moon, 2012; Yergeau, 2013). It also serves to homogenise autistic experience in terms of ‘lack’; autistic individuals are reduced to what they *can’t* do or find difficult (Bagatell, 2007; Brownlow, 2010b; Baines, 2012; Limburg, 2016).

The ‘eccentric scientist’ discourse of autism: autism as ‘relational impairment’

Mainstream research literature is unsurprisingly dominated by the ‘medical’ discourse of autism, with some evidence of the alternative (but still homogenising and negative) ‘disability’ discourse. However, a competing and highly gendered discourse is sometimes deployed, ostensibly to ‘re-brand’ autism as a ‘difference’ rather than a ‘disorder/disease’ or ‘disability’ (Baron-Cohen, 2002b and 2003; Timimi et al, 2010;). It is a construction of autism which is largely consistent with – and serves to reinforce – the EMB theory, and it creates a subject position for the autistic individual as someone who is more interested in maths, science, technology or computers than in relating to other people. Indeed, in an account of autism aimed at the general public, Baron-Cohen chose to illustrate it with a description of a Cambridge professor of mathematics: one who is mathematically gifted but who finds other people to be "mysterious beings who [are] hard to comprehend because they [do] not conform to the laws of physics or maths" (Baron-Cohen, 2003, p. 157).

This 'eccentric scientist' discursive construction of autism is typically deployed (as by Baron-Cohen) to emphasise that it is a different way of being in the world: one that – in the right environment – need not be disabling, nor a bar to professional achievement. At the same time, it associates autism with profound *relational* impairment, such that the autistic individual is unable to relate to others in any meaningful way (Dinishak and Akhtar, 2013), and is instead absorbed in their world of numbers, science or computers (Quirici, 2015): he (or, more rarely, she) is little more than an intellectually-capable version of Raymond Babbitt in the movie *Rain Man* (Johnson, 1988; Draaisma, 2009). In all, it is a dehumanising construction of autism with tragic undertones (Duffy and Dorner, 2011), and it reduces the autistic individual to little more than an unfeeling 'automaton' (Milton, 2014).

Autism from the inside: the neurodiversity discourse

The 'medical', 'disability' and 'eccentric scientist' discourses construct autism from the perspective of the non-autistic "normalising gaze" (Foucault, 1977, p.), under which autistic people are scrutinised and evaluated according to the ways that their behaviours depart from implicit 'neurotypical' norms (Brownlow, 2010a). This grounding in 'outsider' perspectives means that dominant discursive constructions of autism fail to recognise the inner lives of autistic individuals or the possibility that any behaviours deemed non-normative might have underlying meaning or significance to an individual (Milton and Moon, 2012; Milton and Bracher, 2013; Yergeau, 2013; Milton, 2014). The hermeneutic landscapes they create are thus rigid and impoverished, and serve to reinforce currently pervasive stereotypes and misconceptions of autism (Draaisma, 2009; Huws and Jones, 2010; Milton, 2014; John et al, 2018; Treweek et al, 2019).

The alternative to this 'outsider' perspective is the neurodiversity[19] (or neurodivergence) discourse of autism (Bagatell, 2010; Robertson, 2010; Milton and Moon, 2012; Brownlow and O'Dell, 2013; Kapp et al, 2013; Den Houting, 2019). This is autism from the inside: autism as a personal experience, where meaning is attached to supposedly unusual behaviours, or indeed where considerable efforts may be made by individuals to conform to normative societal expectations. It is a discursive construction of autism which foregrounds the strengths, skills and individuality of autistic people and construes it as an enriching and valuable feature of human diversity, albeit one that is associated with difficulties in everyday life as a consequence of living in a world created by and for the neurotypical majority (Robertson, 2010; Brownlow and O'Dell, 2013; Kapp et al, 2013; Den Houting, 2019). Like the dominant 'medical' discourse, it typically deploys brain and neurobiology-related terminology (Blume, 1998; Brownlow and O'Dell, 2013; Ortega, 2013), but does so in terms of *differences* compared to the majority phenotype, rather than 'deficits' or 'impairments'.

Where the dominant discourses of autism are profoundly limiting for the ways that we talk and think about autistic people, constructing autism as a form of 'neurodiversity' means that it is inclusive of different experiences and perspectives. As such, it has evolved and expanded over the years, as it absorbs and accommodates the disparate voices and perspectives of autistic individuals (Hacking, 2009). In its early days it was deployed in a way that rendered autism synonymous with 'geekdom' (Blume, 1998; Nadesan, 2005), and which amounted to an insider perspective on – and reclaiming of - the 'eccentric scientist' discursive construction of autism. More recently, however, it has been progressively transformed by the personal accounts of autistic women (see, for example, Miller, 2003; Simone, 2010; Rowe, 2013a and 2013b; Holliday Willey, 2015; Kim, 2015; James, 2017; Uher, 2017; Cook and Garnett, 2018), which are overturning androcentric assumptions about what it means to be autistic, neurodiverse or neurodivergent.

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[19] July Singer (2016) is widely credited with coining the term 'neurodiversity', and it was first used in a published article in 1998 (Blume, 1998; Silberman, 2015).

2.4 Research aims and questions

The aim of this study is to explore the individual narratives of women who came to self-identify as autistic in adulthood. By focusing on individual stories and experiences, I seek to add to the small body of existing qualitative research in the long-neglected area of female autism (Bargiela et al, 2016; Tierney et al, 2016; Kanfiszer et al, 2017; Webster and Garvis, 2018; Milner et al, 2019; Leedham et al, 2020), which have commonly deployed versions of thematic analysis (Braun and Clarke, 2013). In choosing to focus on individual narrative as the 'unit' of analysis, I share with Hacking (2009) the view that personal stories have a profoundly important role in transforming our understanding of autism. Where mainstream research has generated 'knowledge' which homogenises – as well as silences – autistic individuals (Milton and Moon, 2012; Yergeau, 2013; Milton, 2014), narrative analysis foregrounds the personal and the specific (Bruner 1990 and 1991; Polkinghorne, 1998; Gergen, 2015; Schiff, 2017). In 'giving voice' to autistic women as individuals with rich and interesting stories to tell, my hope is to produce knowledge which challenges existing and impoverished stereotypes of autism (Milton and Moon, 2012; Yergeau, 2013; Milton, 2014; O'Dell et al, 2016). Furthermore, where existing qualitative studies of the experiences of autistic women have (implicitly) treated 'autism' as a unitary construct, I seek to explore the ways that the participants' personal meaning making is constituted (and potentially constrained) by cultural resources of autism, which – as discussed in the previous section - commonly depict it in negative, dehumanising or gendered terms. To date, little attention has been paid by researchers to the implications of this at the level of individual subjectivities, and the rare studies which have done so have focused on young male participants (Bagatell, 2007; Baines, 2012), as is all too common in autism research (Krahn and Fenton, 2012). An additional aim of the study, therefore, is to make a contribution to the developing field of critical autism studies (O'Dell et al, 2016) by exploring the ways that culturally available discourses, narratives and representations of autism may be drawn on or resisted in personal narratives.

As I discuss in the following section, my approach to narrative analysis is informed by the critical realist assumption that individual subjectivities are culturally situated and are mediated by social interactions and processes (Bhaskar et al,2018): a worldview which eschews and transcends the dichotomous view of individual and society which (implicitly or otherwise) pervades mainstream research into autism. Reflecting this critical approach to narrative analysis, my primary research question is:

(i) How do women who have self-identified as autistic in adulthood discursively construct the epistemic category of 'autism' within their narratives?

Related to this, my subsidiary research questions are as follows:

(ii) How did the participants come to identify as autistic?
(iii) What meaning did the participants attach to identifying as autistic?
(iv) [If relevant] How do the participants' personal narratives conform culturally available narrative types, 'plots' or themes? (This is discussed further in the methodology section).

Relevance of the study for the counselling psychology profession

At present, despite the counselling psychology profession's avowed commitment to social justice, and to working with 'difference and diversity', autism and neurodiversity are largely absent from the profession's core texts[20] (BPS, 2005; Milton, 2010; Woolfe, Strawbridge, Douglas and Dryden, 2010; Douglas, Woolfe, Strawbridge, Kasket and Galbraith, 2016; Ade-Serrano, Nkansa-Dwamena and McIntosh, 2017; Milton, 2018) and little research appears to have been carried out by counselling psychologists in this area to date (for a notable exception see Wilson, 2017). Alongside this apparent oversight in the texts of the counselling psychology profession, concern has been periodically expressed about a lack of awareness of - or of potentially unhelpful misconceptions about – autism amongst therapists and other mental health professionals (Hodge, 2013; Hearst, 2014; Wilson, 2017; Au-Yeung et al, 2019; Camm-Crosbie et al, 2019). Bearing in mind our growing understanding about the vulnerability of autistic individuals to mental health difficulties (section 2.2.3 above), it is important that this current epistemic 'gap' is now addressed with research that is grounded in the profession's core values of empathic engagement with individual subjectivities, relationality and social justice. An additional aim of this study,

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[20] With the notable exception of a recent chapter on counselling psychology with autistic clients (Rutten, 2017).

therefore, is to add to the currently limited body of knowledge about female autism as a subjective and socially-contextualised experience, with a view to supporting counselling psychologists (and other therapists and mental health professionals) in our relationally-informed psychotherapeutic work.

3. Methodology

3.1 Introduction

At the outset of my research, my interest in the ways that ‘autism’ is discursively produced as an epistemic category – and the implications of this for identity and subjectivity - meant that critical or Foucauldian discourse analysis (Braun and Clarke, 2013; Willig, 2013) appeared to be the obvious choice for my methodology. However, I soon became concerned that the complexity and individuality of the participants’ lives might be ‘lost’ within an analysis which foregrounded discourse at the expense of lived experience. Bearing in mind counselling psychology’s core values of empathic engagement with first person accounts (BPS, 2005) together with the longstanding silencing of autistic individuals within mainstream research (Milton and Bracher, 2013; Yergeau, 2013), I identified a preference for a methodology that would allow me to explore personal experiences and perspectives, alongside a critical analytic or interpretative stance (Ricoeur, 1970; Josselson, 2004; Willig, 2012). In principle, this preference could have been accommodated by a methodology that appears to be popular amongst counselling psychology researchers (Kasket, 2012): interpretative phenomenological analysis (‘IPA’). However, IPA’s grounding in phenomenological principles and relative neglect of the constitutive role of language for subjectivities and meaning making (Willig, 2013; Burr, 2015) meant that it was incompatible with my interest in the discursive production and construal of ‘autism’ as a socially-situated epistemic concept.

These deliberations during the early stage of my research led me to explore a methodology – narrative inquiry – which rarely seems to be adopted by counselling psychology researchers, despite its evident fit with our core values and social justice principles (BPS, 2005; Cutts, 2013): in particular, it is commonly seen as way of ‘giving voice’ to silenced or marginalised individuals (Smith and Sparkes, 2008; Gergen, 2015; Toolis and Hammack, 2015; Schiff, 2017).   At its heart is the assumption that narrativity is a uniquely human form of mental functioning through which we make sense of our experiences and which provides a sense of continuity to our lives (Fisher, 1984; Sarbin, 1986; Polkinghorne, 1988; Bruner, 1990; Dennett, 1992; Schiff, 2017).

Beyond this claim, narrative inquiry is characterised by a considerable degree of flexibility. There is little consensus as to what constitutes a 'narrative' and researchers are free to analyse their chosen mode of narrative – written, spoken or visual - in whichever way aligns with their epistemological or ontological interests; for example, they may focus on structural or performative features, or approach narratives as transparent representations of lived experience (Murray, 2000; Esin, 2011; Bell, 2013; Esin and Squire, 2013; Silver, 2013). In my case, my personal and professional interests and values align with narrative researchers who are influenced by critical and social constructionist perspectives, and who view personal meaning making as taking place within the context – and confines - of the culturally-available narratives and discourses that we encounter during our lives (Somers, 1994; White and Epston, 1990; Frank, 1995; Hammack, 2008; Smith and Sparkes, 2008a; Verhaeghe, 2012; Hammack and Toolis, 2015; McLean and Syed, 2015; Johnstone and Boyle, 2018).

My exploration of narrative theorising prompted me to reflect on the ways that my childhood and adolescence were permeated with narratives in the form of stories, whether heard, read, watched or written. I recognised that - without me being aware that it was happening - this early immersion in narratives conveyed and reinforced powerful messages about social and cultural norms, including about personhood, morality, gender, family and so on (Somers, 1984; Hammack and Toolis, 2015; McLean and Syed, 2015). This personal resonance with the claims of narrative inquiry was accompanied by a growing interest in narrative as a metaphor for selfhood and therapy (Sarbin, 1986; Polkinghorne, 1988) as I explored different approaches to psychotherapy during my counselling psychology training. In terms of my professional development as a practitioner psychologist, I found myself increasingly influenced by approaches that emphasise the social and cultural contexts of personal meaning making, including those that explicitly draw on narrative and social constructionist perspectives (White and Epston, 1990; Hedges, 2005; Dallos, 2006; Køster, 2017; Johnstone and Boyle, 2018)). Over time, I concluded that narrativity is a key theme that brings together my research and psychotherapeutic interests: a similar view was expressed by Polkinghorne (1988) in one of the early key texts on narrative inquiry.

An additional but important benefit of adopting a narrative methodology for my study is that narrative-based study is found across a broad range of disciplines, including education, sociology, nursing and medicine (see, for example, Casey, 1995; Frank, 1995; Charon, 2001; Polkinghorne, 2007; Lewis, 2011; Hurwitz and Charon, 2013; Souto-Manning, 2014; Wang and Geale, 2015). This mirrors the multi-disciplinary nature of autism research itself.

3.2 Exploring narratives within a critical realist framework

My approach to narrative analysis is characterised by the assumption that personal meaning-making is embedded within a wider social, cultural and political context: that the ways that we make sense of our experiences are simultaneously shaped and limited by the concepts, discourses and narratives that we encounter in society (Souto-Manning, 2014; Burr, 2015; Gergen, 2015; Johnstone and Boyle, 2018). This began with an interest in the potentially stigmatising effects of mainstream discursive constructions and narratives of autism - which variously depict autistic individuals in dehumanising terms (Brownlow, 2010b; Duffy and Dorner, 2011; Dinishak and Akhtar, 2013; Milton, 2014; Quirici, 2015; O'Dell et al, 2016) – and the implications of the growing influence of the brain-based neurodiversity discourse of autism as a potential means of resisting and challenging dominant discourses (Brownlow and O'Dell, 2013; Ortega, 2013). This creates a potential discursive 'battle ground' between those occupying the biomedical mainstream – for whom autism is a 'disorder' which requires diagnosis and possible treatment – and those who construe it as a valuable feature of human diversity (and for some, a matter of personal identity rather than a diagnostic construct (Egner, 2019)).

During the research process, I also became interested in claims that stories conform to a small number of plots or themes (Booker, 2007) which we are assumed to internalise through our lifelong exposure to the narratives that are prevalent in our culture, and which we then reproduce when telling our own stories (McAdams, 2005; Gergen, 2015). Within psychology, research in this area has tended to focus on the apparent prevalence of redemption narratives in American culture (McAdams, 2005): narratives in which the protagonist overcomes a difficult beginning to reach a "position of pride" (Gergen, 2015, p.73). However, my interest was drawn in particular by a sociologist's research into the stories told by individuals experiencing serious illness, which he claimed were comprised of elements of three narrative types: restitution, chaos and quest narratives (Frank, 1995 and 2010). Frank argues that the restitution narrative – characterised by a passive protagonist who is healed through the intervention of 'heroic' experts - is dominant within mainstream medicine. Where conventional recovery is not possible and an individual's experience thus fails to conform to this narrative, she or he is left vulnerable to experiencing life as a 'chaos narrative', characterised by themes of helplessness, 'stuckness' and a lack of meaning or purpose. For Frank, the narrative alternative to this meaningless chaos is the 'quest' narrative in which the protagonist re-claims agency through personal meaning-making and action towards valued goals (even if they do not involve recovery to good physical health) (Frank, 1995 and 2010).

As I explored the mainstream production of 'knowledge' about autism, I came to see Frank's (1995 and 2010) restitution narrative as a metaphor for the current preoccupation with identifying aetiological and neurobiological explanations for autism (Pellicano et al, 2014), as though it is a disease that could be 'cured' if only researchers could identify the 'science' that underlies it. From a neurodiversity perspective, however, autism is not a 'condition' which needs to be cured; its cultural framing within an implicit restitution narrative is therefore not only incongruous but also doomed to fail. For Frank, the failure of the restitution narrative is associated with potential narrative 'chaos', including an inability to make sense of difficulties. Indeed, the distress and confusion commonly described by individuals before they came to acquire the epistemic and hermeneutic concept of 'autism' to explain their difficulties in everyday life seemed to me to hint at the emotional pain of a chaos narrative (Hearst, 2014; Hickey, Crabtree and Stott, 2018; Leedham et al, 2020). Furthermore, the hermeneutic absence that underlies 'chaos' seems to have been occupied by another problematic narrative theme in the common storying of autism as a tragedy (Broderick and Ne'eman, 2008; Duffy and Dorner, 2011). This left me curious about whether themes of chaos or tragedy (Frank, 2010) might be common features in the personal stories of autistic women, or whether this potential narrative 'damage' (Nelson, 2001) might be avoided through the deployment of redemptive, quest or other narrative types.

The underlying theme in these influences on my approach to narrative analysis is the socially and culturally-embedded nature of narrative, and – as my research progressed

– this was increasingly accompanied by an interest in the *processes* by which individuals acquire new ways of understanding their experiences: in particular, the possible ways that different epistemic and cultural resources (such as the neurodiversity discourse of autism) 'travel' and become available to construe and re-interpret one's experiences (Bagatell, 2007 and 2010; O'Dell et al, 2016). These various interests converge under the 'umbrella' of critical realism, with its emphasis on the socially-mediated – and potentially transformative – nature of knowledge, together with its recognition of subjectivity as a distinctive form of reality which is produced through the complex and dynamic interaction of other aspects of reality: biological, social, cultural and so on (Elder-Vass, 2012; Marks and O'Mahoney, 2013; Bhaskar et al, 2018). The critical realist view of the social world thus translates to an approach to research that involves the use of interpretative methodologies – such as narrative analysis – in conjunction with an interest in the social processes that contribute to changes in personal meaning making (Bhaskar et al, 2018).

3.3 Research design

3.3.1 Sample size

The flexibility and heterogeneity of narrative-informed methodology means that there is little in the way of guidelines about practical matters such as sample size. However, my intention to analyse individual narratives in depth meant that IPA was an obvious reference point, in terms of its similar concern with depth of analysis and case-focus (Braun and Clarke, 2013). For IPA, Smith and Osborn (2008) advocate a small sample size - typically between one and six participants - in order to allow researchers to engage with the data in appropriate depth. For the purpose of this narrative analysis, I therefore concluded that a small sample size of between four and six participants would be appropriate, depending on the richness of data produced. Like Smith and Osborn (2008), I considered that this position was validated by the publication of rich and insightful narrative-based studies with small sample sizes from one (Sermijn, Devlieger and Loots, 2008; Smith and Sparkes, 2008; Papathomas and Lavallee, 2012) to four participants (Toolis and Hammack, 2015).

3.3.2 Recruitment and participants

Purposive sampling was used, with the following broad inclusion criteria: women who had identified as autistic after the age of eighteen. It is typically the case that autism-related research studies stipulate that participants must have a 'formal' diagnosis, even for studies with an experiential focus (e.g. Bargiela et al, 2016; Kanfiszer et al, 2017). In this case, my interest was in the participants' personal meaning-making around the category of autism; for some individuals, this could be a neurodiversity-informed approach in which the need for external validation of identity could reasonably be deemed inappropriate. Moreover, sensitivity towards the "social contexts and discrimination" (BPS, 2005, p.2) faced by potential participants includes a recognition that it can be difficult and time-consuming to access autism assessments, especially as an adult (Bargiela et al, 2016; Milner et al, 2019; Zener, 2019). I therefore specified in my recruitment material that a formal diagnosis was *not* required and that it was sufficient that participants 'self-identified' as autistic (or having Asperger's syndrome or being on the autism spectrum).

A Facebook page was created to advertise my search for participants (Appendix 2). I shared this with my personal and professional contacts, and also used it to contact two other Facebook pages: one described as an online support group for autistic women, and the other run by a woman who identifies as autistic and who posts information on female autism. I also advertised for participants on a UK-based parenting website, which has a support and discussion thread for individuals who identify as autistic or otherwise neurodiverse. Potential participants were invited to make contact via email or phone, at which point I sent them the participant information sheet (Appendix 3) and invited them to ask further questions about the study before deciding whether to take point.

This resulted in the initial recruitment of six participants, aged between 31 and 47. Some months after the narrative interview took place, one of the participants subsequently decided that she no longer identified as autistic, and it was therefore agreed that her data would be withdrawn from the study. The remaining five participants are all resident in the UK and recorded that they are either white British/white other according to the Office for National Statistics (n.d.) ethnic group categories. They are also all university educated (three with postgraduate degrees);

four are currently employed or self-employed, while the fifth is taking a career break to be at home full-time with her young children). In terms of relationship status, two are married (opposite-sex marriages), two are divorced (following opposite-sex marriages) and one is single. Further information (albeit in an anonymised form) is provided about each participant in the analysis chapter.

3.3.3 Data collection: narrative interviewing

Participants were offered the choice of taking part via video-conferencing rather than face-to-face, to avoid excluding potential participants who might prefer not to meet in person due to sensory issues or other reasons (Bargiela et al, 2016). In the event, this option was used with two participants due to the potential travel time rather than personal considerations. The other four interviews were conducted in person: three participants elected to meet at their own home, and I met with the fourth (whose data was subsequently withdrawn from the study, as discussed in section 3.3.2) at an office in a mutually convenient location. As required by the university, I followed appropriate 'safety' guidelines when meeting the participants in person.

Prior to the interview, I explained that I would be asking the participant to sign a consent form (Appendix 4) on the day of the interview, and I shared this with them in advance. At the start of the interview, I gave the participants the opportunity to ask further questions before signing the consent form and proceeding.

My aim was to encourage the participants to tell their individual stories, with minimal intervention from me (Schiff, 2017); however, I prepared a prompt sheet (Appendix 5) with optional questions to encourage the exploration of the meaning of an 'autistic identity' for the participant and her life if it seemed that it would be helpful during the session. The starting point for the interview was to explain that I am interested in the events and experiences that lead to adult women realising that they are autistic, and to invite the participant to tell me about her experience(s) of this. Depending on the participant's story, I then asked open-ended follow up questions to encourage further exploration and elaboration of the meaning and significance of autism for her life.

At the end of the interview, the participant was again given the opportunity to ask questions and offer feedback about the interview experience. The interviews lasted between ninety minutes and two hours forty minutes, producing a total of ten hours of interview data (excluding the participant whose data was subsequently withdrawn from the study). They were audio-recorded on a digital recording device, then immediately transferred to a password protected laptop following the interview. I transcribed the interviews verbatim (other than anonymising names and other potentially identifying information) following the convention described by Malson (1998).

3.3.4 Data analysis

The aim of my analysis was to generate an individual 'story' for each participant, which reflected the events and experiences that had led to her identifying as autistic, contextualising this within my interpretations of:

(i) the discursive and cultural resources deployed by the participants when making sense of their experiences;

(ii) any experiences or processes that had led to the participant encountering a 'new' way of constructing autism; and

(iii) any changes that took place in their lives following their experience of self-identifying as autistic.

I carried out the analysis and interpretation of each interview separately, in order to focus on each individual story as a distinctive and unique entity. This involved multiple close readings of each transcript, identifying the deployment of different discursive constructions of autism and other features of the participant's narrative which were relevant to my research questions (see section 2.4). I also prepared an informal 'timeline' for each participant, summarising the key events and experiences that had led to them identifying as autistic, and any which followed the incorporation of this recognition into their narrative identity.

I then drafted the individual 'story' for each participant and shared this draft with the participant and my supervisory team for their comments. I explained to the participants that their draft 'story' included some inevitably subjective interpretation and analysis of the ways that they had talked about and made sense of autism as a concept during their interview, but that I wanted to check if they considered that I had represented their views, life events and experiences in a way that conveyed a meaningful sense of what they had hoped to communicate to me. All five participants confirmed that my interpretation reflected their views and experiences in a satisfactory way, and that their data had been appropriately anonymised (following minor changes requested by one participant).

3.4 Ethical considerations

Ethical approval was obtained from the UWE Faculty Research Ethics Committee before I started to recruit the participants (see Appendix 1). Appropriate steps were taken to protect the participants' anonymity and confidentiality: the audio-recordings of the interviews were deleted after transcribing them, and their names and other potentially identifying details (age, location, family member details and so on) were changed in the transcript. The transcript documents were password protected and only shared with my supervisory team via the university email system. The participants' signed consent forms were stored in a locked storage box. Once the final thesis has been approved, the interview transcripts will be deleted, and paper copies of consent forms will be securely destroyed.

As noted in the Participant Information Sheet (Appendix 3), the participants were advised that they could withdraw their consent to participate at any point (including during the interview) up until the later stages of drafting this thesis without giving a reason. They were provided with my draft interpretations of the stories they had given me during the interview and invited to provide feedback on the draft. As discussed above, this led to the mutual decision to withdraw one of the participant's story analysis from my thesis as she had concluded following further reflection that she no longer found autism a personally meaningful explanation for her lived experiences.

Participants were asked to consider before the interviews whether there might be any experiences or events that might be distressing to disclose to me, and to only talk about experiences that they felt comfortable to share with me. For those participants who had not indicated that they had access to a personal therapist, I provided details of local support services (such as counselling charities or NHS Talking Therapies services) in case they experienced distress after the interview.

3.5 Reflexivity

"Strangely enough, I bring myself everywhere I go…" (Schiff, 2017, p.203).

Researcher reflexivity in always important in qualitative research (Willig, 2013), and this is especially so for 'double hermeneutic' methodologies like narrative analysis, where the researcher is engaged in interpreting the participants' own interpretations of the issue in question: it is inevitable that my interpretations will have been shaped by my interests in social constructionism and critical realism, and my personal values of feminism and social justice (Silver, 2013; Schiff, 2017). My interpretations and indeed my interactions with participants will also have been influenced by my personal stance towards autism. In particular, by the time I conducted my participant interviews, my engagement with the personal accounts of autistic women (Miller, 2003; Simone, 2010; Rowe, 2013a and 2013b; Hearst, 2014; Holliday Willey, 2015; Kim, 2015; James, 2017; Uher, 2017) and with critical perspectives on autism research (Yergeau, 2013; Milton, 2014; O'Dell et al, 2016; Woods, Milton, Arnold and Graby, 2018) meant that my construal of autism was informed not only by counselling psychology's social justice agenda (Cutts, 2013), but also by neurodiversity-informed perspectives which foreground individuality and strengths (while not seeking to deny or minimise the difficulties faced in adapting to the neurotypical world) (Kapp et al, 2013; Den Houten, 2019). This neurodiversity-informed position was strengthened by personal and professional experiences relating to autism during the period of my research. I reflected in depth on these experiences through the use of a research journal and discussions with a peer with expertise and experience in the field of autism and neurodiversity; I also shared my reflections on the implications of these experiences for my research with my supervisory team. However, for reasons of privacy and confidentiality – for myself and for others – my reflections on these experiences are excluded from the thesis.

As my study developed, it seemed to me that the most significant decision for a narrative researcher is whether to produce an interpretation of individual stories or a thematic analysis (Schiff, 2017). Undoubtedly the latter has its attractions, not least that it is currently a more 'conventional' approach to qualitative research and – in particular – it lends itself more readily to producing an article for publication (bearing in mind the usual word limits for publishing in journals). However, I found myself resistant to the lure of the theme, sharing Schiff's view that it would potentially detract from the distinctive nature of narrative analysis. Instead, I remained committed to presenting my personal interpretation of my participants' individual narratives, with the deliberate objective of challenging homogenising and dehumanising accounts of autism through the (re)telling of the participants' rich and unique stories.

4. Analysis

4.1 Introduction

My opening prompt to the participants in the interviews was to explain that I am interested in the event(s) or experience(s) that led to them identifying as autistic, and to invite them to tell me about this. I then followed the participant's lead in the story she told me, asking open-ended follow-up questions to elicit further information where it seemed appropriate but otherwise not seeking to impose any particular direction or expectations on their narratives: an approach which is characteristic of narrative interviews (Emerson and Frosh, 2004; Hollway and Jefferson, 2008; Frank, 2010; Schiff, 2017; Stagg and Belcher, 2019).

My objective of "letting stories breathe" (Frank, 2010) in the interview generated rich and extensive data, which was not neatly temporal in nature: different episodes and experiences were recounted as they appeared to come to the participant's mind (and doubtless in response to my expression of interest at different times). As such, the stories were characteristic of the 'rhizomatic' narrative with its "multiple entryways" to the messy complexity of subjectivity and lived experience (Sermijn et al, 2008; Loots, Coppens and Sermijn, 2013): closer to the tales we hear in social settings (or indeed in the therapy room) than a formally 'edited' and structured version of a story. However, when developing my own interpretations of those stories I introduced a more conventionally temporal structure to the participants' narratives, and I also focused on key elements that I identified as relevant from the perspective of my research questions (section 2.4). My interpretation of the participants' deployment of discursive constructions, and the presence – or otherwise – of underlying narrative 'themes' was also shaped and influenced by my own research into these areas during the period of this project, as discussed previously in sections 2.3 and 3.2. The interpretation of each participant's story was then shared with her for her feedback (see section 3.3.4); the resultant five individual stories are presented in the section that follows.

4.2 Charlie's story: "I have been masking and camouflaging my whole life…"

Charlie is thirty one years old; she is married and works as a social worker in a large city in the South West. She self-identified as autistic at the age of 28, after hearing the story of another autistic woman at an autism conference; she was subsequently diagnosed by an NHS psychiatrist at the age of 29.

Charlie's narrative depicted an early awareness of 'feeling different' and of not fitting in with her peers. Dean et al (2017) report that autistic girls are often on the periphery of social groups, and this is consistent with Charlie's experience of being in a friendship group of "smart kids" at school:

> "…on the surface I had friends but (.) I didn't always feel like I knew what was going on. More often than not, I felt like I was included because I matched with these people [in terms of academics and extra-curricular interests] and we got on well enough but I always felt like I was on the periphery, like I was stood on the edge watching (.) the interactions, and I would sometimes get things (.) wrong and have (.) you know, periodic little (.) not full blown falling outs but like (.) you know, just misunderstandings and I would end up apologising and not necessarily knowing why..."

Growing up, Charlie was able to make sense of this pervasive experience of 'feeling different' to some extent: her parents moved from London to the small Scottish town where she grew up when she was a baby and their accents marked the family out as 'incomers'. The family's incomer status within their community did not, however, account for other difficulties Charlie experienced during her secondary school years, such as negotiating the school buildings between lessons:

> "…changing classes (.) into different parts of the building was an absolute fucking nightmare. Noisy, chaotic (.) my locker was never anywhere near any of my classes (laughs) […] we were allowed to take our backpacks around with us, so I would end up loading up like four periods worth of (.) books and everything with me so I didn't have to try to negotiate (.) dodging round [the school]"

As an adult with insight into autism, Charlie came to understand these difficulties as a consequence of her sensory sensitivities, together with differences in executive functioning: at the time, however, she had no way of making sense of why she struggled with aspects of everyday life at school that her peers seemed to take in their stride.

Unexplained difficulties and social confusion became more frequent for Charlie when she reached her twenties and embarked on a career as a social worker. She found herself struggling to cope with various aspects of working life: for example, restructuring of teams was a common event, and something Charlie found "unsettling" and stressful. Perhaps most problematic on a daily basis, however, was the physical challenge of open plan offices. Charlie described how she often wore sunglasses and headphones to help her cope with the discomfort of fluorescent lighting and distracting noise, resulting in teasing from her colleagues:

> "…my colleagues would joke and say I look like either Stevie Wonder or Ray Charles, and it's like (laughs) 'how this light is not painful for you I will never understand', because it actually gives me a migraine, it makes my head hurt and I cannot concentrate with the noise."

In 'joking' about Charlie's resemblance to famous people with known visual impairments, her colleagues acted as a "normalising gaze" (Foucault, 1977, p.184) that served to highlight her differences to implicit norms. This type of experience reinforced her assessment of herself "*a bit weird*"; a "*bit of an odd duck*" who strugged with aspects of life that others seemed to take in their stride:

> "I always felt like I was (.) you know, just trying to (.) to jam myself into this round hole and was a, you know, not necessarily a square peg, maybe a hexagon (laughs) but, you know, just never never fitting in."

Without any way of making sense of these experiences, the story of this period of Charlie's life was redolent of Frank's (1995, p.97) concept of the chaos narrative, characterised by a sense of "vulnerability, futility and impotence" in the face of a seemingly endless series of problems: in Charlie's case, problems that centred in particular on the workplace. Unsurprisingly, she experienced frequent episodes of work-related stress and anxiety during this period, and on two separate occasions was signed off work for several weeks at a time.

During this stage of her life, Charlie was learning about autism as part of her role as a social worker in a children and families team. The cases of autism she encountered were often associated with intellectual disabilities, but she also became more familiar with Asperger-type presentations (Baron-Cohen, 2002b). Her recollection of her knowledge about Asperger-type autism during that period was consistent with the gendered ’eccentric scientist’ discourse of autism (see p.25):

> “…like um, you know, the one that- the most famous undiagnosed character on TV, Sheldon Cooper on *Big Bang Theory* […] oh he’s textbook, clearly not understanding, you know, social niceties and that. He just sees it as a waste of time. Um so yeah, I never even remotely considered it for myself.”

The discursive construction of autistic individuals as aloof, socially awkward boys and men who are more interested in science (or similar pursuits) than in the people around them (Asperger, 1991; Baron-Cohen, 2003; Quirici, 2015) currently permeates popular culture and is reified within mainstream research literature in the form of the so-called ‘extreme male brain’ theory of autism (Baron-Cohen, 2002). It was irrelevant to Charlie’s experience of herself as a caring woman who worked hard to fit in socially and whose interest in other people had led to her studying psychology as an undergraduate and pursuing a career in social work. For much of her twenties, this left her with hermeneutic ‘absence’ and a resulting inability to make sense of her feeling of being ‘different’ to others.

Charlie’s lacuna in self-understanding finally changed in a dramatic episode when she attended a national autism event for work purposes. She was interested to note that there were female speakers talking about their experiences of autism, and she went to listen to a psychotherapist talk about her experience of being diagnosed as autistic in her thirties.

> “…her story resonated so much with me and (.) I just sat there absolutely gobsmacked (laughs) listening to her speak. And it shook me for the rest of the day.”

Charlie described how she heard key aspects of her own experiences ‘mirrored’ by the psychotherapist’s own story, from feeling on the ‘outside’ of groups to struggling in the loud and busy environment at school and work. It was also an encounter with a new way of construing autism, consistent with the ‘neurodiversity’ discourse, according to which it is possible – as embodied by the psychotherapist speaker – to be both autistic *and* a woman drawn to work in a caring profession. It offered Charlie a single, coherent explanation for the seemingly disparate elements of Charlie’s life experiences: her difficulties coping with change and in ‘de-coding’ social norms, alongside her interest in other people and her capacity to pursue a career as a social worker. Perhaps most significantly, the encounter provided her with a new understanding about the way that light and sound often seem to painfully assault her; she could now construe these sensory experiences as integral features of autism that are largely problematic because of the disabling effects of educational and work environments designed by and for the neurotypical majority.

Charlie subsequently carried out her own research into female autism[21] before concluding that her difficulties and experiences “[made sense] under the lens of autism”. She then experienced a stage of wondering:

> “…is a self-diagnosis sufficient or should I pursue an official diagnosis, and […] I’d felt like I really had no choice but to pursue a formal diagnosis because I didn’t feel like I would be believed (.) you know ‘you can’t be autistic, you can make eye contact’, ‘you can’t be autistic, you’re holding down a job, you’re married’…”

Charlie’s comments here illustrate the potentially ambiguous and fragile nature of an ‘autistic identity’. When discursively constructed as a form of ‘neurodiversity’, autism may be construed as a matter of personal identity and self-knowledge, for which ‘diagnosis’ is no more appropriate than it would be for any other facet of one’s identity. In contrast, within the dominant medical discursive framework, formal diagnosis is unequivocally essential and designated healthcare professionals (such as psychiatrists) act as “authorities of delimitation” (Foucault, 1972, p.46) who determine who may – and may not – be termed autistic. In the extract above, Charlie conveyed a sense that “self-diagnosis” might be sufficient for the purpose of her own identity, but the lack of a “formal diagnosis” would potentially damage the credibility of her claim to be autistic in the eyes of (unstated) others.

[2121] Charlie noted that she found *Aspergirls* (Simone, 2010) – which draws on the personal experiences of autistic women - particularly helpful when carrying out her own research into female autism.

Charlie’s quest for medically-sanctioned validation led to a ‘regressive’ phase (that is, one characterised by moving *away* from a valued endpoint (Gergen, 2015)) within her narrative as she described her struggle to obtain ‘confirmation’ of her new autistic identity in the form of a diagnosis via her local NHS trust. She was required to undergo the Autism Diagnostic Observation Schedule (ADOS) (Hus and Lord, 2014), in which she was faced with a series of tasks, such as being handed a picture book with no words in it and being asked to describe what was happening:

> “It was a story about flying frogs and (.) this is the thing, like (.) how is this appropriate for (.) an adult? […] I thought it was insulting. And they said that I was too creative in that particular thing because um (.) I was able to infer the emotions on the faces of the frogs. But it was (.) a quite exaggerated illustration and I was read to a lot as a child.”

Charlie was subsequently told that a diagnosis would not be forthcoming, on the grounds that she had been assessed as “too sociable and creative” to be autistic. Her narrative conveyed an implicit recognition that autism is constituted within the ‘medical’ discourse as something that cannot be concealed from others, and that she had been unable to perform this version of ‘autism’ satisfactorily after years of striving to conform to neurotypical norms:

> “I have been masking and camouflaging my entire life, trying to (.) feel normal, to fit in, you know […] when you wear these masks for so much of your life they become your face. So it’s really hard (.) it’s really hard to separate that […] I can’t just dial up the autism (laughs) you know, to be able to (.) to get them to see what I actually am dealing with, because then I don’t want [the assessment team] turning round and saying ‘well it just seemed like you were performing’…”

Charlie described herself as “absolutely floored and devastated” at the news that a diagnosis would not be forthcoming, a response that conveys the importance of the external validation of medical professionals and the potential fragility of her new ‘autistic identity’ if it is withheld. Her attempt to obtain a diagnosis could have ended at this point, but her previous research into female autism had left Charlie convinced that it was the correct explanation for her disparate difficulties with social situations; with change and transitions; and – above all – with overwhelming and often painful sensory stimulation. She subsequently wrote a long letter to the assessment team, explaining the effects of a lifetime of “masking and camouflaging” any potentially non-normative social responses and why she therefore disagreed with their conclusion. For example, she highlighted that her training and experience as a social worker had helped her develop skills and compensatory strategies which enabled her to “infer the emotions” of the frogs in the ADOS picture task; a performance that had contributed to her being assessed as *not* autistic:

> “[I explained to them that] it’s hard to unpick (.) what is learned and what is inherent (.) how in the hell do you expect me to (.) you know, say ‘oh I-(.) I’m able to just recognise these emotions, also I studied social work, I was trained effectively (laughs) to be able to- to pick up on these subtle expressions if I’m in a one to one situation with a client and be like ‘you seem a bit upset, do you want to tell me more about how you’re feeling?’. You know, this is stuff that I’ve learnt, I can’t just (.) switch that off […] it’s not like you can (.) you know, re-wind to a stage when I was younger.”

In response to her letter, Charlie was offered a second opinion with a psychiatrist. This was a very different experience; instead of being asked to perform infantilising tasks, the psychiatrist spent over four hours exploring her life experiences with her (and with her husband and parents) before agreeing that a diagnosis of autism spectrum condition “made sense” for Charlie.

Charlie described her “massive, massive relief” when she received confirmation of the diagnosis. For Charlie, diagnosis constituted ‘expert’ confirmation that the difficulties she had experienced in life – such as in conforming to social norms and in coping with sensory stimulation in the workplace – could be explained in terms of her “neurology”:

> “I do not believe [autism] is a disorder, you know, it’s (.) it’s a neurodivergence, a difference (.) yes, some are disordered by it (.) you know, that’s not to say that (.) you know, none of us suffer with autism because some do, some genuinely do (.) but (.) if anything it is a condition, it is a type of neurology, and it shouldn’t try to be corrected, as some people try to do.”

Brownlow and O’Dell (2013) describe how the ‘neurodiversity’ discourse typically deploys and subverts the neurobiological claims of the dominant ‘medical’ discourse of autism (in which autistic ‘behaviours’ are deemed evidence of underlying ‘deficits’ in neurocognitive functioning): this is evident in Charlie’s description of autism as a “type of neurology” that should not be corrected. Being able to construct autism in this way had transformative consequences for Charlie, and meant that she herself no longer tries to “correct” her way of being in the world in an attempt to adhere to neurotypical norms. She described how she has experienced the diagnosis as “permission to be kinder to [herself]”, in the form of lifestyle changes that accommodate her social and sensory needs. For example, she has sought and obtained ‘reasonable adjustments’ in the workplace, such as a quieter office space and permission to work part-time from home. She has also joined an online community of autistic women, which in turn has led to rewarding and mutually supportive ‘real life’ friendships with women with whom Charlie does not feel the need to “mask and camouflage” her ‘authentic self’. With these new friends “there’s no pretence , you know, you can just (.) say what’s on your mind. They get you, they understand you”; an implicit contrast with Charlie’s social experiences with the neurotypical majority.

Despite Charlie’s engagement with the ‘neurodiversity’ discourse of autism, the dominance of the ‘medical’ discourse was evident in the power and significance of her diagnosis within her narrative: it was constructed as an essential step in the transformation of her personal identity from “strange” to autistic:

> “if I hadn’t gotten the diagnosis, if it- if it never came to fruition and I just kind (.) you know (.) almost became a catatonic version of myself, and just continued (.) you know, existing like an automaton and- and like just thinking ‘OK, I’m just a bit strange’ (.) you know. I- I can’t (.) if I had- if I had to forecast my life (.) you know, without diagnosis I can only just see it as being very very grey […] [now] it’s so fucking colourful.”

Charlie’s description of her “colourful” life post-diagnosis was redolent of Booker’s description of the classic ‘rebirth’ narrative in which the protagonist is liberated from the “depths of darkness [and] brought up into glorious light” (Booker, 2007, p.194). He notes that this liberation typically involves a significant figure who ‘awakens’ the protagonist[22] and indeed this was the case in Charlie's narrative with the autistic female psychotherapist serving this key role, setting in train the sequence of events which rescued her from a potentially "grey" and "catatonic" future. Her encounter with the psychotherapist's story resulted in a new and personally meaningful subject position for Charlie to adopt: that of a caring and sensitive autistic woman who is creative and resourceful in finding ways to compensate for the difficulties she experiences as she negotiates 'neurotypical' life.

4.3 Gemma's story: "I don't fight to stay normal any more."

Gemma is a thirty eight year old married mother of two young children, who lives in the South West. After working as a financial analyst in her twenties, she is currently at home full-time bringing up her children, and is actively engaged in local charities and support groups for families with autistic children (her son is autistic). She was diagnosed as autistic three years ago via her local NHS adult autism service.

Gemma's description of her childhood was characterised by two key themes: her father's autism, and her exceptional academic abilities. Her father – who had been diagnosed as autistic before Gemma was born – worked successfully in the construction sector where his perfectionism was prized, and his difficult interpersonal style tolerated. At home, however, he required considerable support in day-to-day life from Gemma's mother, and he was prone to "spectacular meltdowns": Gemma described her childhood with him as being like "living with Vesuvius". She chose to escape this at the age of eleven when she won a place at a highly academic girls' boarding school.

Gemma enjoyed the first few years of boarding school life. From her vantage point as an adult with insight into autism she described how its rules and regulations, and small class sizes were "perfect for an autistic person": in this environment, she formed close friendships with two girls who remain friends to this day. A gifted musician, Gemma also enjoyed the unlimited access to musical instruments at the school, and she went on to play no fewer than six different instruments to a high level. In sixth form,

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[22] Booker (2007, p.193) cites Sleeping Beauty as a classic example of the rebirth narrative, with the sleeping princess being awoken from the "dark spell" by the prince.

however, she recalled finding the relative lack of structure problematic and – at the age of seventeen - she developed depression for the first time. At that point, she had no way of making sense of this episode, but she speculates now that it was a response to the girls being given more freedom in sixth form:

> "I wasn't used to that lack of direction (.) didn't like that really. Because before [sixth form] you had the full teaching timetable with no breaks (.) then suddenly you've got a load of breaks. That's really odd."

Gemma noticed that other girls tended to use their free time to socialise, while she "struggled" to adapt to the lack of structure. Despite this – and her difficulties with depression during sixth form - she excelled at A levels and went on to university to study history. She found university life very different to the structure of boarding school, and she chose to live alone rather than endure the "racket" of university accommodation. Nonetheless, her studies continued to go well and she graduated with a first; she also met her partner during this period and they married soon after graduation.

Life subsequently took a significant downturn for Gemma in her twenties; she described how she found herself struggling to adapt to working life despite her exceptional achievements at school and at university. She excelled at the analytic and technical aspects of her role, but experienced considerable difficulties with the noise and distractions of open plan offices, and with the unwritten social "rules" of the workplace:

> "…they seem to expect you to go for lunch with them and things. Why would you have to do that? I work with you, I'm not your friend. I don't want to be your friend. There was quite a strong element of that and they had quite a lot of evening things that you were kind of viewed as expected to attend. I couldn't see why you should (.) but it was kind of seen as you were a bit miserable if you didn't."

Many years later – following her diagnosis of autism – Gemma was able to construe her difficulties in the workplace as a consequence of struggling to conform to neurotypical social norms and the sensory stimulation of open plan offices: "too many people, too much noise (.) constant phones". At the time, however, she had no way of understanding why she seemed unable to cope with office life and she struggled with seemingly intractable depression throughout her twenties, resulting in recurrent episodes of being signed off work for long periods. Gemma was also diagnosed with anxiety and obsessive compulsive disorder (OCD) during this period, which – as with her depression – were not helped by psychological therapies. For a decade, she was prescribed increasing levels of psychotropic medications, and suffered a range of side effects as a result:

> "That level of drugs just made me bloody ill. And then you take more of them because that's what you get told to do. Then you take meds to help you with the side effects from the previous meds (.) and the next thing you know you've got a whole cupboard full. But you keep taking them because you're convinced you're ill […] It stops your brain working. I've got a really quick brain and- and for it to be dulled down to that point actually is really scary. I thought I was losing my mind. But I wasn't, I was just heavily medicated."

Gemma eventually decided to stop taking psychotropic medication due to the unpleasant side effects she experienced. She remained under the care of the community mental health team, however, and it was at a review meeting with a recently qualified psychologist that autism was first suggested as a possibility. By this point in her early thirties, Gemma had two children, the younger of whom had been diagnosed as autistic. As a result of this, she was involved in a support group for parents with autistic children where she had noticed that it was not unusual for parents to identify autistic traits in themselves – and sometimes to seek diagnosis – as they learnt about autism in relation to their child. That had not happened in Gemma's case, however: her young son was largely 'non-verbal' at the time, and she did not recognise herself in his behaviours. Furthermore, she explained that her knowledge about autism in adults at that point was largely informed by her experiences with her father.

> "I didn't have a very good understanding of [autism] because my dad is low functioning autistic so I kind of thought of most people with autism as being on the lower end. (.) He needs full time care (.) pretty much. He'd say he's independent but he's not. He couldn't organise his own meals. He'd sit hungry

> rather than go and find something. He can't answer the phone. (.) He couldn't be left for any length of time on his own because he just doesn't function."

Her father's need for a high level of day-to-day support, and his propensity for angry "meltdowns" bore no relation to her own experiences as a capable mother of young children. Gemma therefore appears to have given little credence to the psychologist's suggestion at the time, and she recalled giving the matter no further thought until the assessment itself, at which – like Charlie – she was taken aback and annoyed to be faced with a series of infantilising tasks including being asked to create stories in response to a picture book and a bag of toys. She refused to engage with these story-telling tasks: "What a stupid bloody thing to make an adult do […] It's completely inappropriate for adult diagnosis". Nonetheless, Gemma subsequently received a diagnosis of 'autism spectrum disorder' from the local adult autism service.

Gemma's initial response to the diagnosis appeared to be one of indifference: "all right then (laughs) (.) add it to the list of diagnoses" (i.e. her longstanding diagnoses of depression, anxiety and OCD). However, she subsequently carried out her own research into autism in women and discovered that it was a single explanation that appeared to account for her difficulties with various aspects of day-to-day life - such as experiencing noise and bright lights as overwhelmingly uncomfortable, and her frequent confusion in social situations – alongside her strengths, such as her capacity to "hyper-focus" which had stood her in good stead in her academic studies. She recounted her initial response of anger that it had taken her mental health team so long to identify the possibility that there might be an underlying reason for her apparent depression and anxiety (that is, an emotional response to the stress of dealing with the demands of the neurotypical world) and that she had endured many years of being unnecessarily medicated as a consequence:

> "I phoned the psychiatrist and told him I wasn't seeing him again (.) I wasn't that polite to him to him to be honest (.) I said you're obviously not very bloody competent if you've been treating something [i.e. OCD, anxiety and depression] that hasn't existed for the last ten years (.) I was really angry at that point because of the bloody meds. Anyway, I haven't seen him since."

Gemma described the psychiatrist's "surprise" at her autism diagnosis and inferred that he appeared to be unaware of the different ways that autism can 'present' in women. For her part, the new epistemic framework of autism helped her make sense of the difficulties she had encountered over the years with psychological therapies which had failed to take into account the different ways that she experiences the world. For example, she was now able to re-frame her apparently 'obsessive' behaviours as 'repetitive' behaviours associated with autism and this provided an explanation as to why CBT for OCD had been unsuccessful in her case: "OCD is simply repetitive behaviours connected to autism, it's not OCD (.) but you won't treat OCD because it isn't OCD." She also recalled the "hell" of sessions with a psychotherapist who was a "horrible eye contact seeker"; she could now construe this experience as an inappropriate (and potentially shaming) attempt to impose neurotypical social norms on her.

Being able to reinterpret her experiences in this way was transformative for Gemma's identity, and she described how she made immediate changes in her life to reflect this:

> "I don't fight to stay normal any more. I immediately dropped the mask. Completely dropped it. If I don't want to go to a social situation that I don't like I just say I'm not going. […] Whereas I would have forced myself to go (.) which obviously added to the anxiety and then the low mood and everything else came with it. I don't do any of those things now. If it's noisy I leave."

Gemma identified that "[fighting] to stay normal" had included struggling to adhere to implicit social norms that she had previously found baffling, for example:

> "Like some people ask what you think about what they're wearing. Why ask me? (.) Don't ask me (.) you might not like the answer (laughs). No, that- those sort of things I still find quite tricky. I've learnt that you do not give the honest answer (laughs) but it is a learnt thing not to do it."

Whereas pre-diagnosis Gemma had no way of making sense of this type of experience, afterwards she could construe such episodes of social confusion as evidence of fundamental moral differences between autistic and neurotypical people:

> “It appears neurotypicals prefer lies” [whereas] “…I actually think most people with autism are more honest (.) better levels of integrity […] I find less judgemental in general too.”

This description of the shortcomings of neurotypical people is consistent with a ‘strong’ version of the ‘neurodiversity’ discourse which constructs the neurotypical majority as impaired relative to autistic people, including from a moral perspective (Brownlow, 2010a; Brownlow and O’Dell, 2013). Gemma’s engagement with this discursive construction of ‘neurotypicality’ was especially powerful in her narrative because it was grounded in the personal experience of being the mother of an autistic child whose behaviour in public often differs from normative expectations, and attracts judgement and intolerance from (neurotypical) others. It was unsurprising to hear, therefore, that a significant part of the lifestyle changes she made post-diagnosis was to retreat from the judgemental “normalising gaze” (Foucault, 1977, p.184) of the neurotypical world as far as possible:

> “[now] I only have people around me that are either autistic or have autistic family members. I don’t mix with NTs[23] at all […] unless they have really strong autism links. No, I don’t mess about with NTs (.) it doesn’t work for me so I don’t do it. (Laughs) If they’re not autism friendly I don’t bother with them.”

Gemma explained that she found that ‘NT’ parents with autistic children often became knowledgeable about autism as a result of their family experiences, and if so would not judge her ‘unmasked’ behaviours from a normative frame of reference:

> “If you’re a bit on the blunt side well that’s OK [“autism friendly NTs”] don’t think anything of that (.) they don’t misinterpret that as you’re grumpy or anything, it’s just (.) OK, that’s how it is (laughs) er and they know if it gets too loud you’ll leave but you’re not being rude, you just can’t cope with the noise and you’ve left. But they don’t misinterpret that whereas NTs who think you’ve (.) got stroppy over something and left (.) and they wouldn’t realise it’s actually intolerable. They would view you as intolerant rather than the situation isn’t tolerable to you.”

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[23] i.e. neurotypical or non-autistic individuals.

With her new understanding of the diversity of autism, Gemma placed new significance on similarities between aspects of her father's experiences and her own, such as their shared sensory sensitivities and difficulties with executive function relating to planning and organisation. Furthermore, where previously his tendency to outbursts of anger had seemed so different to her own long periods of depression, she could now construe both as emotional responses – in her case internalised rather than externalised - to the stress of struggling to adapt to the neurotypical world:

> "I've got some intolerances that dad's got. Like noise and people (.) excessive bright light […] but I don't have the spectacular meltdowns that my dad has where things get thrown, there's a lot of shouting and swearing going on. I don't have that (.) that's why I got mentally ill of course, isn't it, cos it was all internal. Whereas the men I think are more explosive (.) and probably better for them. It's not perhaps better for everybody around them but it's perhaps better for them."

Despite drawing parallels with aspects of her father's experiences, Gemma also drew a clear distinction between his need for full-time support in his life and her capacity to live independently (and, indeed, to provide support to her young son). She did so by creatively deploying the 'disability' discourse to define autism as a disability for some autistic individuals – like her father - but not for her:

> "Do I consider [autism] a disability in me? No (.) but I do in other people depending at what level they are. My dad is disabled by his autism because he couldn't manage his own life without support. So for him it's a disability (.) and the cut off for me is, can you manage your own life without support? If you can, it's not a disability. If you can't, it is."

Gemma's overall story took the form of a subversive take on a classic restitution narrative. Whereas this type of narrative typically involves recovery to health as a result of medical interventions administered by 'expert' professionals (Frank, 2013), Gemma's mental health was transformed when she chose to reject the normative expectations of society, including those of the healthcare professionals she had encountered in the community mental health team:

> "…I was pushing for ['normality'] because I thought well why can't I do it? This is stupid, I should be able to do it. Well now there's a proper reason for not being able to, that's OK. And the stress just disappears with that (.) yeah, the diagnosis has solved what five psychiatrists and about twenty therapists couldn't (laughs). And half the NHS pharmaceutical bill (laughs)."

Within Gemma's narrative, her recovery from her mental health difficulties has given her the opportunity to direct her emotional resources in productive and creative ways: in "fighting" to secure appropriate support for her young son and his education, and in supporting other families with autistic children through involvement in local groups and charities. For Gemma, therefore, her new 'autistic identity' has been accompanied by an enhanced sense of agency and community, in the form of a powerful commitment to her local autistic community.

4.4 Jane's story: "I started realising that I had more in common with the [autistic] kids I was teaching than with the staff…"

Jane is a forty five year old teacher who works in a comprehensive school in the South West. Divorced, she lives with her teenaged son and daughter: her son, now fifteen, was diagnosed with Asperger's syndrome at the age of seven. Jane subsequently self-identified as autistic at the age of 40; she was formally diagnosed via her local NHS adult autism service two years ago.

From the outset, Jane's story was characteristic of a redemption narrative in which a protagonist overcomes setbacks to reach a "position of pride" in life (McAdams and McLean, 2013; McAdams and Guo, 2015; Gergen, 2015, p.73); she described her experiences as a "difficult" child and adolescent from the vantage point of an experienced 'special educational needs' (SEN) teacher who is now responsible for supporting young people with *their* struggles. She recounted her "rigidity" around routines when she was growing up, and the uncomfortable feelings she experienced when these were interrupted for any reason. Jane was eventually able to identify those feelings as anxiety, but she had no such insight as a child. Instead, she experienced physical responses such as vomiting, and a confusing sense of "dread" at the prospect of events like Christmas or family holidays: ostensibly happy events, but ones which involved a change in her normal routines. This response to change was especially debilitating when Jane moved to secondary school[24] at the age of eleven. The distress which this transition evoked in her led to a period of ‘school refusal’, and she was diagnosed with anxiety and depression during this time.

Jane recalled few overt social difficulties when she was young, describing herself as a “stellar actress” and “social chameleon” who became one of the “cool kids” at secondary school. From her current perspective as an adult with insight into autism she attributed this to her ability to imitate her peers, and identified its negative effect on her emotional wellbeing:

> “I was a very very good people watcher from a very early age. So copy, absorb, do the same (.) um and I would say that it was exhausting, yeah, and my anxiety was at peak levels [as a teenager].”

At the time, Jane had no way of making sense of her growing difficulties with anxiety, but she found that alcohol helped her feel more relaxed in social situations. She described how she developed a “high functioning” alcohol addiction as a result of this:

> “…[alcohol] enabled me to socialise (.) you know, to go out and be in busy pubs and stuff […] it was the thing that stopped the anxiety, well temporarily obviously. Obviously it was still there the next day, and worse obviously. But at that time, it stopped the anxiety. It allowed me to relax, it stopped me overthinking, it stopped me analysing every conversation I’d had that day and what I’d got wrong…”

Jane continued to struggle with anxiety, alcohol addiction and intermittent bouts of depression throughout her early adulthood, but alongside these difficulties she embarked on a career as a maths teacher; she also married and was able to overcome her alcohol dependency before starting a family. She recalled recognising that “developmentally something was askew” with her first child early in his life and described her subsequent efforts to understand this and to obtain appropriate support

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[24] In Tierney et al’s (2016) IPA study of the experiences of ten adolescent autistic girls, they found that the transition to secondary school was a common trigger for an increase in difficulties which led to a diagnosis of autism. They cited the larger size (and accompanying increase in sensory stimulation) of secondary schools as potentially problematic, alongside the need to make new friends.

for him at school. This culminated in a diagnosis of Asperger's syndrome for him at the age of seven.

Within Jane's narrative, the story of her experiences of successfully obtaining educational support for her son was itself redemptive: she described how she decided to use her experience with her son to help other families facing similar difficulties, and therefore undertook further training as a special educational needs (SEN) teacher. Once working in that field, Jane came to realise that she was particularly skilled at relating to autistic children and adolescents, and experienced an "epiphany" that this was because their difficulties in the school environment mirrored her own experiences:

> "I started realising that I had more in common with the kids I was teaching than with the staff in the school (laughs) a lot of the time […] [Other teachers] just kept commenting about the fact (.) that they'd come to me and say 'this kid's having a meltdown, this kid's having a problem […]' and I instinctively always knew (.) what the problem was, and I knew how to communicate very well with them. And it was- there was just an epiphany of (.) you know because you've experienced it…"

In Jane's narrative, the significance of her 'epiphany' was that it resulted in a radical shift in her identity; she could finally draw on a coherent explanation for her years of unexplained mental health and addiction issues. This epiphany occurred when she already had substantial 'knowledge' of autism as a potentially limiting disability through her experiences with her young son and her work as an SEN teacher; however, deficit-focused constructions of autism had not appeared relevant to Jane's experience of herself as a professional woman and accomplished (albeit secretly anxious) "social chameleon". Instead, it was direct interpersonal encounters with her pupils' embodiment of social and sensory overstimulation in the form of 'meltdowns' that provided Jane with an alternative way of construing her previously inexplicable vulnerabilities. She went on carry out her own research into autism in women, which confirmed her view of herself as autistic.

Jane described her response to identifying as autistic as follows:

> “It was quite a watershed moment, [I remember] having an instant sense of relief (.) a very big sense of relief. It really felt like a missing piece (.) had come together. And for a long long time I didn’t share it with anyone, I didn’t really feel the need to. I was very very happy (.) um with that realisation. I started doing some research on the internet, which kind of confirmed (.) what I knew, started looking more at women on the spectrum (.) and reading their experiences, read some books and things like that. Um and for a quite a long time being quite happy just to know and not really feeling the need to talk to anybody about it. Er because (.) um (.) it was probably the first time in my life I actually felt comfortable in my own skin.”

Within the hermeneutic framework of autism, Jane finally encountered a meaningful explanation for her need for routine and predictability; the anxiety she experiences in response to change and transitions; and her difficulties with overwhelming sensory stimulation (such as noise, bright lights and so on). It also accounted for potentially problematic aspects of self, such as her “reputation for being a bit abrupt and blunt” with colleagues which she now construed as a consequence of features of autism such as “rigidity” towards the behaviour of others:

> “…the autism in me wants to go ‘for the love of God, are you stupid?’ (.) you know, I want to be blunt, I want to just say it like it is […] um but I know that that’s not socially acceptable…”

Here, autism is constructed as something disruptive within the self; a source of potentially transgressive behaviours. However, in Jane’s narrative it was also a source of considerable strength, in the form of her high professional standards and her longstanding interest in other people. Within a neurodiversity-informed understanding of ‘autism’, the latter could now be construed as an (autistic) ‘special interest’ which had had significant benefits for her personal and professional development:

> “…[my special interest as a child] was watching other people […] and I think I’m probably, from that point of view, far far better than most (.) you know, neurotypical people. Er I’m far more observant of very small changes in people.

> I probably read body language and facial expressions (.) and tone far far better than most neurotypical people. Which is a huge benefit in work."

Jane's new 'autistic identity' thereby provided a coherent explanation for disparate strengths and difficulties. For over two years, this insight remained a largely private matter, although she eventually shared it with close family members such as her mother and sister. She described how helpful this proved to be for their relationships as they could now make sense of her "rigid" need for routine; something which had sometimes led to conflict in the past. Now that family members could understand this to be an integral feature of autism, Jane found that they were more accepting of her needs in this area.

Jane eventually decided to seek a diagnosis via the NHS, describing the decision underlying this as follows:

> "I felt I deserved the validation almost, the (.) um you know the validation from other professionals and people that I wasn't kind of like (.) I dunno, making excuses for problems I've had in the past and my behaviour sometimes. Um [..] I didn't even suspect it, I knew, I knew that I was right (.) but I wanted the validation of someone confirming that…"

Like Charlie, Jane's stance towards diagnosis illustrates the conflict between the competing neurodiversity and 'medical' discourses of autism, and the core issue of whether the individual has agency in determining her autistic/neurodiverse status. Her narrative conveyed an unsettling uncertainty resulting from this: she could experience herself as 'knowing' that her difficulties could be understood within a (neurodiversity-informed) framework of autism and yet designated experts would have the power to deny her self-knowledge and deem her to be "making excuses" for the ways in which her behaviour and mental health had sometimes failed to conform to normative expectations.

In fact, for Jane the diagnostic process[25] proceeded relatively smoothly, although she recalled objecting to the "male-centric" autism screening questionnaire used by the

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[25] From Jane's description, it appeared that the diagnostic process took the form of the interview based DISCO (Diagnostic Interview for Social and Communication Disorders) procedure (National Autistic Society, 2017)

GP. However, it also resulted in a surprising discovery: her GP reviewed her medical notes since childhood for evidence to support a referral, and found that autism had been recorded as a possibility on two separate occasions. The first was when Jane was diagnosed with 'depression and anxiety' at the age of eleven; the possibility of autism being the underlying explanation for this episode was noted in her medical records but was not communicated to Jane's family. The second occasion was more recent; following a course of CBT for anxiety in her late thirties, Jane's therapist had written to her GP to suggest that she might be autistic. The therapist had not, however, suggested this to Jane herself and she was not copied in on the letter.

The reason for excluding Jane (or her parents, when she was a child) from speculation about autism was not recorded in her notes, but – irrespective of their underlying intent – the professionals' silence constituted acts of hermeneutic injustice in which knowledge that may help an individual understand their experience is withheld by individuals in positions of epistemic power (Fricker, 2007). The effect of the resulting lacuna in Jane's understanding of her difficulties was apparent in her description of her complex emotional response to receiving a diagnosis from her local adult autism service:

> "I was (.) very happy and very sad at the same time […] um and then I was quite overwhelmed, I was quite upset […] I think I just felt very sad for that little girl. Not me now, because (.) you know (.) I've made a really good life for myself. I've been successful, I have beautiful children (.) I was very sad for that kid, really […] I think all the years of not knowing. Knowing something was wrong, especially when I was a teenager and a young adult and always being told it was mental health."

This was a poignant moment in Jane's story, but her narrative quickly reverted to a redemption theme, in which earlier struggles are construed as essential in shaping the "successful" person she has become:

> "…would [an earlier diagnosis of autism] have held me back? Would I have tried (.) less? Would I have avoided situations that actually I eventually overcame? […] I did put myself in lots of what you would think now were ridiculous

> situations for someone on the spectrum. But- but I managed to, even though sometimes it was very hard, I managed to be successful in those situations."

Jane's comments display a concern about the psychological effects of internalising dominant negative discourses of autism which depict it as disabling impairment which places inevitable constraints on an individual's life. Her awareness of the pervasive effects of conventional 'tragedy' narratives of disability in which the individual is portrayed as incapable of living a fulfilling life was grounded in her personal experiences of encountering prejudice towards autism in her working life, even amongst colleagues working in the SEN field. As a result of this, she decided to inform very few colleagues about her diagnosis:

> "There's only two people in my team that are aware of [my diagnosis], and they are by far the most competent people, like by a country mile (.) um are probably the people I'm closest to on that team, you know. So they're aware of it, but the others don't know (.) it would colour the way they looked at me, they wouldn't- they struggle with the young people they support, to differentiate between them."

Davidson and Henderson (2010) explored the issue of disclosure of one's 'autistic identity' through a discourse analysis of published autobiographies of autistic individuals. They concluded that it is a highly complex process which entails a careful weighing up of the potential responses of others, and a recognition that they may be influenced (consciously or otherwise) by deficit-focused and stigmatising stereotypes and representations of autism. Consistent with this, Jane described her concern about the potential responses of colleagues, commenting that "they'd start to talk to me in a slow voice". Implicit in this comment was the assumption that her colleagues' stereotypical views of autism would result in them treating Jane differently – as somehow 'lesser' - if she were to tell them about her diagnosis. As a result, she was highly selective about the colleagues to whom she disclosed her new 'autistic identity', confining it to those she trusted not to treat her differently (and – for practical purposes – the school's headteacher In order to arrange a 'reasonable adjustment' in the form of a quiet office space).

The redemption theme of Jane’s narrative was especially notable in her description of her present day professional life and her role as a dedicated SEN teacher, in which she is committed to providing excellent support to the young people in her care, and to helping them achieve their full potential. For Jane, an integral part of the latter includes changing societal attitudes towards autism:

> “…we need to find a way as a community, to make an autistic diagnosis (.) actually not negative. You know, more as a just- you know, the whole neurotribes, just a different tribe as opposed to a disability. And I know that’s not useful when you’re not high functioning (.) it’s got to be classed as a disability. But I think for high functioning (.) we almost need a different script.”

Within Jane’s story, her call for a “different script” had particular resonance bearing in mind her experiences of healthcare professionals withholding the suggestion of autism from her and thereby implicitly constructing it as something too awful or tragic to speak of. Discovering a different way of understanding autism has allowed her to develop a new ‘script’ for her own life, in which her personal struggles have been integral to her development as a successful ‘autism professional’ who is now in a position to help and educate others.

4.5 Rowan’s story: “[I’m] a social justice warrior and a feminist and I don’t play by, you know, gendered rules.”

Rowan is a forty two year old communications consultant; she is divorced and lives in London with her children. She self-identified as autistic (with attention deficit hyperactivity disorder ‘ADHD’) two years ago and subsequently sought a formal diagnosis; however, her general practitioner refused to refer her for an autism assessment on the grounds that Rowan does not need “support” in her everyday life.

Rowan’s description of her early life was characterised by a clear sense of ‘difference’ but her response to this was not to adopt a ‘mask’ in an attempt to fit in socially: instead, her narrative was characterised by themes of self-acceptance and pride in not conforming to social norms. She attributed her response to her sense of ‘difference’ to her parents, who prized originality over mundane ‘normality’:

> "My mother and my father used to call me weird […] and if anybody ever would object to that my parents would be like 'well no-one ever wrote a book about someone who was normal, why would you want to be normal?'"

Rowan explained that – within her family – the term "weird" was understood to be "a statement of fact and a good thing" and that she experienced it as a "mark of pride". The encouragement Rowan encountered at home for her originality, however, was very different to her time at school where she experienced social isolation and frequent attempts to bully her. She described how her parents' acceptance and understanding, combined with two very different 'coping strategies' – creative writing and a willingness to fight back against potential bullies – helped her weather these challenges:

> "[my parents' acceptance] provided me with a very very very solid foundation, it was like the fortress that I could retreat to (.) when I felt under siege. And, you know, I had this incredibly (.) um elaborate interior life with the writing which always gave me somewhere to go in my head to retreat to, so I had that protection […] I had that coping strategy internally [….] [then] whenever somebody picked a fight or tried to bully me (.) because I'm naturally a pugilist I always fought back, I never was cowed."

Rowan's descriptions of episodes of 'pugilism' throughout her life were a notable feature of her narrative, subverting traditional discourses of femininity which construct women as helpless and fearful victims of violence: instead, her story was reminiscent of a traditional narrative - the 'heroic saga' – which is typically associated with a male protagonist who overcomes foes and setbacks before emerging victorious (Gergen, 2001; Gergen, 2015). Within Rowan's personal story, this implicitly gendered narrative type was accompanied by an explicit rejection of gendered social norms for her sex, which she construed as a response to being raised alongside two brothers:

> "…I've been raised with the entitlement of a straight white man which means I behave a lot of the time with the entitlement of a straight white man so so (.) er I have a lot of quite masculine- (.) traditionally masculine, I'm going to put that in quotes (.) traits."

For Rowan, this stereotypically (straight white) male “entitlement” – alongside her “pugilistic” nature - was protective for her sense of self as she negotiated the challenges of social and working life in her early adulthood. After university – including a master’s degree in law - she embarked on a career in media analysis and communications, and soon found that office life was incompatible with her working style of periods of procrastination followed by a short burst of intense activity to complete assignments on time. Rowan discovered that – irrespective of the quality of her work – her lack of compliance with the implicit ‘rules’ for workplace life was deemed problematic by employers, and for many years she was unable to hold down a job for more than a year before being fired. Alongside this difficulty with adhering to normative workplace expectations, Rowan had identified by early adulthood that there were aspects of everyday life which made no sense to her, rendering her an “outsider”:

> “[I’ve] always been an outsider, always been fucking odd. Never been able to work it out either. I mean, I’m not stupid by any stretch of the imagination and I would watch these people who have the IQ of toasters being able to hold a perfectly normal conversation with somebody and not make them spit their drink. And I’d be thinking ‘how come that [person] can do it and I can’t?’ (.) And I assumed at some point I was going to get the hang of it.”

As this extract illustrates, at this stage of life Rowan lacked any meaningful epistemic resource for making sense of her apparent difficulties in normative social interactions; something that was all the more difficult to understand bearing in mind her intellectual capabilities. However, this experience of ‘difference’ was mediated by her self-acceptance:

> “It never occurred to me that I was the problem, it was always the rest of the world. So like, you know, this is my place, I will occupy it, I will own it and if you don’t let me then fine, we pick a fight […] So that’s the reason I think I don’t have anxiety or depression now.”

This interpretation of difference was an evident source of strength for Rowan, and one that was construed as protective for her emotional wellbeing. Rather than submit to employers’ demands that she comply with their ‘rules’, she worked as a self-employed communications consultant for over a decade and established a reputation in her field based on the merits of her work. During this period, Rowan also married and had two children, but this episode of conformity to societal expectations for 'compulsory' heteronomativity (Rich, 1980; Hammack and Cohler, 2011) did not last long: her husband became physically abusive towards her when their children were small. Rowan was faced with another battle with a 'foe' in the form of her violent husband, and she described her sense of pride as a result of successfully re-building her life in the aftermath of their divorce:

> "I know what I'm made of. I know I've been tested. I know what is left when you take away all the artifice so it gave me a really really really decent sense of self. So having, you know, climbed back from (.) you know the absolute bottom rung of society frankly as a single parent on benefits with fuck all [.] umm and managed to climb out of that pit […] it's given me the- er a very very very strong sense of who I am."

It was with this strong sense of self that Rowan's career flourished after the divorce. Describing herself as a "social justice warrior and a feminist" she focused on working in the not-for-profit sector on projects that aligned with her personal values. One such project involved working alongside a psychiatrist to prepare reports and applications for asylum seekers, and this led to Rowan's first encounter with 'autism' as a potential explanation for her longstanding sense of 'difference':

> "[my colleague said] 'Christ you're the highest functioning person with ADHD and Asperger's I've ever met'. And I went (.) 'that would make a lot of sense'. And that was the first time it ever occurred to me. Like I've been- (.) I've been so weird all my life. Like so weird, never fitted in anywhere, never occur- never occurred to me that it would be autism."

This was a dramatic episode in Rowan's story: the comment was made in an informal social setting when the colleagues attended a conference overseas together, but the power inherent in the psychiatrist's professional status imbued it with medical authority. For Rowan, it was a wholly unexpected 'evaluation', but one that immediately made sense to her. She explained that, at the time, her understanding of autism was largely informed by the television series *Sherlock Holmes* (Vertue and

Cameron, 2010) and that its portrayal of the (assumed) autistic Holmes as a brilliant non-conformist meant that it had no negative connotations for her:

> "I didn't think holy shit I'm disabled (.) umm this is terrible. What I thought was (.) ah OK yeah, no that would explain […] the fact that I've never fitted in in my life."

The new epistemic resource of autism did not catalyse a process of radical identity reappraisal within Rowan's narrative: instead, it acted as an "explanation" and "context" for her longstanding and accepted sense of 'difference', and could therefore be "incorporated into [her existing] identity". In the aftermath of the encounter with her colleague, Rowan went on to read several books and articles about autism, and her response to this was ambivalent. She disliked the "clinical" stance that characterised some publications – "I don't really need to be reduced to a diagnosis" – but discovered that autism offered a coherent explanation for seemingly disparate aspects of her life, including embodied experiences such as the high pain threshold which had proved helpful when faced with physical aggression and her tendency to fidget or 'fiddle' with objects. Within the epistemic framework of autism, these experiences could now be construed respectively as examples of sensory hypo-sensitivity and of 'stimming'[26]. Similarly, Rowan now discovered a useful explanation for her erratic working style:

> "…I always thought I was lazy. Umm cos you know like when you're not depressed but you don't really want to do anything you think 'am I depressed? Hang on a minute, I haven't gotten out of bed for the last four days. Am I depressed? Is that depression? I don't feel sad, is that depression?' Turns out that it's just shit executive functioning so I'm like wahoo [now I've got a] name for it."

While Rowan recognised certain key aspects of her experiences within published descriptions of autism that she read, she found that she did not identify with the

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[26] The term 'stimming' is widely used within the autistic community to refer to "self-stimulating repetitive movements" of various types (Belek, 2019, p.33). Within the 'medical' discourse of autism these are framed as 'symptoms' which are often the focus of behavioural interventions (Milton and Moon, 2012), and included with the formal diagnostic criteria as forms of 'restricted, repetitive patterns of behaviour" (APA, 2013). In contrast, within the neurodiversity epistemic community, these behaviours have meaning or purpose for individuals; they may, for example, relieve stress or they may simply be enjoyable (Zamzow, 2019).

pervasive theme of ‘masking’ within the accounts of autistic women, leading her to conclude that she “[presents] more as an autistic man than an autistic woman”. She attributed her lack of ‘masking’ to her parents’ encouragement of ‘difference’, together with her subversive stance towards gendered norms – “gender’s always been a bit of a toy for me […] I don’t play by, you know, gendered rules” – which meant that she had never been drawn to conform to societal expectations for female social behaviours.

Although autism had never occurred to Rowan herself as an explanation for her sense of difference, she discovered that her longstanding therapist was unsurprised when she raised this with her:

> “…I’ve been seeing a psychologist for years and years now, the same one (.) and umm er cos again weird (.) don’t fit in, bit odd and umm (.) er I went to her and I’m like ‘So I had this conversation [with my psychiatrist colleague] […] what do you think about it?’. And she was like (.) yeah. And I’m like ‘why haven’t you said anything?’. She’s like ‘Cos I’m a psychologist, I can’t diagnose.’”

The reference to ‘diagnosis’ within this extract is consistent with the dominant ‘medical’ discursive construction of autism, according to which autism is defined and categorised within diagnostic manuals such as the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM) (APA, 2013). Within this discursive framework, autism is assumed to be characterised by overt behavioural idiosyncracies which can be identified and evaluated by designated ‘autism experts’[27]. This reification of ‘autistic behaviours’ was challenged by Rowan within her narrative:

> “I think that (.) er reducing autism to diagnostic criteria is troublesome and I’ve never been comfortable with the whole DSM criteria anyway. The idea that you can put the whole of humanity into a book that big really it does not sit well with me.”

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[27] In the UK, the NICE (2012) guidelines stipulate that autism assessment should be carried out by members of multidisciplinary teams which draw on “a range of professions and skills”. In relation to this, the guidelines recommend that such teams should include clinical psychologists (alongside psychiatrists, occupational therapists, speech and language therapists and social workers); there is no reference to counselling psychologists.

Despite her scepticism about the classificatory paradigm of the DSM (APA, 2013), Rowan nonetheless spoke to her GP about a potential referral for an autism assessment: a request that was refused on the grounds that she does not require "support" to cope with daily life. This stance is arguably consistent with the UK's 'clinical excellence' guidelines, which recommend that autism assessment should be considered where an individual's seemingly 'autistic' qualities[28] result in problems in their daily life (such as with relationships or in "obtaining or sustaining employment") or are accompanied by a history of mental health difficulties (NICE, 2012). It is a stance that does not recognise that it may be helpful for an individual's wellbeing to have their identity confirmed via a diagnosis by a healthcare professional (Hearst, 2014; Stark, 2018). Furthermore, in Rowan's case, the GP failed to take into account her history of difficulties with "sustaining employment" (NICE, 2012) and in interpersonal situations: difficulties that she had been able to overcome through her intellectual abilities and resourcefulness, for example by becoming self-employed and by learning to apply logic[29] to make sense of social situations.

Within the 'medical' discursive construction of autism, an individual seeking an autism assessment must submit to the scrutinising 'gaze' of healthcare professionals (NICE, 2012) who serve as "authorities of delimitation" in determining who is to be designated autistic or otherwise (Foucault, 1972, p.46; Foucault, 1973). This was challenged within Rowan's narrative, with her description of the way that she evaluated her own 'autistic' qualities with reference to the relevant diagnostic criteria:

> "I look at the diagnostic criteria, I'm bright enough to be able to look at those (.) to say how many I identify with, on balance (.) yes. I don't think that there is any reason to get a specialist in to do exactly the same checklist that I've just done."

The lack of professional 'validation' in the form of a diagnosis thus did not detract from Rowan's sense that autism is a meaningful way of interpreting important aspects of

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[28] These are specified in the NICE (2012) guidelines as one or more of the following:

- persistent difficulties in social interaction;
- persistent difficulties in social communication;
- stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests.

[29] Rowan commented: "With human beings all of their actions are A plus B equals C. And there is a formula, you've just got to work it out."

her experience and selfhood. Within her narrative, her identity as an autistic individual was constructed as a consequence of distinctive neurobiological functioning:

> “I am autistic, it is the- the absolute root of who I am as a human being. We are only ever our neurological function and this is my neurological function.”

Within Rowan’s narrative, this neurobiologically-based ‘autistic identity’ intersected with her identity as a ‘social justice warrior’ and feminist: a personal viewpoint that was consistent with a politically-informed variant of the ‘neurodiversity’ discourse of autism (Ortega, 2013). Within this discursive framework, autism is constructed as a distinctive minority identity: autistic individuals are oppressed by expectations that they should conform to neurotypical social norms (Milton and Moon, 2012;). Furthermore, their identity may be threatened and minimised by neurotypical claims that “’everyone’s a bit autistic’“:

> “I think that the experience of autistic people is unnecessarily difficult [.] and made difficult by neurotypicals. I think that there is increasingly as we um get together online and find each other and find our communities and our places within our communities (.) umm there is increasingly an us and them mentality developing. [...] I think that there is an increasing amount of anger in the [autistic community] that until now has been turned inwards and I think that it is beginning to turn outwards.”

Within her narrative, Rowan’s view of the potentially emancipatory effects of ‘turning anger outwards’ mirrored her personal coping strategies of “fighting back” against the bullies at school. It was a personal viewpoint that was strengthened by joining an online community of autistic women, and finding that her strong sense of self and emotional health were unusual: in contrast, many women described mental health difficulties, and a lack of agency in responding to experiences of being ‘othered’ and ostracised, including within their own families. She interpreted these women’s accounts through the ‘lens’ of social justice and feminism, identifying that their vulnerabilities to mental health difficulties mirrored those associated with other minority groups (Cromby et al, 2013) who are similarly “forced to mask and code-shift and pretend to be something that they are not” in order to conform to hegemonic cultural norms:

> “Transgender people and gay people [suffer] disproportionately from mental ill health and anxiety and depression I think for the exact same reasons autistic people do as well. I think that when you are told that you are wrong or when you are called weird and it’s a bad thing and you don’t know how to make sense of things and you don’t know how to do things that other people can do (.) I think that- and you pretend to be somebody that you’re not […] you are going to be anxious and depressed after 20 years of that.”

Rowan’s response to the high levels of anxiety and depression she encountered amongst the online community was to adopt an informal ‘mentoring’ and leadership role, organising social events and workshops with the personal objective of helping other autistic women develop their confidence and learn how to cast aside their ‘masks’. She combined these personal efforts, however, with an awareness of the importance of change at a societal level, highlighting the need for a move away from the current preoccupation with ‘deficits’ in functioning amongst researchers:

> “…more research [is needed] and more interest- but more positive research […] [researchers] only tend to look at the people who are (.) you know, really suffering with it. Umm and then it becomes a tragedy and then it’s- they don’t look at it in terms of its positive aspects. They don’t look at the [things] you can do, it always focuses on the things that you can’t.”

At the time of telling her story, then, Rowan was still engaged in a ‘heroic’ struggle (Booker, 2007; Gergen, 2015), but with a wider focus on ways of potentially transforming societal attitudes towards autism and on supporting other autistic women in developing their own strong sense of self and emotional wellbeing.

4.6 Laura’s story: “[I’ve] spent so many years building up that mask it’s extremely difficult to just drop it…”

Laura is a thirty six year old radiographer who lives in the South West; she has been “very happily single” for several years after a series of “disastrous” relationships in her twenties, including one in which she was emotionally and financially abused. She self-

identified as having Asperger's[30] *[syndrome] four years ago, and subsequently obtained a formal diagnosis through her local NHS adult autism service.*

The story of Laura's early life was one of academic and musical achievement, marred by seemingly inexplicable social difficulties which damaged her confidence when she was growing up. Laura described her growing awareness by early adolescence that it was difficult for her to fit in with her peers and for two years (from the age of twelve to fourteen) she recalled that "nobody wanted to be my friend". From her vantage point as an adult with Asperger's, she can now identity that her response to this was to try to conform to social norms by observing other girls and "mimicking" their behaviours, without being fully aware at the time what she was doing:

> "I spent years and years (.) um observing other girls in my peer group and every so often I would find a- a hand gesture that one of them would do and I would- I never did it consciously (.) I was vaguely aware of it but it was never a conscious thing (.) I would copy it and it became something I did."

Her social experiences gradually improved through her mid to late teens; perhaps in part as a result of these 'camouflaging' behaviours but also through her participation in music-related activities and groups, where she met young people with whom she ad more in common:

> "…I still found [social interactions] very difficult but I think because we all had the music in common and we were all […] I think there were a lot of people there like me who possibly even had undiagnosed Asperger's for all I know. So I tended to get on quite well with [musical] people."

Laura's social situation took a downturn, however, when she went to university to study radiography. The course was female-dominated and – in the absence of the shared interest in classical music that had previously helped her develop friendships - she recalled that she often found herself sitting in silence as the other students chatted about "handbags and parties and drinking". Such experiences exacerbated her sense that she was "definitely different" to her peers, and this continued after she

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[30] Laura's preferred way of talking about autism was 'having Aspergers', so this is used throughout her story.

graduated and moved to London to begin work as a radiographer: she described how effortful she found it to make ‘small talk’ with patients and colleagues, and how she struggled to understand the unofficial ‘social rules’ in her workplace, such as the apparent expectation that staff in her department should have lunch together. In Laura’s case, she preferred to go for a walk at lunchtime to have a break from interacting with others; however, she recalled being criticised for her lack of engagement with colleagues at lunchtime in more than one performance review.

Within Laura’s narrative, it was evident that she had lacked a meaningful way of making sense of difficult aspects of her life during her twenties. She recounted how she had assumed at the time that her social difficulties were a result of ‘social anxiety’, but this failed to account for other struggles in her daily life, such a difficulty in processing and remembering sequences of instructions given to her verbally. This was potentially anxiety provoking for Laura in her professional role, and it seemed inexplicable bearing in mind her otherwise good memory. She also experienced frequent migraines and found it difficult to tolerate loud or busy environments. These difficulties contributed to her leaving London in her late twenties to live in a rural area and work in a smaller hospital. Alongside this, she made other adaptations to help her cope with aspects of everyday life which she found stressful; for example, she started going to the supermarket late at night to avoid noise and crowds.

The greatest challenge for Laura in her twenties, however, was her romantic life: she described how she all too often placed her trust in men who ended up treating her poorly. The resulting “trail of disastrous relationships” culminated in a two year relationship with a man who proved to be a “con man” and who deceived, manipulated and financially exploited Laura. She described how her mother and friends had expressed concern to her about her then partner’s motives and behaviours, and yet he had always been able to convince Laura that “the sky was pink rather than blue” before leaving her with a string of debts when he abruptly moved abroad. In addition to debts, however, he left her with another legacy that ultimately had a positive outcome in Laura’s narrative: he was the first person to reference ‘autism’ in relation to her, doing so in a characteristically disruptive fashion the first time he met her parents:

> "…he had never discussed [autism] with me prior to meeting my parents and when he met my parents he announced that he thought that I was autistic. So that was a bit of a shock […] I heard the word autistic and I didn't relate it to Asperger's. I didn't know they were even connected, I had no idea. If he'd said Asperger's I probably would've twigged (.) and maybe I would've followed up and done some research myself but he said autism and I- I just completely dismissed it because I thought- I thought autism was a learning disability and I thought clearly I'm not learning disabled (laughs). So I just thought it was really really weird..."

In this episode, Laura's partner's behaviour contravened social norms, but it appears that it was the use of his term 'autistic' – rather than Asperger's – that rendered his announcement impossible to assimilate. As Laura explains, at the time she understood Asperger's and autism to be discrete 'entities', with the former having some potential relevance to her sense of herself as "different" to the majority of her female peers, with her "nerdy" interests in science, nature and classical music:

> "I knew vaguely about Asperger's being sort of nerdy type boys (.) geeky type boys with, you know [.] um [.] but I didn't link that with autism at all. I didn't know they were connected."

For Laura, then, the association between Asperger's and 'geekiness' – consistent with the 'eccentric scientist' discursive construction of autism (see p.25) – might have led her to explore its possible relevance for her own experiences despite its gendered connotations. Instead, her interpretation of her boyfriend's pronouncement was informed by the disability discourse of autism, illustrating the way that it can be subject to discursive 'slippage' in which autism is subsumed within a broader – and potentially misleading – epistemic category of disability. In Laura's case, the resulting misconception that autism is synonymous with a learning disability meant that it appeared to be irrelevant for making sense of her life and sense of self.

The story of Laura's relationship with her "con man" former partner had tragic potential, with its themes of betrayal and loss. Within Laura's narrative, however, it was an episode with redemptive characteristics as she described how it contributed to an active decision to eschew romantic relationships and instead focus on other areas of life, such as hobbies, friendships and pets. As part of this, she started volunteering at a local wildlife charity, and here she found others with whom she felt comfortable; a community of people – mainly retired men – who shared her interests in nature and photography. As was the case earlier in her life in music groups, she found that these shared interests helped her feel more relaxed socially:

> "…I even manage to do the small talk a little bit with them because (.) I just feel quite relaxed. I can be myself with them and I don't feel any judgement […] I just fit in. I've never fitted in to a team of people in my life but that's the first time (.) and er the fact that it's a group of retired men and I'm a [much younger] female is a bit odd, I suppose."

As well as catalysing the ultimately redemptive process of turning away from romantic relationships, Laura's ex-boyfriend had another key role in her narrative: the strange episode of his meeting with her parents indirectly paved the way to a more personally meaningful engagement with Asperger's as a potential hermeneutic resource. This took place during a country walk with a friend four years ago:

> "[the friend] said she thought I was autistic because her brother had Asperger's and she noticed a lot of similar traits in me. And at that point I was like 'this is the second time this has happened, this is not normal! (laughs) Why are people saying this to me?' Um so that was when I- I thought right, I'm going to research it now. And I did, I googled it, and I- everything I read about females with Asperger's- […] every single thing I read I thought 'ooh, that's me!' (laughs). And I mean literally it was as if the people writing the articles had known me all my life. It was so weird."

Laura discovered from her research online that Asperger's in women can be very different to the male-focused stereotypes, and she encountered personal descriptions of female autism in which she recognised her own experiences and qualities:

> "[qualities like] asking loads of questions about everything, being very curious about everything (.) life, the universe, everything, why we're here […] Liking Harry Potter, you know, fantasy literature, being- having a good vocabulary sort of ahead of my peer group and um (.) almost everything. I mean obviously music

> (.) er having certain talents but being terrible at other things like social situations."

This is a view of Asperger's which is consistent with the neurodiversity discourse of autism and is in stark contrast with the deficit-focus of the biomedical discourse: instead, it foregrounds qualities and capacities such as tendency to be a 'deep thinker'; to have an excellent and detailed long term memory[31]; and to have interests in areas like fantasy literature or music. Laura also identified through her online research that Asperger's offered a coherent explanation for other apparently disparate aspects of her experiences, including her sensitivity to noise; her difficulty assimilating information given verbally[32]; and her tendency to form friendships which transcend conventional gendered and age-related cultural norms. She described her immediately positive response to this

> "…I was (.) quite excited because I'd finally- I always knew that I was different and I didn't know why and that really frustrated me. And [.] I knew that other people could see it but I couldn't pinpoint why […] So to find that my difference had a name was (.) er quite amazing."

Laura's next response to identifying a "name" for her sense of difference was to share this information with her mother: something that she did tentatively by giving her copies of the salient articles and leaving her to draw her own conclusion. Her mother's response validated her own: "she took [the articles] away, she gave it a lot of thought […] and she came back and she said 'yeah, this is you'". This shared interpretation of Laura's experiences proved to be reparative for their relationship, which had been strained at the time due to her mother's frustration with what she perceived to be Laura's poor judgement in her romantic life. Laura and her mother could now re-frame these experiences as an inevitable consequence of being unable to identify potentially untrustworthy (neurotypical) men, and their relationship improved as a result.

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[31] For example, Laura described how she can remember all the number plates for the cars her family has owned since she was four years old.

[32] The widely reported difficulties amongst autistic individuals with assimilating verbal instructions can be explained within the framework of the monotropism model of autism (Murray et al, 2005) or may be attributed to differences in executive function; sensory processing differences or difficulties inferring the motives/intentions of neurotypical others may also contribute to such experiences.

As Laura subsequently deliberated over whether to pursue a formal autism assessment, she sought the advice of a friend who is a psychiatrist. She discovered that he had only a "vague" awareness of autism and that she needed to explain her new insight into Asperger's, especially in relation to women. His response surprised her: he expressed concern that her new 'identity' as a woman with Asperger's constituted a "pathologisation" of her interests in science, philosophy and so on, and questioned the relevance of a diagnosis for her. This is a position that suggests the intersection of two competing discourses of autism: the dominant biomedical discourse that construes it as 'pathological' and the 'eccentric scientist' discourse, which associates autism with scientific abilities and social idiosyncrasies (see p.25). For Laura, this was an unexpected challenge but it helped to reinforce her view that her sense of 'difference' was not simply a matter of her interests and strengths: it also included features which have a "negative impact on [her] life", not least her notable difficulties in inferring the motives and interpretations of others, which she could now identify had left her vulnerable to her manipulative former partner:

> "…I can see [people's] facial expressions and their hand movements, I can hear what they're saying but beyond that I have no idea of their intentions, no idea of their motivations, I've no idea what they're thinking (.) um (.) I am constantly surprised by people's reactions…"

Following the challenge of her psychiatrist friend, Laura decided to pursue the "validation" of a professional diagnosis, explaining that this was for her mother's benefit as well as her own. In practical terms, the diagnostic process proceeded smoothly for Laura – she described the assessing team of an occupational therapist and a clinical psychologist as "brilliant" - although like Charlie and Gemma she noted that she found the story-telling elements of the assessment "very strange". It also led to a pivotal moment in her narrative, when the occupational therapist asked Laura a question about how often she feels able to 'be herself':

> "I genuinely didn't understand the question. I couldn't answer it. […] I said something- 'do you mean <u>by</u> myself?' and she said no, <u>be</u> yourself. I just sat there in silence, I couldn't answer the question. And she said 'you're struggling to understand the question, aren't you?' and I said yeah."

After the diagnosis, this exchange prompted a period of reflection about the ways in which Laura has engaged in ‘camouflaging’ behaviours in an attempt to comply with the social norms, and the consequences of this for her sense of self. She described her efforts to conform to stereotypical female social behaviours, and the effects of that for her wellbeing:

> “…that constant vigilance and constant monitoring of my facial expressions and tone of voice (.) my body language, my hand gestures is completely exhausting and after interaction with other people it takes me a long time to de-compress and unwind and- (.) and de-stress. And often I do get a migraine afterwards as well.”

Laura’s new insight into the personal cost of camouflaging was accompanied by an overall ‘quest’ theme within her narrative of her life post-diagnosis. The traditional quest narrative involves the search for a valued goal (Booker, 2007), and at the time of telling her story, Laura’s quest was to uncover a ‘true self’ that had been concealed by years of camouflaging. She has received help in this quest from an unexpected source after disclosing her diagnosis to a doctor colleague, who then revealed that he too considers himself to have Asperger’s (but has not felt a need to pursue a diagnosis). Laura discussed with him the difficulties she experiences in trying to adapt to social norms in the workplace:

> “I explained to [my colleague], you know, I’m so exhausted at the end of the working day cos I’m trying so hard to get a rapport with my patients and (.) talk to them and constantly be smiley and bubbly and I really don’t feel like it (.) and it’s completely draining and exhausting and awful. And he just said- and he wasn’t being funny he was just genuinely trying to help and it’s a- it’s a point I actually did take to heart (.) he said well don’t try so hard.”

Laura described how – in the aftermath of this encounter – she has been striving to reduce her efforts to conform to implicit expectations that women should be “smiley and bubbly” in social situations. This has been helped by forming a close friendship with Emma, another woman with Asperger’s, who Laura met on a post-diagnosis support course run by her local NHS autism service. Like Laura, Emma works in a demanding professional role (teaching) which involves a high degree of interpersonal contact, and the two women can therefore provide each other with ‘mirroring’ (Kohut, 1977) about the challenges they face in the workplace and in social situations. Nonetheless, Laura noted that:

> “[even with Emma] I think it’s very difficult to completely (.) take the mask off (.) because I don’t know how much of it is the mask and how much of it is really me any more.”

At the time of telling her story to me, Laura’s quest to uncover a ‘true self’ – the self who is “really me” behind the “mask” - therefore remained an unresolved ‘identity project’, but one in which she is being supported and encouraged within a trusting friendship with another woman with Asperger’s.

5. Discussion

5.1 Summary of key research findings

The focus of my analysis was the meaning and construction of 'autism' in the participants' narratives and the significance for them of identifying as autistic. The fact that they had come to identify as autistic in adulthood indicates that at some point there was a transformation – whether gradual or sudden - in their personal subjectivity, and I was interested in exploring how this had come about.

Like other researchers, I found that 'autism' acted as an explanation for a longstanding sense of 'difference', including struggling with some aspects of everyday life which seem to come naturally to others (Bargiela et al, 2016; Kanfiszer et al, 2017; Stagg and Belcher, 2019; Leedham et al, 2020). The participants' individual stories highlighted the socially mediated nature of this experience and provided insight into the process by which the epistemic construct of autism had become available as a personally meaningful way of interpreting it. This involved a process of transformation of their personal knowledge (Bhaskar et al, 2018) which took place in response to encountering a discursive construction of autism which was broadly consistent with the 'neurodiversity' discourse (Bagatell, 2010; Robertson, 2010; Brownlow and O'Dell, 2013; Ortega, 2013; Kapp et al, 2013; O'Dell et al, 2016). For the participants, this 'new' way of construing autism had personal significance because it was a way of making sense of disparate elements of their experiences, including strengths and accomplishments as well as vulnerabilities and difficulties. As I discuss below, this transformation of the participants' knowledge was followed by 'real life' changes, which were typically associated with an improvement in their wellbeing.

5.1.1 The discursive construction of autism and the hermeneutic possibilities of neurodiversity

"If we all classified ourselves in terms of what we were not able to do
then you know (.) we'd all be disabled." Rowan.

The participants' stories of how they came to identify as autistic included descriptions of the various ways that they had experienced themselves as 'different' to others. These experiences were heterogeneous and individual to each participant but nonetheless clustered into the various themes that characterise the diagnostic criteria for autism, such as differences in social communication and behaviours; difficulties with change and a tendency to be inflexible; and sensory sensitivities (APA, 2013; WHO, 2016). Charlie, Rowan and Gemma also described issues relating to executive function – such as planning and organising – which had caused various difficulties for them at school or in the workplace: although executive function differences are not formally included as 'diagnostic criteria' they appear to be common in autism and are thought to underlie or contribute to other differences associated with it ((Geurts, Verté, Oosterlan, Royers and Sargeant, 2004; Hill, 2004; Chown, 2016; Fletcher-Watson and Happé, 2019). For all the participants except Rowan, a particularly notable feature of the 'differences' they described was their sensory sensitivities and the difficulties they could cause in everyday life, especially at school, in the workplace or other public spaces such as shops. Issues with noise and light (such as fluorescent lighting at work) were common themes. Other examples were more idiosyncratic; for example, Gemma recounted a difficult period at work due to the overwhelming smell of a new carpet, and the problems she experienced due to an unbearably "scratchy" woollen jumper that was part of her school uniform.

Bearing in mind the participants had already reinterpreted their lives through the discursive 'lens' of autism by the time they told their stories to me, it is possible that the emphasis the participants placed on these various differences was at least in part evidence of Hacking's 'looping effect', according to which behaviour – as well as personal meaning making – may change in response to receiving or identifying with a diagnostic classification (Hacking, 1999). Nonetheless, it was evident from all five stories that – before they came to understand it through the 'lens' of autism – the participants experienced seemingly inexplicable difficulties in their everyday lives: difficulties that were all the more perplexing bearing in mind their accomplishments and intellectual capacities.

At the heart of narrative inquiry is the assumption that we instinctively seek to make sense of our lives and our experiences – giving meaning and shape to them where there might otherwise be none – and it was apparent from the participants' stories that it was difficult for them not to have access to meaningful hermeneutic frameworks for understanding their perceived differences from an implicit norm. Indeed, three of the participants described how they deployed 'partial' explanations for their experiences of not fitting in socially. Charlie, for example, was able to construe her tendency at school to be on the periphery of social groups and to experience episodes of unexplained social confusion and misunderstanding as being a result of her family being 'incomers' in their small Scottish community. Rowan, on the other hand, interpreted her social 'differences' through a gendered lens, and understood it as a result of being brought up with brothers and refusing to "play by gendered rules". Laura lacked 'external' explanations of this type, and instead assumed that her sense of being socially 'different' was evidence of social anxiety. None of these explanations, however, accounted for other key aspects of the women's experiences, such as their problematic sensory sensitivities (Charlie and Laura) or issues relating to executive function (Rowan and Charlie).

Feeling different under the "normalising gaze" of others

The participants' narratives highlighted the ways that 'feeling different' is a socially mediated experience. For Laura, Rowan and Charlie, this began in the school years, in the form of peer rejection or – in Charlie's narrative – an awareness that she had to behave in ways that did not necessarily make sense to her (such as apologising for misunderstandings without understanding how they had arisen (see p.43)) in order to avoid the risk of rejection. Rowan was also regularly targeted by bullies during her school years.

In Jane and Gemma's case, an awareness of social difference emerged later in their narrativized life, when they embarked on their careers: Jane found that she was often perceived as "blunt" by her colleagues, while Gemma was perplexed by the apparent expectation that she should be sociable with hers. Laura encountered similar difficulties in the workplace to Gemma and recalled being criticised for not taking lunch with colleagues; meanwhile, Charlie was ‘teased’ by her colleagues for taking steps (such as wearing headphones) to mitigate the sensory challenges of an open plan office. Rowan encountered perhaps the most significant problems during her early career; her ‘boom bust’ working style was viewed as distracting for others and resulted in her getting sacked on a number of occasions (an issue she resolved by becoming successfully self-employed).

In the participants’ narratives, then, peers, colleagues and managers served as a “normalising gaze” (Foucault, 1977, p.184), according to which they were judged, criticised or rejected if they failed to adhere to societal norms. It was in the context of such experiences that the participants came to perceive themselves as ‘different’ and (with the exception of Rowan) to engage in various camouflaging strategies in an attempt to conform. Bruner (1996) claims that school acts as a key site of enculturation in which children ‘learn’ societal (and gender specific) norms and values, alongside the explicit curriculum itself: in the participants’ narratives, this role was then taken up by their workplace. The normative values that were being ‘policed’ in the workplace were implicitly those associated with neoliberal economic principles and an untrammelled drive for profitability (see Verhaeghe, 2014; Monbiot, 2016; Johnstone and Boyle, 2018). These underlying principles typically equate to highly competitive work cultures in which employees are expected to be willing to change jobs, teams or roles frequently in order to enhance employers’ (and shareholders’) profits; to be (superficially) sociable; and to be able to work effectively despite the potential noise and distractions of open plan offices (Senechal, 2011; Verhaeghe, 2012 and 2014). Such workplaces do not favour those who prefer routine and predictability; need time to adapt to change; have sensory sensitivities; or who are already working hard to conform to normative social expectations. From this perspective, then, the participants’ narratives give insight into the wider cultural context in which the experience of being autistic in the workplace may be more problematic for many individuals than it would have been in the past, when long term commitment to employers would have been valued, and small offices were the norm.

For Gemma, Laura and Rowan, the “normalising gaze” led to a neurotypical other suggesting that they may be autistic: this constituted their first encounter with autism as a possible explanation for their experiences. It was only in Gemma’s case that this occurred in a conventional ‘medical’ setting (during a mental health review); for the other two, it took place in informal or social settings and took the form of a suggestion or assumption by a friend, partner or colleague (as discussed in Laura and Rowan’s stories). Such experiences are consistent with Foucault’s (1977) claim that we internalise normative behavioural standards, and then ‘police’ our own and others’ behaviours according to those norms (Davy, 2010).

Constructing ‘old’ autism: ‘disability’, Sherlock and Sheldon Cooper

In exploring the meaning-making around the participants’ sense of ‘difference’ I had wanted to understand why autism had not been available to them as a hermeneutic resource before they identified as autistic. It turned out that – aside from my opening question – this was the one question I needed to explicitly ask the participants as otherwise it seemed unlikely to be addressed, indicating perhaps the extent to which autism had previously been irrelevant to them as a way of making sense of their lives. I found that each participant had been aware of autism to some extent before they identified as autistic: however, it had been discursively constructed in a way that had made it seem irrelevant to her personal experiences and qualities.

For Jane, Gemma and Laura, their ‘old’ understanding of autism was largely consistent with the ‘disability’ discourse of autism, with its emphasis on ‘impairments’ and the need for support from others in order to cope with everyday life. In Jane’s case, this had reflected her ‘formal’ knowledge of autism in her capacity as a special educational needs teacher focusing on supporting pupils with considerable social difficulties at school: very different from her own experience at school where she had been one of the “cool kids” (although she subsequently came to attribute that to her ability to ‘people watch’ and to mask potential differences). For Gemma, on the other hand, her previous knowledge of autism had been constructed through personal rather than professional experience, and was informed by her father’s extensive needs for support from her mother: this epistemic ‘version’ of autism had seemed irrelevant to Gemma’s own life, bearing in mind her ability to live independently and to act as carer for her young son. Conversely, Laura's 'old' understanding of autism was grounded in lay knowledge rather than either professional or personal experience, but it was similarly consistent with the 'disability' discourse. For Laura, this led to an assumption that autism was characterised by learning difficulties, illustrating how the 'disability' discourse of autism might lead to it being conflated with a different discursive category of disability: in this case, intellectual disability. Discursive 'slippage' of this type might contribute to some of the negative misconceptions and 'myths' that are commonly associated with autism (Huws and Jones, 2010; John et al, 2018; Treweek et al, 2019). At the level of individual subjectivity, it meant that autism was for many years unavailable to Laura as a personal hermeneutic resource, as she herself does not have learning disabilities.

In Charlie's case, she was also familiar with the discursive construction of autism as a 'disability': her role as a social worker includes working with families with autistic children with accompanying learning disabilities who are, indeed, considerably disabled by autism (at least in the context of modern society and its expectations around formal education and working life). However, she had also encountered an alternative construction of autism in the form of the character Sheldon Cooper on the TV show The Big Bang Theory (Belyeu, 2007). Sheldon is an adult version of the 'little professors' originally described by Hans Asperger (1991) and the character embodies the gendered 'eccentric scientist' discourse of autism deployed and reified within the EMB theory: an aloof, socially awkward man who is more interested in science (or similar pursuits) than in the people around him (Baron-Cohen, 2002b and 2003). As Charlie explained (see p. 45), this was a construction of autism that seemed wholly irrelevant to her bearing in mind the importance of close relationships to her (she is happily married) and her career as a social worker.

Rowan's 'old' construction of autism was similar to Charlie's but in her case it was embodied by the recent TV incarnation of Sherlock Holmes (Vertue and Cameron, 2010), with his social non-conformity and exceptional capacity to identify patterns and connections (Dixon, 2013). As she noted, this understanding of autism had no negative connotations for her and meant that it immediately 'made sense' to her when a colleague assumed that she is autistic: nonetheless, it had not – for whatever reason – become personally relevant until that happened. She had, instead, been content to consider herself gender non-conforming and “weird”, with weird being construed in positive terms as preferable to the mundanity of the majority. In this respect, Rowan’s creative usage of ‘weird’ was redolent of the deployment of the term queer[33] in relation to gender and sexuality (Eliason and Beemyn, 1996).

For each of the participants, then, their previous understanding of autism was informed by mainstream discursive constructions and tropes of autism that seemed irrelevant to their individual experiences and sense of self. Other than the ‘partial’ explanations of ‘differences’ noted above, this left them with hermeneutic ‘absence’: a lack of any way to make sense of their disparate experiences in a coherent or personally meaningful way (Fricker, 2007; Bhaskar et al, 2018).

Transforming personal understanding: discovering the ‘neurodiversity’ discourse of autism

For all five participants, their lack of a meaningful and coherent hermeneutic resource for making sense of their ‘differences’ was resolved by encountering a new discursive construct of autism: one which was broadly consistent with the ‘neurodiversity’ discourse of autism (Bagatell, 2010; Robertson, 2010; Brownlow and O’Dell, 2013; Ortega, 2013; Kapp et al, 2013; O’Dell et al, 2013). From a critical realist perspective, an important area of interest is the way that changes in subjectivity are socially mediated (Elder-Vass, 2012; Bhaskar et al, 2018) and for Charlie and Jane this took place within the context of moving and dramatic episodes of intersubjectivity in which they encountered important aspects of their experiences mirrored by an autistic individual, thus prompting the sudden recognition that they themselves are autistic too. In Charlie’s case, her “moment of realisation” took place as she listened to the personal story of another autistic woman who described clear parallels with Charlie’s own life, including previously inexplicable episodes of social confusion and misunderstandings and of sensory overwhelm, alongside marriage and a career in a people-oriented profession (in the other woman’s case, as a psychotherapist). For Jane, on the other hand, her “epiphany” took place in an embodied rather than narrativized moment of intersubjectivity, which involved the sudden recognition that

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[33] The term ‘neuroqueer’ is also becoming more widely used online as a variant on neurodiverse or neurodivergent (Egner, 2019).

the deep empathy she experiences towards her students' sensory and emotional overwhelm is rooted in personal experience: " you know [how to help them] because you've experienced it".

For Charlie and Jane, then, hermeneutic transformation took place through a powerful experience of 'twinship' (Kohut, 1977) with another autistic individual. In contrast, for the other participants, their initial encounter with autism took the form of an 'evaluation' by a non-autistic other, as discussed above. This prompted an intense process of personal research[34] through which they discovered accounts of the diversity of autism, especially in relation to girls and women. The internet has provided an important opportunity for autistic individuals to share their stories and form communities (Bagatell, 2010; Bertilsdotter Rosqvist, Brownlow and O'Dell, 2013; Brownlow and O'Dell, 2013; Parsloe, 2015), and unsurprisingly it was an important source of information (especially about female autism) for all the participants. In terms of obtaining information from books, Rowan described her dislike of the "clinical" tone she encountered in some publication; in general, the participants tended to report a preference for books by other autistic individuals, which provide a rich and personal insight into autism which is anything but 'clinical' (see, for example, Simone, 2010; Rowe, 2013a; Cook and Garnett, 2018).

Whether in person or online, these encounters with a different discursive construct of autism acted as a gateway to a new 'epistemic community' (O'Dell et al, 2016): one which is characterised by a neurodiversity-informed understanding of autism (Bagatell, 2010; Brownlow, 2010a and b; Parsloe, 2015; Den Houting, 2019). Epistemic communities were originally defined as "[networks] of professionals with recognized expertise and competence in a particular domain and an authoritative claim to [knowledge] within that domain" (Haas, 1992, p.3). However, within the neurodiversity epistemic community, expertise by lived experience determines epistemic authority, rather than 'professional' status. This grounding in 'insider' perspectives means that it is inclusive of diversity and heterogeneity of subjectivities and experiences (Strand, 2017), and its construction of autism is correspondingly

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[34] Charlie and Jane also described their engagement in a similarly intense period of personal research following their respective real life 'epiphanies', in order to learn more about female autism and confirm their new 'autistic identity'.

expansive and fluid. In contrast with the rigidity of mainstream discursive constructions of autism, then, the neurodiversity discourse is rich with possibility as a hermeneutic resource for an autistic individual, and especially for autistic women. The growing number of online and published accounts of life as an autistic woman contribute to a discursive landscape in which it is possible to be autistic and professionally accomplished (including in a caring profession); to be autistic and value close personal relationships; and – above all – to be autistic and female (Simone, 2010; Rowe, 2013; Hendrickx, 2014 and 2015; Halliday-Willey, 2015; Kim, 2015; James, 2017; Uher, 2017; Cook and Garnett, 2018). Thus, the neurodiversity discourse encompasses the full range of human experience and individuality, inextricably linked with the experience of being autistic (Strand, 2017).

For the participants, discovering autism as a personally meaningful hermeneutic resource provided them with a coherent way of making sense of seemingly disparate strengths and vulnerabilities. It was notable that this was typically associated with a recognition of the ways that 'neurotypical' norms and expectations create problems for their daily lives. For example, a common theme in the participants' narratives was the reinterpretation of mental health difficulties as an understandable response to the experience of being autistic in the neurotypical world, rather than a problem that is 'internal' to them. The potentially self-limiting or distressing effects of societal norms and values is a cornerstone of narrative therapy and underpins its key intervention of 'externalising' problems rather than locating them 'within' the individual (White and Epston, 1990; Davy, 2010). The participants' descriptions of construing their difficulties within a neurodiversity-informed epistemic framework were consistent with this process of 'externalising' difficulties, and – as discussed in section 5.2.2 below – were associated with changes in their everyday lives to mitigate the potentially negative effects on them of social and sensory aspects of the neurotypical world.

Going into discursive battle: defining and defending neurodiversity

As the term *neuro*diversity implies, it is a way of discursively constructing autism which – like the 'medical' discourse – often foregrounds the neurobiological and the brain (Brownlow and O'Dell, 2013; Ortega, 2013; Singer, 2016). As such, it is a way of resisting the dominant 'medical' discourse by occupying its 'scientific' territory and challenging or undermining it with an emphasis on *difference* rather than 'deficits' or 'impairments' (Meyerding, 2014; Singer, 2016). Of the participants, Rowan and Charlie both deployed 'neuroterminology' within their narratives. Rowan termed autism a "neurodivergence" and depicted her relationship with her 'different' brain as one of affection and fascination:

> "I love my brain. My brain and I have a very separate relationship where it does stuff and I stand there and go 'wow, that was really clever!'".

Here the brain-based neurodiversity discourse of autism is deployed in a way which subverts the traditionally judgemental 'gaze' of researchers on the autistic brain: instead of classifying 'deficits' and 'impairments', Rowan's 'gaze' is one of enjoyment and admiration.

Like Rowan, Charlie described autism as a "neurodivergence" and also as "a type of neurology" that should not be "corrected". She explicitly challenged its classification as a 'disorder', a stance which was given extra weight by her professional status as a social worker whose role involves a statutory responsibility for the care and support of autistic children:

> "All the reports that I get for work say autism spectrum disorder (.) and I just write it as autism in the EHCP[35]s because I do not believe it is a disorder, you know it's (.) it's a neurodivergence, a difference (.) yes, some are disordered by it (.) that's not to say that (.) you know, none of us suffer with autism because some do, some genuinely do."

This extract illustrates the discursive 'work' that needs to be accomplished with the neurodiversity discourse in order that it encompasses *all* autistic individuals - including those who have lifelong care needs - without conflating autism with dependency and limitations. In Gemma and Jane's narratives (quoted on pages 56 and 64 respectively), this involved deploying the 'disability' discourse of autism to define *some* individuals – those needing support to cope with everyday life – as a sub-set within the wider

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[35] EHCP: Education, health and care plan for children and young people with additional educational or other care needs under the Children and Families Act 2014.

"neurotribe" (Jane, p.63, referencing Silberman, 2015) of 'neurodiverse' autistic individuals.

An additional and interesting feature of the neurodiversity discourse of autism is that it may be deployed either in a way to construct neurodiversity as a continuum (according to which *everyone* is 'neurodiverse' to some degree), or as a dichotomy[36] in which one is either autistic or neurotypical/non-autistic (Brownlow and O'Dell, 2013). All the participants constructed autism in the latter sense, making a clear distinction in their narratives between the autistic and the non-autistic or neurotypical ('NT') mainstream. This stance was particularly overt in Gemma and Rowan's narrative. In Gemma's case, her narrative constructed neurotypicality in terms of a tendency to be judgemental (especially of autism) and dishonest (as illustrated, for example, by the use of 'white lies' in social situations). From this discursive position it follows that it would be helpful for her as an autistic individual to minimise social contact with 'NTs', unless they have become 'autism friendly' through lived experience with autistic family members.

In Rowan's narrative, the dichotomous construction of neurodiversity was used to challenge the increasingly common trope that "we're all a bit autistic". While this comment may be framed as a humorous or otherwise well-intentioned deployment of the 'neurodiversity continuum' discourse, within the 'dichotomy' discursive framework[37] it is typically construed as a potentially undermining and disrespectful appropriation of a minority identity which serves to minimise the challenges faced by autistic individuals in the neurotypical world (Bonnello, 2017; Hirschberg, 2017; Lynch, 2019). Rowan described an incident in which she challenged an acquaintance who claimed that "we're all on the spectrum somewhere":

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[36] Within the 'dichotomy' construction of neurodiversity, there may still be a continuum but with a very clear distinction between those who are autistic and those who are not. The term 'neurodivergent' may be associated with this dichotomous construction, as it carries the implication of divergence from the (mainstream) 'other'.

[37] Concern about the ways that the concept of the autism 'spectrum' may be misappropriated or otherwise misunderstood (for example, assumed to mean that autistic individuals have identical characteristics to varying degrees, from 'mild' to 'severe') has led to creative suggestions from members of the autistic community online for alternative ways of visualising autism that emphasise its distinctive and heterogeneous nature: see, for example, Hearst's (n.d.) model of the autism 'constellation' or Burgess's (2019) 'comic strip' representation of the non-linearity of autistic experiences.

> "[I told her] 'no way, no that's an outright lie' […] you saying that is like me saying well, you know, I get pins and needles sometimes so everyone's (.) I'm a bit paraplegic on that basis'. [The concept of the autism spectrum] doesn't work like that. Um it's a fundamental misunderstanding of the fact that I do not see the world the same way that you do."

This extract illustrates another instance of creative 'discursive work' that needs to be done in order to delineate and defend a personally meaningful 'autistic identity': in this case one that is characterised by a distinctive way of "seeing the world" compared with the neurotypical majority, rather than a 'disability' or a medicalised 'condition'.

5.1.2 Life with an 'autistic identity': self-acceptance, self-compassion and social connections

From a critical realist perspective, an important area of interest is the transformative potential of a change in subjectivity for the life and wellbeing of the individual (Bhaskar et al, 2018): a view that is of particular relevance and interest in the context of my psychotherapeutic practice as a practitioner psychologist in training. I found it interesting to note, then, that the participants all reported that they made changes in their lives after they identified as autistic, and that these were variously depicted as positive for their wellbeing. While such changes were specific to each participant and her life, they commonly included experimentation with *reducing* camouflaging behaviours and with making more adaptations in everyday life to mitigate the effects of sensory hypersensitivities. The participants also described different ways in which they have made or increased social connections (online or in person) with other autistic individuals, and the positive effects of this for their lives.

"Dropping the mask" and coping with sensory sensitivities

For all the participants other than Rowan, a key theme in their descriptions of life after identifying as autistic was that they no longer struggle to the same extent to conform to societal norms, especially for social behaviours. For example, Gemma noted that she "immediately dropped the mask" after her diagnosis, while Laura described how she has been "trying not to try so hard" to conform to gendered normative social expectations, such as her previous assumption that she should be "smiley and bubbly" with her patients at work. Similarly, Charlie described how her new understanding of herself as autistic “gives me permission to be kinder to myself”; for example, she is now more selective about which social events to attend, preferring to socialise with smaller numbers of people and in quieter settings. In Jane’s case, she has been able to explain to close family members about her need for routines and predictability, and they can now take this into account, for example when organising social events.

Rowan was the notable exception to this theme of ‘dropping the mask’. Within her narrative, she highlighted that she had never sought to conform to societal behavioural norms (especially gendered ones), attributing this to her family’s celebration of ‘difference’ and her resulting strong sense of self. Furthermore, long before she identified as autistic she had already made significant changes to her working life by becoming self-employed and had therefore already identified a successful solution to problems that she had previously experienced as a result of not conforming to the ‘invisible’ social rules of the workplace. Nonetheless, she described her realisation that she would never “get the hang of” neurotypical social situations as “liberating”, suggesting that her new ‘autistic identity’ was associated with some benefits to her sense of self, however marginal.

In addition to ‘dropping the mask’ in relation to normative social behaviours, all but Rowan[38] explained how they had made more adaptations in their lives to ameliorate the effects of sensory sensitivities – such as to lighting, sounds and smells – after being able to construe them as common features of autism (Leekam, Nieto, Libby, Wing and Gould, 2007; Ben-Sasson et al, 2009; Smith and Sharp, 2013; Ross, Elcheson and Cook, 2018; Belek, 2019; Fletcher-Watson and Happé, 2019) rather than something to be ignored or struggled with. For Charlie, this built on her previous attempts to ameliorate the effects of an open plan office by wearing sunglasses and headphones: she now feels more comfortable about doing so if needed, and she has also been able to negotiate a quieter workspace and permission to work from home part-time. Following Jane’s diagnosis, she has also been able to negotiate a ‘reasonable adjustment’ (in line with the Equality Act 2010) in the form of an individual office space, and she has made other changes in her everyday life, such as going to the supermarket in the late evening when it is quieter. Similarly, Laura now recognises

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[38] Rowan explained that she is *hypo*- rather than hyper-sensitivity to sensory stimulation, including in relation to physical pain.

that taking a walk alone at lunchtime is an essential way of looking after her wellbeing in a busy clinical workplace, rather than an 'unsociable' eccentricity.

Joining an 'autistic community'

For three of the participants – Charlie, Rowan and Laura – an important change that followed their autistic self-identity was to develop new friendships with other autistic women. For Charlie and Rowan, this started by joining online communities of autistic women; over time, this has resulted in 'real life' get-togethers and friendships forming. In Laura's case, she attended a post-diagnostic course organised by her local NHS trust, where she met another autistic woman with whom she had much in common: they have subsequently forged a close and mutually supportive friendship. Social interaction with other autistic adults was a new experience for Charlie, Rowan and Laura. Gemma, on the other hand, was already well integrated into an 'autistic community' in the form of charities and support groups for families[39] of autistic children but her engagement with this further increased after identifying as autistic and choosing to reduce her contact with 'neurotypicals'. In Jane's case, her 'autistic community' is currently home-based; she described her close relationship with her autistic teenaged son, and the peaceful, routine-based home life they have created together.

The participants typically depicted social contact with other autistic individuals as an opportunity to be oneself, rather than to struggle to conform to neuronormative social expectations. Kohut (1971) argued that recognising one's own qualities in another person – experiencing 'twinship' - is an important element of developing a robust sense of self and emotional wellbeing. Experiences of 'twinship' were notably absent from the participants' stories of their early lives, but evident in their descriptions of friendships with other autistic women. For example, Charlie commented of her (online and 'real life') friendships with other autistic women:

> "You know that you're coming from the same place and that they just get you (.) you know, and- and I feel like (.) they perhaps get me better than anyone else."

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[39] Gemma explained that it was not unusual for parents to identify that they too are autistic or have autistic qualities after recognising similarities with their children.

In terms of emotional wellbeing, this experience of other people “getting me” is undoubtedly important to anyone, but especially so for women who grew up with a pervasive sense of ‘difference’ from others (Campbell, 2018).

In Rowan’s case, the benefits of engagement with an ‘autistic community’ was depicted rather differently as she has never engaged in camouflaging-type strategies. Instead, she described how she draws on her own strong sense of self in order to mentor and support other autistic women, in the hope that they too may develop a positive self-image.   She also noted that social media is providing an important opportunity for autistic individuals to share their experiences (Bagatell, 2010; Brownlow and O’Dell, 2013) of marginalisation, rejection and bullying, in a way that is helping them identify neuronormative society as problematic, rather than themselves as individuals:

> “Social media with all of its problems (.) has enabled [autistic people] to get together and it will er increasingly mobilise us as we start to realise- you know, the Me Too kind of phenomenon […] I think that the autistic community are increasingly defiant against (.) um what has been unbelievably unfair treatment most of their lives.”

Rowan’s social justice stance was shared by the other participants, who variously expressed a wish to ‘change the narrative’ of autism to a neurodiversity-informed position, and to improve awareness of the experiences of autistic girls and women. For the participants, self-identifying as autistic was thus typically accompanied by a wider objective of improving life for autistic people in general. Indeed, in Jane’s case, this is an important and integral part of her professional role as a special educational needs teacher in a large secondary school. She described her efforts to frame autism in positive terms when explaining it to non-autistic pupils, and to depict autistic children as “kind of like superheroes”. Unbeknownst to the autistic pupils themselves, she draws on her own experiences to support them; for example, helping them develop their “emotional articulacy” in the hope that this will reduce the risk of them developing mental health difficulties of the type that were so problematic for her in late adolescence and early adulthood.

5.1.3 Personal stories as counter-narratives

At the outset of my research, my hope was that the study would generate data which would serve as counter-narratives (Bamberg and Andrews, 2004), resisting and challenging the prevailing tendency to story autism as a tragedy, and the autistic individual as profoundly isolated from others (Baron-Cohen, 1995; Broderick and Ne'eman, 2008; Duffy and Dorner, 2011; Yergeau, 2013; Milton, 2014; Quirici, 2015). Only minutes into the first interview I was confident that this was going to be so, and this continued to be the case throughout the subsequent interviews. The participants were open and generous with what they told me, sharing experiences of vulnerabilities and setbacks, alongside stories of achievements, resourcefulness and fulfilment. Contrary to depictions of the autistic individual as tragically alone (Baron-Cohen, 1995; Duffy and Dorner, 2011) these were richly populated narratives: parents, siblings, partners, children and friends variously played significant 'roles' in their stories.

In my own interpretations of the participants' stories I have highlighted themes that seemed to me apparent as I listened to their stories on the day of the interview and subsequently, as I transcribed the interviews and then immersed myself in the transcripts: themes of redemption (Jane) (Gergen, 2015; McAdams and Guo, 2015) and rebirth (Charlie) (Booker, 2007); heroic struggles (Rowan) (Gergen, 2015) and quest for one's 'true self' (Laura) (Frank, 1995; Booker, 2007); and Gemma's subversion of the classic restitution narrative (Frank, 1995) in which she returned to good health by disengaging from the medicalisation of her distress. These are inevitable simplifications of the complexities of the narratives I heard and reflect my idiosyncratic interpretations which might not have been shared by anyone else. Nonetheless, they are intended to capture something of the intersubjective experience of listening to those particular stories on those particular days, and to highlight above all that the participants' narratives were anything but tragic. Instead, they were characterised by resilience, relationality and a generous hope that by sharing their stories with me they would improve awareness and understanding of female autism.

5.2 Implications of the study for counselling psychologists

"[Counselling psychologists will] make themselves knowledgeable about the diverse life experiences of the clients they work with [and] challenge the views of people who pathologise on the basis of such aspects as sexual orientation, disability, class origin or racial identity and religious and spiritual views." (BPS, 2005, p.7)

The participants' narratives illustrate the ways that neurodiversity-informed discursive constructs of autism may be creatively deployed as personally meaningful hermeneutic resources by individuals to make sense of seemingly disparate experiences and aspects of 'self'. Prior to this, they had faced hermeneutic 'absence', with gendered or disability-focused constructions of autism appearing irrelevant to their lives. Fricker (2007, p.154) writes of the injustice that results from having important aspects of one's experience "obscured from collective understanding owing to persistent and wide-ranging hermeneutical marginalisation"; a description which encapsulates the consequences of the longstanding neglect of female autism by researchers and clinicians. Indeed, it was striking that the participants' discovery of personally relevant and meaningful ways of construing autism was largely informed by the experience and knowledge of other autistic individuals (whether encountered in person, online or in published accounts) rather than the "clinical" and dehumanising accounts of autism produced by mainstream research and currently reified in diagnostic manuals (APA, 2013; WHO, 2016; Chown and Leatherland, 2018).

During my research, it has been hard to avoid the conclusion that the counselling psychology profession has been inadvertently complicit in the 'hermeneutical marginalisation' of autistic women (and autistic individuals in general), and therefore in the wider implications of that for individual lives (Robertson, 2010; Milton and Moon, 2012; Yergeau, 2013; Milton, 2014). With rare exceptions (Murphy, 2017; Rutten, 2017; Wilson, 2017), the profession has been largely silent on the subjects of autism and neurodiversity, and there are currently no requirements to include these important areas during our training. Instead, any discussion of working with 'difference and diversity' in the profession's core texts[40] typically centres on the

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[40] It was concerning to see that the *sole* reference to autism in the latest edition of the Handbook of Counselling Psychology (Douglas et al, 2016) relates to its prevalence in forensic settings, in the form of this comment: "…a large proportion of prisoners have a recognised learning disability or a neurodevelopmental disorder such as autism." (Sims, 2016, p.468).

‘traditional’ themes referred to in the above quotation from our professional practice guidelines (BPS, 2005; Milton, 2010; Woolfe, Strawbridge, Douglas and Dryden, 2010; BPS, 2013; Douglas, Woolfe, Strawbridge, Kasket and Galbraith, 2016; Ade-Serrano, Nkansa-Dwamena and McIntosh, 2017; Milton, 2018). In terms of deconstructing (Parker, 1999) this ‘absence’, my impression is that autism is often perceived as a specialist area by counselling psychologists and other mental health professionals, and therefore assumed to be of little relevance to those working outside autism services. In addition, it may be also be implicitly conflated with an amorphous category of ‘disability’ (Olkin, 2011; Parritt, 2016; Milton, 2018) in a way that obscures the heterogeneity (and strengths) associated with autism (Orsini and Davidson, 2013; Egner, 2019; Russell et al, 2019). If so, this is a deeply problematic (implicit) stance, bearing in mind the findings of this study and others (Bagatell, 2007; Brownlow, 2010; Baines, 2012), which demonstrate that autistic individuals may engage in ‘discursive work’ in order to avoid, resist or challenge the ‘disability’ discursive construction of autism. If psychologists or other therapists overlook this and conflate autism with disability, they may mis-attune to their client and re-produce in the therapy room the negative hegemonic discourses that she or he is seeking to resist: a profound misrecognition of an individual’s experience and subjectivity that Moon (2011) describes as epistemically-based ‘violence’ within the therapeutic relationship.

Whatever the reason(s) for the counselling psychology profession’s current neglect of autism and neurodiversity, evidence of high levels of distress and secondary mental health difficulties amongst autistic individuals (see section 2.2.3) highlight that this is not a niche issue, and is instead relevant for all practitioners, irrespective of the settings in which they work (Hearst, 2014; Botha and Frost, 2018; Au-Yeung et al, 2019; Brugha, 2019; Camm-Crosbie et al, 2019). Alongside this, there has been an important shift within autism studies towards prioritising the production of knowledge which reflects the needs and priorities of autistic individuals, rather than the preoccupations of researchers to elucidate aetiological and neurobiological explanations. Unsurprisingly, this typically includes a preference for research which focuses on quality of life and wellbeing-related areas (including the difficulties faced in relation to employment (NAS, 2016b); which improves awareness and understanding amongst relevant professionals and the general public; and which challenges stigmatising stereotypes and misconceptions about autism (Pellicano et al, 2014). On the face of it, the counselling psychology profession's focus on subjectivities, relationality and wellbeing (BPS, 2005; Strawbridge and Woolfe, 2010) means that practitioners are well-placed to engage with research and therapeutic practice which aligns with such priorities. However, this requires a significant change from the current position of non-engagement and neglect of this area.

In order to highlight autism and neurodiversity as an important area for counselling psychologists, I would recommend that the development of awareness and knowledge in this area should become a formal requirement of our training. To support us in our stated commitment to "challenge the views of people who pathologise" (BPS, 2005, p7) in the context of autism, such training should be grounded in critical perspectives on the continuing 'pathologisation' of autism and of autistic individuals (Milton and Moon, 2012; Kapp et al, 2013; Orsini and Davidson, 2013; Yergeau, 2013; Milton, 2014; O'Dell et al, 2016; Woods et al, 2018) and address the wider implications of this, including (i) the continuing dominance of deficit-focused discourses of autism, (ii) the longstanding neglect of autistic subjectivities and experiences, and (iii) the 'hermeneutic injustice' which has resulted from (ii), including in specific areas such as female autism and sensory sensitivities. In relation to our practice, it also important that such training addresses the differences associated with female autism, in particular the prevalence of camouflaging amongst autistic girls and women and the potential implications of this for 'selfhood' and mental health (Bargiela et al, 2016; Tierney et al, 2016; Hull et al, 2017; Lai et al, 2017; Hull et al, 2019; Lai et al, 2019; Livingston, Shah and Happé, 2019; Mandy, 2019).

5.3 Limitations of the study

The main potential limitations of the study are its individual case focus (and corresponding small sample size) and the 'narrow' demographic profile of its participants: characteristics that typically attract criticism for lack of potential generalisability from those who adhere to a positivist worldview (Braun and Clarke, 2013; Willig, 2013; Carminati, 2018; Smith, 2018). Critical realism, however, embraces both positivist *and* hermeneutic/relativist methodologies as needed to explore different facets of reality, provided that the chosen methodology is compatible with the mode of reality under inquiry (Bhaskar et al, 2018; Wiltshire, 2018). From this perspective, issues of universality and statistical generalisability are irrelevant to the study of human subjectivity; it is of necessity an endeavour that requires a focus on the particular and on contextualised meaning making (Bhaskar et al, 2018). The merit of the individual 'story' focus of my study is therefore that it seeks to make transparent – as much as is possible within the confines of the word limit of a professional doctorate thesis – the social and cultural context of each participant's interpretation of what it means to be 'autistic'.

It should first be noted that all of the participants recorded their ethnic identity as white British/other. Concern has recently been expressed about a lack of research into the experience of being autistic amongst non-white ethnic groups (Burkett, 2020); an absence which has taken place within an epistemic landscape which – as previously discussed – has tended to (implicitly or otherwise) position autistic individuals as somehow outside of or oblivious to usual social or cultural influences. The ethnic profile of the participants meant that this study unintentionally contributed to this omission, so it is important to highlight the need for future research with the aim of addressing this oversight by conceptualising autism through the lens of intersectionality (Strand, 2017), considering its effect as one of multiple intersecting identities including not only gender (Saxe, 2017) but also ethnicity (Burkett, 2020), sexuality (George and Stokes, 2018), class and so on.

In terms of the educational and employment status of the participants, they undoubtedly constituted an 'atypical' group when compared with UK demographic data and employment statistics for autistic individuals. The participants were all highly educated (all were university graduates, and three had postgraduate qualifications) and all are working in professional roles on an employed or self-employed basis (with the exception of Gemma who is currently raising her family but was previously employed in a professional role). This stands in contrast with the UK's population: the most recent data available on education (Office of National Statistic, 2017) indicate that around 42% of the population aged between 21 and 64 are university graduates. The participants' employment status is particularly notable bearing in mind current estimates that only 32% of autistic individuals are in paid work (16% in full-time paid work): indeed, the National Autistic Society reports that four in ten autistic individuals have “never worked” (NAS, 2016b). It remains to be seen how these employment figures change in future if more women are diagnosed as autistic in adulthood after a lifetime of ‘masking’: nonetheless, the participants’ employment status stands in stark contrast with the current (and deeply concerning) employment data for autistic people as a group (NAS, 2016b).

In addition to their ‘explicit’ demographic characteristics, the participants were also a self-selected group who were willing to talk to me – either in person or via Skype – about their experiences of and perspectives on autism. The social communication differences associated with autism mean that autistic individuals all too often experience interpersonal interactions with non-autistic others that are characterised by a lack of empathy and understanding on the part of the latter (Milton, 2012; Milton and Moon, 2012; Yergeau, 2013; Milton, 2014): participating in an interview-based study therefore required taking a ‘leap of faith’ that it would not involve another potentially distressing or invalidating interpersonal interaction with me as a non-autistic researcher. It is undoubtedly the case, therefore, that my study will have ‘ruled out’ potential participants who would be put off by the interview format, leaving a potentially unrepresentative sample (in the context of autistic people as a group or class).

The study can therefore be criticised on the grounds that the participant demographics are in no way representative of UK-based autistic adults: at the same time, I would argue that this is a strength as well as a potential limitation. As Rowan observed, mainstream research has tended focus on autistic individuals who are “really suffering” in their daily lives. In doing so, it has served to reproduce and reify the dominant biomedical discourse which constructs autism in terms of ‘impairments’ and ‘deficits’, in turn reinforcing an implicitly ‘tragic’ cultural narrative of what it means to be autistic (Duffy and Dorner, 2011). In contrast, the data generated by my study is consistent with the neurodiversity perspective on autism: the participants’ stories illustrate the ways in which their vulnerabilities are accompanied by strengths, resilience and resourcefulness.

5.4 Post-analysis reflexivity

Since I embarked on this study in 2015, there has been an important development in the field of autism studies, in the form of a growing awareness and acknowledgement of the ethical importance and epistemic benefits of including autistic individuals in the process of production of knowledge about autism, ideally as partners throughout the research process (Gillespie-Lynch et al, 2017; Woods et al, 2018; Fletcher-Watson et al, 2019; Milton, 2019). This has highlighted for me the discomfort I experienced at times during the research process when I have questioned whether I have any 'right' as a non-autistic researcher to attempt to represent the experiences and perspectives of autistic women. There was no easy answer to this bearing in mind the need for my doctoral research project and thesis to be wholly 'mine', but I sought to address my concerns as best I could by sharing the participants' stories at a draft stage and inviting their feedback. From a position of hindsight, however, it would arguably have been 'better practice' in terms of participatory research (Fletcher-Watson et al, 2019) to have incorporated an initial consultative stage – perhaps in the form of a focus group or qualitative survey – to get feedback from members of the autistic community about the proposed direction of my research.

Alongside my experience of ethical considerations, another important feature of the research process was my shift to critical realism as a philosophical 'framework' for my study, from a starting point of 'moderate' social constructionism (Burr, 2015; Johnstone and Boyle, 2018). This change took place during the interview, transcription and analysis phase, as my understanding of autism as an embodied and systemically-embedded experience developed. Although the social constructionism that originally informed my research – such as Ussher's (2000) material-discursive-intrapsychic approach - recognises the significance of non-discursive forms of reality for individual subjectivities (Burr, 2015; Johnstone and Boyle, 2018), I was increasingly drawn to the more extensive ontological theorising that characterises critical realism. I found that the critical realist view of reality as complex and systemic (Bhaskar et al, 2018; Wiltshire, 2018) not only aligned with another personal area of interest – in systems theory and its influence on psychotherapeutic practice (Hedges, 2005; Capra and Luisi, 2014) – which had developed during the early stages of my counselling psychology training, but also served as a useful framework for reflecting on the phenomenon (or phenomena) of autism. Furthermore, I found other principles of critical realism -such as the transformational model of social activity ('TMSA') and judgemental rationality (Bhaskar et al, 2018; Wiltshire, 2018) – helpful for situating my research as a counselling psychologist in training. For example, I would argue that the TMSA offers a useful conceptual framework for exploring the social processes that contribute to change at the level of individual subjectivities, while I see judgemental rationality as justifying and informing a wellbeing and social justice-oriented approach to autism research.

Aside from these aspects of critical realism, as my research proceeded it became important to be able to delineate my view on the ontological status of autism bearing in mind controversial (Milton, 2016) speculation that it is a 'mere' social construct (Timimi et al, 2010; Timimi and McCabe, 2016). This came to my attention because it is couched in gendered language, with the assertion that an alleged 'feminisation' of education and working environments has led to an increase in the behaviours of boys and men being deemed problematic and in some cases classified as autistic. While I share the authors' interest in the effects of social and cultural contexts on individual lives, I was concerned by their construction of autism as a 'medicalisation' of the "social and emotional competence" of boys and men, and view this as an unequivocally retrograde step in terms of the identities and wellbeing of autistic girls and women. Aside from its other 'attractions', critical *realism* thus seemed to me to serve as an important way of distancing myself from this regressive re-gendering of autism, by highlighting that I view it as having some underlying biological 'reality' (Hacking, 2009), no matter how poorly understood at present (Fletcher-Watson and Happé, 2019).

5.5 Recommendations for further research

Research which focuses on the needs and quality of life of autistic individuals is barely in its infancy (Robertson, 2010; Milton and Bracher, 2013; Pellicano et al, 2014; Fletcher-Watson et al, 2019) and this study – with its focus on the narratives of autistic women – highlighted a number of potential research directions, including the importance of continuing research into the ways that autistic individuals' lives and wellbeing are affected by the neurotypical norms and values that pervade ‘institutional’ settings such as schools, universities and workplaces. In particular, difficulties in work-related settings were a significant theme across the participants’ narratives and such experiences have received little attention to date from researchers (Pellicano et al, 2014), despite the concerning levels of unemployment amongst autistic individuals (National Autistic Society, 2016b). As previously discussed, the participants of this study were unrepresentative in that they are highly educated compared to the population as a whole and they are all (or have been) employed or self-employed in professional fields. However, they have achieved in this way *despite* experiencing a range of difficulties due to neuronormative expectations relating to social communication and interaction; sensory processing; executive function and so on. While concerns have been expressed that cognitively able individuals who can find ways of adapting to or coping with societal norms may not be representative of autistic people in general (Fletcher-Watson et al, 2019), nonetheless I would argue that – if we are to take the ‘double empathy problem’ (Milton, 2012) perspective as seriously as I believe we should – they constitute experts in ‘autistic experience’ (Hacking, 2009; Milton, 2014; Gillespie-Lynch, 2017; Milton, 2019) in a way that non-autistic researchers and professionals can never hope to, no matter how well-intentioned. As such, their participation in research into work and career related areas would be an important and productive development.

The participants’ stories also highlighted the need for research into the effects on individual lives of sensory sensitivities of various kinds. Sensory sensitivities are known to be common amongst autistic individuals (Leekam et al, 2007; Ben-Sasson et al, 2009; Smith and Sharp, 2013; Ross, Elcheson and Cook, 2018; Fletcher-Watson and Happé, 2019) but appear to have been another ‘casualty’ in the widespread marginalisation of autistic voices and subjectivities within mainstream research: such experiences and their effects need to be self-reported – and to be listened to by clinicians and researchers - if they are to be explored in any meaningful way (Belek, 2019). For the participants of this study, the effects of their heterogeneous sensory sensitivities were widespread and particularly relevant in the context of ‘public’ spaces – such as schools, workplaces, shops and social spaces – which are currently constructed to suit the sensory tolerances of the neurotypical majority. Despite their resourcefulness in coping with such experiences, it was evident that sensory features of the environment could constitute an effective barrier towards – for example – participation in certain social events or being able to concentrate fully in the workplace: Laura and Charlie also identified excessive sensory stimulation as potential migraine triggers for them. From a social justice perspective, then, an important (and of necessity participatory) research direction would be to explore ways of making public environments more comfortable and accessible for those who experience sensory sensitivities (Milton, Martin and Melham, 2016; Bölte, 2019), rather than expecting them to cope with unpleasant side-effects or exclude themselves altogether. Bearing in mind the heterogeneity of such experiences, there are inevitable limitations on the extent to which individual needs can be met, but nonetheless research in this area is likely to identify some commonly problematic issues around lighting, lack of sound insulation in open plan offices and so on.

Previous studies have identified concerningly high levels of sexual abuse amongst adolescent girls and women (Bargiela et al, 2016; Ohlsson Gotby et al, 2018). I did not ask the participants about experiences of abuse, but two volunteered stories of relationship-based experiences of physical, emotional and/or financial abuse. I subsequently discussed the question of increased vulnerability to abuse when I presented the preliminary findings of my study at the 2019 BPS Division of Counselling Psychology conference, and a number of members of the audience confirmed that they too have observed this amongst their female autistic clients. This therefore appears to be another key area for further research, perhaps using a qualitative survey as a starting point bearing in mind the sensitivity of the issues involved (Braun and Clarke, 2013), and aimed not only at improving awareness and understanding of this issue, but also at developing appropriate training and educational materials for autistic girls and women, and all relevant professionals.

Counselling psychology-focused research

The above recommendations for further research relate to the wellbeing and quality of life of autistic individuals, but this study has also highlighted an apparent epistemic ‘gap’ in relation to how counselling psychologists view and understand autism and neurodiversity. This is of particular importance in light of the findings of studies which suggest that negative constructions of autism may have potentially detrimental effects for the mental health of autistic individuals, whereas neurodiversity-informed constructions of autism may have protective effects for wellbeing and promote self-acceptance (Kapp et al, 2013; Cooper et al, 2017; Botha and Frost, 2018; Cage et al, 2018). This raises the question of how individual practitioners construct autism/neurodiversity and the potential implications of this for their work with autistic clients: whether, for example, they may unintentionally reproduce and reinforce negative and stigmatising dominant discursive constructions of autism in the therapy room (Hare-Mustin, 1994; Sinclair, 2007). A useful starting point for further research in this area would be a study of the ways that counselling psychologists and other therapists discursively construct autism, perhaps employing a story completion-based approach (Walsh and Malson, 2010; Shah-Beckley, 2016; Braun et al, 2019) bearing in mind the likelihood of social desirability bias amongst this participant group.

5.6 Conclusions

This study contributes to a 'new' way of understanding autism that is grounded in the lived experiences and subjectivities of autistic individuals. It is not unusual for mainstream research articles to make an initial explicit reference to the heterogeneity of autism, but this is then implicitly undermined by what follows: a focus on homogeneous behavioural characteristics or biological features. In carrying out a narrative-based study, I sought to demonstrate the importance of understanding autism (whatever its biological underpinning may be) as a personal experience within the social and cultural contexts of a specific life; I also hoped that my participants' stories would serve to challenge prevailing stereotypes of autism. Indeed, this proved to be the case: the participants' stories were characterised by relationality, resilience and self-awareness, standing in stark contrast to the tendency to 'story' autism in tragic terms, and to caricature autistic individuals as socially-disengaged and oblivious. Furthermore, their narratives illustrate the creative ways in which autistic individuals may deploy the neurodiversity discursive construction of autism as a means of resisting negative and dehumanising discourses. In doing so, they are actively engaged in a wider process of reclaiming and transforming the epistemic landscape of autism.

For the counselling psychology profession, there is now a pressing need for us to recognise and acknowledge the social justice implications of our current neglect of autism and neurodiversity. Our core values of relationality and empathic engagement with subjectivities mean that we are well-placed as a profession to contribute to the production and dissemination of knowledge grounded in ‘insider’ perspectives, both in the form of further research and through the incorporation of formal training requirements for neurodiversity-informed awareness and understanding for counselling psychologists. The deeply concerning levels of mental health difficulties amongst autistic individuals highlight that autism/neurodiversity can no longer be positioned (implicitly or otherwise) as a specialist area; it is instead an important issue for all counselling psychologists and other mental health professionals, irrespective of the settings in which we work.

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Appendix 1: Faculty Research Ethics Committee approval letter

University of the West of England
BRISTOL

Faculty of Health & Applied Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 XXX XXXX

UWE REC REF No: HAS.16.06.171

3rd August 2016

Jacqui Pearse
[ADDRESS]

Dear Jacqui

Application title: The construction of identity and self in the narratives of women on the autism spectrum

Thank you for resubmitting your ethics application, this was considered by the Committee and based on the information provided was given ethical approval to proceed.

You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx.

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web: http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx

The following standards conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

2. You must notify the University Research Ethics Committee if you terminate your research before completion;

3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

We wish you well with your research.

Yours sincerely

[SIGNATURE]

[NAME]
Chair
Faculty Research Ethics Committee

c.c Director of Studies

Appendix 2: Recruitment of participants (message shared via Facebook page "Research into the lives of women on the autism spectrum")

Research into the lives of women on the autism spectrum

19 September 2017 ·

RESEARCH PARTICIPANTS NEEDED

Are you a UK-based autistic woman who only realised that you're on the autism spectrum in adulthood?

Would you be interested in taking part in research aimed at improving understanding about the diversity of autism in women, and the challenges autistic women can face in trying to access support and understanding?

I'd love to hear from you if you might be interested in taking part in my doctoral research. It would involve talking to me about your experiences and perspectives for about an hour or so, either in person (I'm based in Bristol but can travel up to about 90 mins each way to meet up) or via Skype.

My research has been given ethical approval by the University of West of England, and is being conducted in accordance with the British Psychological Society's code of ethics and conduct,

Contact details: my name is Jacqui Pearse and my email address is jacqueline2.pearse@live.uwe.ac.uk

Appendix 3: Participant Information Sheet

Participant Information Sheet

Exploring the experiences and perspectives of women on the autism spectrum

Before you decide whether or not to take part in this research study, please read the following information carefully and discuss it with others if that would be helpful in making your decision.

If there is anything that is unclear or if you need any additional information before making your decision, please contact me (Jacqui Pearse) on [NUMBER] or jacqueline2.pearse@live.uwe.ac.uk.

What is the purpose of the study?

I'm carrying out the study as part of my doctorate in counselling psychology. Existing research often focuses on the shared features of autism spectrum conditions: in contrast, the purpose of the present study is to explore the lived experiences and personal perspectives of individual women, and the social and cultural influences on them.

Why have I been invited to take part?

I'm seeking to recruit around 6 to 8 women who realised or identified that they are autistic during adulthood (after the age of 18), and who are interested in talking about their experiences and perspectives on the significance of autism for their lives.

NB: You don't need to be formally diagnosed with an autism spectrum condition to take part.

Do I have to take part?

No - it's your decision whether to take part in this research or not. If you do decide to take part, you'll be given this information sheet to keep and will be asked to sign a consent form.

If you decide to take part, you are still free to withdraw from the study at any time until 31 January 2019, either by phone or email. You won't need to give a reason for doing so.

If you wish to withdraw from the study after 31 January 2019, my thesis will be in the final stage of completion and it is likely to be difficult to remove your anonymised data. However, you can still discuss this with me, and I will try to modify my thesis if possible.

What will I be asked to do if I take part in the project?

You'll be asked to meet with me at a mutually convenient place and time (I'm based in Bristol but can potentially travel for up to about 2 hours to meet with you). Alternatively, if you prefer, we could use Skype rather than meeting in person – let me know if you'd prefer that option.

Before we start, you'll have the opportunity to ask me any further questions about the research. If you're happy to proceed, I'll ask you to sign a consent form (I'll send you a copy of this beforehand) and give you a copy to keep.

I'll then ask you questions about a number of areas, such as how you came to realise that you're autistic; whether or not you sought a formal diagnosis (and what that experience was like for you); what effect you think it had that you weren't identified as autistic earlier in life; and the meaning and significance of autism for your life. I may also ask questions in response to what you say (e.g. to obtain more background or detail), but if you don't want to answer a particular question, that will be fine and you won't need to give a reason.

The intention is that the session will be relaxed and informal, rather than a formal "interview". I'd expect it to last for about an hour, but this is dependent on how much you want or feel able to contribute – it'll be fine if it's much shorter than that, and you can end it whenever you wish.

Some participants like to meet for a second time in order to expand on what they talked about in the first session. This second session is optional, and would again be held at a convenient location for you (or via Skype if preferred).

The session will be audiotaped, and I will then transcribe it verbatim (other than changing any names or other identifying information). The recording, transcript and any other records will be stored confidentially and securely (see below).

What are the possible benefits of taking part in the study?

By taking part, you'll be helping to increase knowledge and awareness about the diversity of experiences of women on the autism spectrum, thereby challenging existing stereotypes and misconceptions about autism. It is also hoped that the study may help to identify potential areas for improving support for autistic girls and women.

Some people also find it personally rewarding to reflect on and talk about their experiences when they take part in a study of this type (i.e. based on people talking about their lives rather that answering questionnaires or completing tasks).

What are the possible disadvantages or risks of taking part in the study?

There's a small possibility that talking about some aspect of your life might prove upsetting for you – please take this into account when deciding whether or not to take part in the study, and in thinking about what you would be willing to share with me if you take part.

If you are aware of feeling upset at any point during the session, please feel free to ask to end it straightaway. You won't need to give a reason.

What if I have any complaints?

If you have any complaints about your experience of the research, you can contact my supervisor, Dr Helen Malson (email: Helen.Malson@uwe.ac.uk) or the Programme Leader for the Professional Doctorate in Counselling Psychology, Dr Zoe Thomas (email: Zoe2.Thomas@uwe.ac.uk).

Will my taking part in this study be confidential?

Yes - your name and any other potentially identifying information (eg age, family details etc) will be changed in my thesis and any articles based on the study in order to protect your anonymity. You'll be welcome to check that you are happy with the way that this has been done.

All personal information collected in this research project will be processed by the University in accordance with the terms and conditions of the 1998 Data Protection Act. Your data will be held securely and will not be made available to any third party unless required to do so by law. Your contact details will be stored securely and separately to the anonymised research data; they will only be accessible by the researcher and her supervisor.

What will happen to the results of the research study?

The results of the research study will be written up for my thesis for a professional doctorate in counselling psychology. In addition, I'm intending to submit at least one article to a professional journal for publication, and may also present the findings of my research at professional conferences (eg the annual conference for the Division of Counselling Psychology of the British Psychological Society).

If I am interested in taking part in the study, what happens next?

If you decide you wish to take part, please contact me, either via email or phone (contact details: jacqueline2.pearse@live.uwe.ac.uk or [NUMBER]).   We can then arrange a suitable time and place for meeting up.

Thank you for taking the time to read this information sheet.

Appendix 4: Participant Consent Form

CONSENT FORM

Exploring the lives of women on the autism spectrum

Name of researcher: Jacqui Pearse (jacqueline2.pearse@live.uwe.ac.uk)

		Please initial box
1.	I confirm that (i) I have read and understand the participant information sheet for the above study and (ii) I have had the opportunity to ask questions about the study which have been answered to my satisfaction.	
2.	I understand that my participation is voluntary and that I am free to withdraw from the study at any stage before, during or after the interview with the researcher (up until 31 January 2019[41]).	
3.	I agree to take part in the above research study.	
4.	I agree to my interview with the researcher being audiotaped and transcribed by the researcher.	
5.	I agree to anonymised[42] material from my interview being used and discussed in the researcher's thesis.	
6.	I agree to the use of anonymised material from my interview being used in publications (eg articles in professional journals) and in presentations at conferences.	

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[41] As explained in the Participant Information Sheet (see attached), the researcher's thesis will be in the final stages of completion after 31 January 2019 and it may be difficult to remove analysis and discussion that draws on your anonymised interview. However, you are still welcome to contact the researcher at this point, and all reasonable efforts will be made to modify the thesis accordingly.

[42] As explained in the Participant Information Sheet, your name and any other potentially identifying information will be changed by the researcher to protect your anonymity. You will be able to check that you are happy with the way this had been done.

Name of participant	Date	Signature
Researcher	Date	Signature

One copy to be retained by the participant and one copy to be retained by the researcher.

The personal information collected in this research project (e.g., on any form/questionnaire/survey) will be processed by the University in accordance with the terms and conditions of the 1998 Data Protection Act. We will hold your data securely and not make it available to any third party unless required to do so by law. Your personal information will be used/processed as described on the participant information sheet.

Appendix 5: Optional prompt questions for the narrative interviews

1. **As you know, I'm interested in the experiences of women who only realised or identified that they're on the autism spectrum in adulthood. Can you tell me about the events or experiences that led to this realisation about yourself?**
   - What was your understanding of autism at this point? Had/has it changed over time?
   - Did you see yourself differently after you started to view yourself as being on the autism spectrum?
   - Did you seek a diagnosis for autism? What were your reasons for deciding to/not to?
   - [if relevant] what was the diagnostic process like for you?
   - [If relevant] do you think the diagnosis has been helpful in any ways?

2. **Do you think it would have made much difference for you and your life had you been identified as autistic when you were a child or teenager? If so, in what sorts of ways?**

3. **Can we talk a bit now about what life is like for you now as an adult…**
   - working life – has being on the autism spectrum had any impact on your job/career do you think?
   - What about relationships and friendships – can you tell me a bit about these?
   - Do you have friendships/contact with others on the autism spectrum? Has this been helpful? [if so/if not] in what ways?
   - women on the autism spectrum often talk about hiding their difficulties from others – would you say you do this? [if so] what affect does this have on you?
   - How about healthcare professionals, eg your GP – do you find they understand what autism is like for you and the way it affects your life? [if not] how does that affect you?
   - Did things change at all after identifying that you're on the autism spectrum?

4. **I'm interested in the strengths associated with the autism spectrum as well as the difficulties people experience – are there specific features of autism that you experience as assets/strengths?**
5. **What's your view of the support and resources available for autistic girls and women at the moment? Have you got any suggestions for how things**

could be improved based on your personal experiences of existing support?

6. **Is there anything else you'd like to share with me about your experiences?**

Appendix 6: Article

Behind the mask: a critical narrative analysis of a woman's story of identifying as autistic in adulthood

Abstract

Until recently, autism was assumed to be a predominantly male phenomenon, but a growing number of women are now being diagnosed as autistic in adulthood after many years of unexplained difficulties in their everyday lives. Their longstanding 'invisibility' challenges the prevailing epistemic landscape which characterises autistic individuals as unreflective performers of non-normative behaviours and raises questions about the effects of gendered and dehumanising discursive constructions of autism for the subjectivities and identities of autistic women. The aim of the present study was to explore this through a critical narrative analysis of the personal story of a young woman, Charlie, who was diagnosed as autistic in her late twenties. It was found that Charlie only came to view herself as autistic after discovering the neurodiversity discourse of autism, which construes it as a valuable facet of human diversity. This discursive construction was deployed to construct a narrative identity of a sociable, creative and caring autistic woman, whose difficulties in everyday life are a consequence of being autistic in a world created by and for the 'neurotypical' majority. Charlie's story thus serves to challenge and potentially transform the existing deficit-focused conceptualisation of autism.

Introduction

The focus of this study is the personal narrative of a 31 year old woman, Charlie, who came to identify (and was subsequently diagnosed) as autistic in her late twenties. For many years, experiences like Charlie's were all but absent from the research literature, reflecting a longstanding assumption that autism was characterised by overtly unusual social behaviours and interests that would typically be identified early in life by non-autistic 'experts' such as psychiatrists and paediatricians. This assumption is now being over-turned by a growing understanding that these behavioural characteristics were gleaned from studies with predominantly young male participants, and that autism in girls and women may be expressed rather differently (Krahn and Fenton, 2012; Kreiser and White, 2014): in particular, they appear more able (or are more motivated) than their male counterparts to conceal or compensate for the difficulties they experience in everyday life (Dean, Harwood and Kasari, 2017; Lai et al, 2017; Hull et al, 2019). As a result of this, autistic girls and women were largely 'invisible' to researchers and clinicians for many years (Gould and Ashton-Smith, 2011, Krahn and Fenton, 2012; Hearst, 2014).

The recognition of the longstanding neglect of female autism has served to highlight the epistemological – as well as ethical - consequences of the inherent power imbalance within academic research that has led to the exclusion of autistic individuals from the processes of production of 'knowledge' about autism (Milton and Bracher, 2013; Yergeau, 2013; Pellicano, Dinsmore and Charman, 2014; O'Dell, Woods, Milton, Arnold and Graby, 2018). As a result of this, autistic 'voices' and subjectivities have been marginalised for many years, thereby limiting and distorting 'knowledge' in this area, especially in relation to female autism. This has started to change in recent years, with the publication of a small but growing body of qualitative research with the aim of exploring female autism as a lived experience (Baldwin and Costley, 2016; Bargiela, Steward and Mandy, 2016; Tierney, Kilbey and Burns, 2016; Kanfiszer, Davies and Collins, 2017; Milner, McIntosh, Colvert and Happé, 2019; Leedham, Thompson, Smith and Freeth, 2020). A common finding of such studies is that being autistic and female is typically accompanied by a pervasive sense of 'difference', together with considerable efforts to fit in socially by 'camouflaging' perceived differences from others. Mental health difficulties are also reported to be common amongst participants (Baldwin and Costley, 2016; Bargiela et al, 2016; Leedham et al, 2020): a finding that is consistent with a large scale population-based study which reported rates of 34% and 36% respectively for depression and anxiety amongst autistic women (compared with 22% and 26% respectively for autistic men, and 10% and 9% for the mixed sex control group) (Croen et al, 2015). More recently, self-reported camouflaging behaviours have been identified as a risk factor for increased levels of mental health difficulties (Cassidy, Bradley, Shaw and Baron-Cohen, 2018; Cage and

Troxell-Whitman, 2019): a concerning finding, bearing in mind the reported prevalence of camouflaging amongst autistic women (Lai et al, 2017; Hull et al, 2019).

Such findings highlight the importance of further research into the experiences and wellbeing of autistic women, and this study sought to add to the small body of existing qualitative research in this area – which is largely characterised by thematic approaches to analysis – by exploring the individual narrative of a woman who came to identify as autistic in adulthood. This approach is informed by the principles of narrative inquiry, and its central claim that narrative is an expression of socially mediated and culturally embedded subjectivity through which individuals make sense of their experiences and lives (Bruner, 1990; Somers,1994; Gergen, 2015; Hammack and Toolis, 2015; McLean and Syed, 2015; Schieff, 2017). It is an approach which is often used to explore and illuminate the experiences of the "unheard and marginalised" (Gergen, 2015, p.73), a description that encapsulates the status of autistic women within mainstream research until very recently.

Narrative-based research is characterised by a considerable degree of flexibility as to its underlying ontological and epistemological assumptions (Esin, 2011; Silver, 2013). The present study was informed by critical and constructionist perspectives which assume that personal meaning-making is embedded within a wider social, cultural and political context: that the ways in which we make sense of our personal experiences are simultaneously shaped and limited by the concepts, discourses and narratives that we encounter in society (Emerson and Frosh, 2004; Souto-Manning, 2014; Burr, 2015; Gergen, 2015; Bhaskar, Danermark and Price, 2018; Boyle and Johnstone, 2018). From a critical perspective, the current dominance of deficit-focused discursive constructions and 'tragedy' narratives of autism (Broderick and Ne'eman, 2008; Brownlow, 2010; Duffy and Dorner, 2011; Kapp, Gillespie-Lynch, Sherman and Hutman, 2013; Milton, 2014; Quirici, 2015) is not a neutral or transparent reflection of its ontological status, and is instead a value-laden consequence of inherent power imbalances in knowledge production (O'Dell, Bertilsdotter, Ortega, Brownlow and Orsini, 2016). It raises important questions about the implications of this 'discursive negativity' at the level of individual subjectivities and especially for autistic women, bearing in mind the current association between autism and 'masculinity' (Baron-

Cohen, 2002; Jack, 2011; Krahn and Fenton, 2012). To date, little attention has been paid to this in the research literature (for notable exceptions see Bagatell, 2007; Baines, 2012), although there is recent evidence of a potential link between stigmatising constructions of autism and increased vulnerability to mental health difficulties in autistic individuals (Cooper, Smith and Russell, 2017; Botha and Frost, 2018; Cage, Di Monaco and Newell, 2018). This highlights the need for further research into personal meaning making by autistic individuals, and the present study sought to explore this by asking how a woman who self-identified (and was subsequently diagnosed) as autistic in adulthood discursively constructs 'autism' as an epistemic category within her narrative. A subsidiary aim was to consider how the participant's personal narrative conformed to culturally available narrative types, 'plots' or themes.

Method

Following approval from the University Ethics Committee, contact was made with a number of online communities for autistic women, explaining that participants were being sought for a study aimed at improving understanding of autism amongst women who had identified as autistic in adulthood. After making contact, Charlie was provided with written information about the purpose and scope of the study and was given the opportunity to ask further questions before deciding whether or not to participate. She chose to be interviewed at her home, and was reminded before the interview that she was free to end the interview or withdraw from the study at any time without needing to provide a reason.

The aim of the narrative interview was to encourage Charlie to tell her individual story, with minimal direction or intervention (Emerson and Frosh, 2004; Schiff, 2017). It began with an invitation to talk about the events and/or experiences that had led to her realising that she is autistic; follow up questions were asked in response to this in order to encourage an exploration of the meaning and significance of her 'autistic identity' for her life. The interview lasted one hour and forty five minutes and was audio-recorded on a digital recording device. It was then transcribed verbatim (other than anonymising names and other potentially identifying information) by the researcher, following the convention outlined by Malson (1998).

The analysis of the interview data involved multiple close readings of the transcript, through which discursive and narrative features of the text were identified and analysed: an informal 'time line' was also created, summarising the key events and experiences that had led to Charlie identifying as autistic (and the implications for her life subsequently). From this, an interpretation of Charlie's story was drafted and shared with her for her feedback; she confirmed that her data had been appropriately anonymised and that the interpretation reflected her views and experiences in a way that conveyed a sense of what she had hoped to communicate during the interview.

Analysis

The unstructured nature of the narrative interview (Emerson and Frosh, 2004; Schiff, 2017; Stagg and Belcher, 2019) generated rich and extensive data, which was not neatly temporal in nature. For the purpose of the interpretation below, however, a more conventionally temporal narrative structure was deployed, alongside a focus on discursive and narrative features of Charlie's story (Foucault, 1972; Potter and Wetherell, 1987; White and Epston, 1990; Frank, 1995; Emerson and Frosh, 2004; Booker, 2007).

Charlie's story: "I have been masking and camouflaging my entire life"

Charlie is a thirty one year old white British woman, who is married and works as a social worker in a large city in the South West of England. She self-identified as autistic at the age of 28, after hearing the story of another autistic woman at an autism conference; she was subsequently diagnosed with an 'autism spectrum condition' by an NHS psychiatrist at the age of 29.

Charlie's narrative depicted an early awareness of 'feeling different' and of not fitting in with her peers. Dean et al (2017) report that autistic girls are often on the periphery of social groups, and this is consistent with Charlie's experience of being in a friendship group of "smart kids" at school:

> "…on the surface I had friends but (.) I didn't always feel like I knew what was going on. More often than not, I felt like I was included because I matched with these people [in terms of academics and extra-curricular interests] and we got on well enough but I always felt like I was on the periphery, like I was stood on the edge watching (.) the interactions, and I would sometimes get things (.) wrong

> and have (.) you know, periodic little (.) not full blown falling outs but like (.) you know, just misunderstandings and I would end up apologising and not necessarily knowing why..."

Growing up, Charlie was able to make sense of this pervasive experience of 'feeling different' to some extent: her parents moved from London to the small Scottish town where she grew up when she was a baby and their accents marked the family out as 'incomers'. The family's incomer status within their community did not, however, account for other difficulties Charlie experienced during her secondary school years, such as negotiating the school buildings between lessons:

> "…changing classes (.) into different parts of the building was an absolute nightmare. Noisy, chaotic (.) my locker was never anywhere near any of my classes (laughs) […] we were allowed to take our backpacks around with us, so I would end up loading up like four periods worth of (.) books and everything with me so I didn't have to try to negotiate (.) dodging round [the school]"

As an adult with insight into autism, Charlie came to understand these difficulties as a consequence of her sensory sensitivities, together with differences in executive functioning: at the time, however, she had no way of making sense of why she struggled with aspects of everyday life at school that her peers seemed to take in their stride.

Unexplained difficulties and social confusion became more frequent for Charlie when she reached her twenties and embarked on a career as a social worker. She found herself struggling to cope with various aspects of working life: for example, restructuring of teams was a common event, and something Charlie found "unsettling" and stressful. Perhaps most problematic on a daily basis, however, was the physical challenge of open plan offices. Charlie described how she often wore sunglasses and headphones to help her cope with the discomfort of fluorescent lighting and distracting noise, resulting in teasing from her colleagues:

> "…my colleagues would joke and say I look like either Stevie Wonder or Ray Charles, and it's like (laughs) 'how this light is not painful for you I will never understand', because it actually gives me a migraine, it makes my head hurt and I cannot concentrate with the noise."

In ‘joking’ about Charlie’s resemblance to famous people with known visual impairments, her colleagues acted as a “normalising gaze” (Foucault, 1977, p.184) that served to highlight her differences to implicit norms. This type of experience reinforced her assessment of herself “*a bit weird*”; a “*bit of an odd duck*” who struggled with aspects of life that others seemed to take in their stride:

> “I always felt like I was (.) you know, just trying to (.) to jam myself into this round hole and was a, you know, not necessarily a square peg, maybe a hexagon (laughs) but, you know, just never never fitting in.”

At the heart of narrative inquiry is the assumption that we instinctively seek to make sense of our lives and our experiences in a coherent and meaningful way (Sarbin, 1986; Polkinghorne, 1988; Bruner, 1991). Consistent with this view, it was evident that it was difficult for Charlie to lack a hermeneutic framework for understanding her sense of “never fitting in” and her perceived differences from an implicit norm of an individual who is at ease in social situations; readily adaptable to change; and comfortable with the sensory stimulation associated with public spaces. In narrative terms, a lack of hermeneutic possibilities leaves an individual adrift in potential narrative ‘chaos’, characterised by a sense of “vulnerability, futility and impotence” (Frank, 1995, p.97) in the face of seemingly endless and insurmountable problems. In Charlie’s case, these problems centred in particular on the workplace: unsurprisingly, she experienced frequent episodes of work-related stress and anxiety during this period, and on two separate occasions was signed off work for several weeks at a time.

During this stage of her life, Charlie was learning about autism as part of her role as a social worker in a children and families team. The cases of autism she encountered were often associated with intellectual disabilities, but she also became more familiar with Asperger-type presentations. She recalled that at this point her knowledge about Asperger-type autism was chiefly constituted by the gendered ’eccentric scientist’ discourse:

> “…like um, you know, the one that- the most famous undiagnosed character on TV, Sheldon Cooper on Big Bang Theory […] oh he’s textbook, clearly not understanding, you know, social niceties and that. He just sees it as a waste of time. Um so yeah, I never even remotely considered it for myself.”

The discursive construction of autistic individuals as aloof, socially awkward boys and men who are more interested in science (or similar pursuits) than in the people around them (Asperger, 1991; Baron-Cohen, 2003; Quirici, 2015) currently permeates popular culture and is reified within mainstream research literature in the form of the so-called 'extreme male brain' theory of autism (Baron-Cohen, 2002). It was irrelevant to Charlie's experience of herself as a caring woman who worked hard to fit in socially and whose interest in other people had led to her studying psychology as an undergraduate and pursuing a career in social work. For much of her twenties, this left her with hermeneutic 'absence' and a resulting inability to make sense of her feeling of being 'different' to others.

Charlie's lacuna in self-understanding finally changed in a dramatic episode when she attended a national autism event for work purposes. She was interested to note that there were female speakers talking about their experiences of autism, and she went to listen to a psychotherapist talk about her experience of being diagnosed as autistic in her thirties.

> "…her story resonated so much with me and (.) I just sat there absolutely gobsmacked (laughs) listening to her speak. And it shook me for the rest of the day."

Charlie described how she heard key aspects of own experiences 'mirrored' by the psychotherapist's own story, from feeling on the 'outside' of groups to struggling in the loud and busy environment at school and work. It was also an encounter with a new way of construing autism, consistent with the 'neurodiversity' discourse, according to which it is possible – as embodied by the psychotherapist speaker – to be both autistic *and* a woman drawn to work in a caring profession. It offered Charlie a single, coherent explanation for the seemingly disparate elements of her life experiences such as her difficulties coping with change and in 'de-coding' social norms, alongside her interest in other people and her capacity to pursue a career as a social worker. Perhaps most significantly, the encounter provided her with a new understanding about the way that light and sound often seem to painfully assault her; she could now construe these sensory experiences as integral features of autism that are largely problematic because of the disabling effects of educational and work environments designed by and for the neurotypical majority.

Charlie subsequently carried out her own research into female autism, focusing in particular on the personal accounts of autistic women (see, for example, Simone (2010); James (2017); Uher (2017); Cook and Garnett (2018)). She found that this confirmed for her that her disparate difficulties and experiences "[made sense] under the lens of autism". She then experienced a stage of wondering:

> "…is a self-diagnosis sufficient or should I pursue an official diagnosis, and […] I'd felt like I really had no choice but to pursue a formal diagnosis because I didn't feel like I would be believed (.) you know 'you can't be autistic, you can make eye contact', 'you can't be autistic, you're holding down a job, you're married'…"

Charlie's comments here illustrate the potentially ambiguous and fragile nature of an 'autistic identity'. When discursively constructed as a form of 'neurodiversity', autism may be construed as a matter of personal identity and self-knowledge, for which 'diagnosis' is no more appropriate than it would be for any other facet of one's identity. In contrast, within the dominant medical discursive framework, formal diagnosis is unequivocally essential and designated healthcare professionals (such as psychiatrists) act as "authorities of delimitation" (Foucault, 1972, p.46) who determine who may – and may not – be termed autistic. In the extract above, Charlie conveyed a sense that "self-diagnosis" might be sufficient for the purpose of her own identity, but the lack of a "formal diagnosis" would potentially damage the credibility of her claim to be autistic in the eyes of (unstated) others.

Charlie's quest for medically-sanctioned validation led to a 'regressive' phase (that is, one characterised by moving *away* from a valued endpoint (Gergen, 2015) in her story as she described her struggle to obtain confirmation of her new autistic identity in the form of a diagnosis via her local NHS trust. She was required to undergo the Autism Diagnostic Observation Schedule (ADOS), in which she was faced with a series of tasks, such as being handed a picture book with no words in it and being asked to describe what was happening:

> "It was a story about flying frogs and (.) this is the thing, like (.) how is this appropriate for (.) an adult? […] I thought it was insulting. And they said that I

> was too creative in that particular thing because um (.) I was able to infer the emotions on the faces of the frogs. But it was (.) a quite exaggerated illustration and I was read to a lot as a child."

Charlie was subsequently told that a diagnosis would not be forthcoming, on the grounds that she had been assessed as "too sociable and creative" to be autistic. Her narrative conveyed a recognition that autism is constituted within the 'medical' discourse as something that cannot be concealed from others, and that she had been unable to perform this version of 'autism' satisfactorily after years of striving to conform to neurotypical norms:

> "I have been masking and camouflaging my entire life, trying to (.) feel normal, to fit in, you know […] when you wear these masks for so much of your life they become your face. So it's really hard (.) it's really hard to separate that […] I can't just dial up the autism (laughs) you know, to be able to (.) to get them to see what I actually am dealing with, because then I don't want [the assessment team] turning round and saying 'well it just seemed like you were performing'…"

Charlie described herself as "absolutely floored and devastated" at the news that a diagnosis would not be forthcoming, a response that conveys the importance of the external validation of medical professionals and the potential fragility of her new 'autistic identity' if it is withheld. Her attempt to obtain a diagnosis could have ended at this point, but her previous research into female autism had left Charlie convinced that it was the correct explanation for her disparate difficulties with social situations; with change and transitions; and – above all – with overwhelming and often painful sensory stimulation. She subsequently wrote a long letter to the assessment team, explaining the effects of a lifetime of "masking and camouflaging" any potentially non-normative social responses and why she therefore disagreed with their conclusion. For example, she highlighted that her training and experience as a social worker had helped her develop skills and compensatory strategies which enabled her to "infer the emotions" of the frogs in the ADOS picture task; a performance that had contributed to her being assessed as not autistic:

> "[I explained to them that] it's hard to unpick (.) what is learned and what is inherent (.) how in the hell do you expect me to (.) you know, say 'oh I-(.) I'm

> able to just recognise these emotions, also I studied social work, I was trained effectively (laughs) to be able to- to pick up on these subtle expressions if I'm in a one to one situation with a client and be like 'you seem a bit upset, do you want to tell me more about how you're feeling?'. You know, this is stuff that I've learnt, I can't just (.) switch that off […] it's not like you can (.) you know, re-wind to a stage when I was younger."

In response to her letter, Charlie was offered a second opinion with a psychiatrist. This was a very different experience; instead of being asked to perform infantilising tasks, the psychiatrist spent over four hours exploring her life experiences with her (and with her husband and parents) before agreeing that a diagnosis of 'autism spectrum condition' "made sense" for Charlie.

Charlie described her "massive, massive relief" when she received confirmation of the diagnosis. For Charlie, diagnosis constituted 'expert' confirmation that the difficulties she had experienced in life – such as in conforming to social norms and in coping with sensory stimulation in the workplace – could be explained in terms of her "neurology":

> "I do not believe [autism] is a disorder, you know, it's (.) it's a neurodivergence, a difference (.) yes, some are disordered by it (.) you know, that's not to say that (.) you know, none of us suffer with autism because some do, some genuinely do (.) but (.) if anything it is a condition, it is a type of neurology, and it shouldn't try to be corrected, as some people try to do."

Brownlow and O'Dell (2013) describe how the 'neurodiversity' discourse typically deploys and subverts the neurobiological claims of the dominant 'medical' discourse of autism (in which autistic 'behaviours' are deemed evidence of underlying 'deficits' in neurocognitive functioning): this is evident in Charlie's description of autism as a "type of neurology" that should not be corrected. Being able to construct autism in this way had transformative consequences for Charlie; in particular, it meant that she herself no longer tried to "correct" her way of being in the world in an attempt to adhere to 'neurotypical' norms. She described how she has experienced the diagnosis as "permission to be kinder to [herself]", in the form of lifestyle changes that accommodate her social and sensory needs. For example, she has sought and obtained 'reasonable adjustments' in the workplace, such as a quieter office space and permission to work part-time from home. She has also joined an online community of autistic women, which in turn has led to rewarding and mutually supportive ‘real life’ friendships with women with whom Charlie does not feel the need to “mask and camouflage” her ‘authentic self’. With these new friends “there’s no pretence , you know, you can just (.) say what’s on your mind. They get you, they understand you”; an implicit contrast with Charlie’s social experiences with the neurotypical majority.

Despite Charlie’s engagement with the ‘neurodiversity’ discourse of autism, the dominance of the ‘medical’ discourse was evident in the power and significance of her diagnosis within her narrative: it is constructed as an essential step in the transformation of her personal identity from “strange” to autistic:

> “if I hadn’t gotten the diagnosis, if it- if it never came to fruition and I just kind (.) you know (.) almost became a catatonic version of myself, and just continued (.) you know, existing like an automaton and- and like just thinking ‘OK, I’m just a bit strange’ (.) you know. I- I can’t (.) if I had- if I had to forecast my life (.) you know, without diagnosis I can only just see it as being very very grey […] [now] it’s so fucking colourful.”

Booker argues that the stories we tell conform to a small number of basic plots or themes, and Charlie’s description of her “colourful” life post-diagnosis was redolent of his description of the classic ‘rebirth’ narrative in which the protagonist is liberated from the “depths of darkness [and] brought up into glorious light” (Booker, 2007, p.194). He notes that this liberation typically involves a significant figure who ‘awakens’ the protagonist[43] and indeed this was the case in Charlie’s narrative with the autistic female psychotherapist serving this key role, setting in train the sequence of events which rescued her from a potentially “grey” and “catatonic” future. Charlie’s encounter with the psychotherapist’s story provided her with a new and personally meaningful subject position to adopt: that of a caring and sensitive autistic woman who is creative and resourceful in finding ways to compensate for the difficulties she experiences as she negotiates ‘neurotypical’ life.

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[43] Booker (2007, p.193) cites Sleeping Beauty as a classic example of the rebirth narrative, with the sleeping princess being awoken from the “dark spell” by the prince.

Discussion

Charlie's story of how she came to identify as autistic included descriptions of various ways in which she had experienced herself as 'different' to others over the years. These experiences clustered around the themes that characterise the diagnostic criteria for autism (WHOS, 1992; APA, 2013), such as apparent difficulties in making sense of social situations, and in coping with change (WHO, 1992; APA, 2013; Fletcher-Watson and Happé, 2019). Perhaps most significant of all in terms of her daily life, however, were her experiences of sensory sensitivities, especially in public spaces such as school and the workplace. Unusual sensory sensitivities have long been known to be associated with autism (Ben-Sasson et al, 2009), but have received comparatively little attention from researchers to date, despite the potentially detrimental effects they are reported to have for individuals' quality of life (Smith and Sharp, 2013; National Autistic Society, 2016; Ross, Elcheson and Cook, 2018; Belek, 2019). Personal accounts like Charlie's therefore play an important part in developing an 'insider perspective' on this poorly understood aspect of autistic experience.

Fricker (2007, p.154) writes of the injustice that results from having important aspects of one's experience "obscured from collective understanding owing to persistent and wide-ranging hermeneutical marginalisation"; a description that encapsulates the consequences of the longstanding neglect of female autism by researchers and clinicians. Charlie's story illustrates the potential effects of this epistemic injustice for the lives of individual autistic women, for whom androcentric constructions of knowledge about autism provide no way of making sense of their lived experiences. During this period of 'hermeneutic absence', Charlie experienced recurrent bouts of stress and anxiety without being able to make sense of underlying contributory factors, such as episodes of social confusion and misunderstandings, or of difficulties coping with the sensory stimulation of working in an open plan office.

Charlie's experience of hermeneutic 'absence' (Bhaskar et al, 2018) was eventually resolved by encountering a new discursive construct of autism: one that was broadly consistent with the 'neurodiversity' discourse of autism (Bagatell, 2010; Robertson, 2010; Brownlow and O'Dell, 2013; Ortega, 2013; Kapp et al, 2013; O'Dell et al, 2013). In contrast to the deficit-focus of dominant medicalised discursive constructions of autism, the neurodiversity discourse construes it as an enriching and important feature of human diversity, albeit one that is currently under-valued and that is associated with difficulties in everyday life as a consequence of living in a world created by and for the neurotypical majority (Robertson, 2010; Brownlow and O'Dell, 2013; Kapp et al, 2013; Strand, 2017; Den Houting, 2019). Furthermore, where the 'medical' discourse of autism constitutes the autistic individual as an oblivious performer of non-normative behaviours which are readily apparent to the "normalising gaze" of others (Foucault, 1978, 1977, p.184), the neurodiversity-informed perspective recognises that – for some - autism may be a largely private experience, not least as a consequence of a lifetime of working hard to conform to societal behavioural norms (Bargiela et al, 2016; Hull et al, 2017). It is rich with possibility as a hermeneutic resource for autistic women, creating a discursive landscape in which it is possible to be autistic and professionally accomplished (including in a caring profession); to be autistic and value close personal relationships; and – above all – to be autistic and female (Simone, 2010; Rowe, 2013; Hendrickx, 2014 and 2015; Kim, 2015; James, 2017; Uher, 2017; Cook and Garnett, 2018).

Charlie's narrative illustrates the potentially transformative effects of the neurodiversity discursive construction of autism at the level of individual subjectivity. Instead of continuing to wonder "what in the hell is wrong with me" as she struggled with aspects of daily life that seemed to come easily to others, she could now construe such difficulties as the inevitable consequence of being autistic in a world created by and for the 'neurotypical' majority. Within her narrative, this was associated with a new sense of self-acceptance and changes in her everyday life in order to mitigate the potentially stressful effects of the 'neurotypical world'. It also led to social transformation for Charlie (Bhaskar et al, 2018), in the form of joining an online community of autistic women where she no longer needs to "mask and camouflage", and which has led to her developing supportive and rewarding 'real life' friendships. This profoundly challenges dominant deficit-focused constructions of autism, which typically depict the autistic individual in stereotypical terms as 'relationally impaired' and lacking in normative social motivation (Broderick and Ne'eman, 2008; Duffy and Dorner, 2011; Milton and Moon, 2012; Milton, 2014; Jaswal and Akhtar, 2019).

In focusing on a single narrative, the findings of this study are not intended to be generalisable and instead are illustrative of the socially contextualised meaning-making of a specific individual (Bhaskar et al, 2018). In particular, Charlie's professional career as a social worker stands in contrast with the current and highly concerning employment data for autistic individuals as a group: in 2016, the National Autistic Society reported that only 16% of autistic individuals were in full-time paid work, and a further 16% in part-time paid work. At the same time, Charlie's personal story serves to highlight the epistemic and ethical limitations of conceptualising autism solely in terms of 'deficits' and 'impairments' (O'Dell et al, 2016; Chown and Leatherland, 2018) and illustrates the need to develop knowledge about autism that fully recognises its rich heterogeneity and associated strengths (Russell et al, 2019). In this way, the individual stories of autistic individuals such as Charlie are transforming the ways that we understand autism (Hacking, 2009).

References

[see main reference list]