# "More than a mask": A multidimensional model of autistic women's experience of camouflaging

Counselling Psychology Doctoral Thesis

Ruth Millman

# Acknowledgements

First and foremost I extend my deep thanks and admiration to my research participants.

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### **Abstract**

Autistic individuals may engage in various strategies to better align with non-autistic social stereotypes; most commonly termed camouflaging. Previous research has suggested that autistic women are more likely to camouflage than autistic men. However, there is debate concerning the nature of any gender differences, how best to define and measure camouflaging and its impact on health and well-being. This study explores how nine autistic women conceptualise, experience and engage in camouflaging. A narrative approach is used to analyse the data, in particular, thematic analysis and the narrative tools of broadening, burrowing and restorying.

Four over-arching themes were generated from looking at the women's stories. The first theme was "camouflaging as a multifaceted and individualised process", which captured the breadth and variety of each participant's camouflaging repertoire. The subthemes included methods of camouflaging, awareness of camouflaging, and individualised process. The second theme was "camouflaging and relationships", with the subthemes of camouflaging inhibiting and enabling relationships, camouflaging within close relationships, and authenticity versus intimacy. The third theme was "societal pressure", which explored the effect of sociocultural factors on the participants' camouflaging. The subthemes included, pressure to conform to a non-autistic majority, camouflaging as protection, and interaction between gender and camouflaging. The final theme was "diagnosis and camouflaging", with the subthemes of pre-diagnosis experience of camouflaging, diagnosis revealing and reframing camouflaging, restorying the past, and future camouflaging.

The findings support viewing camouflaging within a multidimensional and intersectional frame, that acknowledges how co-morbidity, gender, ethnicity, age (and other identity factors) affect the type of adaptive repertoire individuals use and their experience of it. The dynamic nature of camouflaging, and the women's relationship to it, is captured, including the impact of diagnosis. Considering camouflaging in this multidimensional way may help clinicians to better assess and support autistic people. Further research is needed to consider how factors such as co-morbidity and socio-cultural background may influence camouflaging and impact mental health.

# Statement of authorship

This dissertation was written by Ruth Millman and gained ethical approval from the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University. It is submitted in partial fulfilment of the requirements of these institutions for the Degree of Doctor of Counselling Psychology. The author reports no conflicts of interest, and is alone responsible for the content and writing of the dissertation

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## 1.Introduction

Autistic writers and advocates have long since described "pretending to be normal" (Holliday Willey, 1999). Adapting their behaviour and whole way of being to better align to the non-autistic people around them. It is only very recently that the scientific community has started to explore what this experience is like for autistic people and the consequences on their lives. Most notably, performing in stereotypically non-autistic ways (camouflaging) has been linked to the under-diagnosis of autistic women and girls. Previous theories that autism is predominantly seen in men have now been corrected, with new studies indicating a ratio of 3:1, males to females (Loomes et al., 2017). Research has suggested that the camouflaging of autistic traits is crucial in why autistic women have been (and continue to be) overlooked for diagnosis.

Studies into camouflaging have begun to define and operationalise the experience. Quantitive research has started to explore prevalence within different groups, the possible cognitive processes involved, and the consequences of camouflaging. However, there is a great deal of variation in how camouflaging is measured, and it remains unclear how best to define this phenomenon. What is consistent within the literature is the extreme effort many autistic people have to expend to keep up with non-autistic social performances. There is evidence that camouflaging may link to higher levels of mental illness, although the exact nature of this relationship is not yet evident. The connection between camouflaging and mental illness is significant as autistic individuals experience more psychiatric conditions and greater suicidality (Cassidy et al., 2014).

A small number of qualitative studies have provided some insight into the lived experience of camouflaging for autistic people (Hull et al., 2017; Schneid and Raz, 2020; Allely, 2018). In recent years, it has been argued that to fully understand camouflaging, attention must be given to the social and cultural context in which autistic people are situated. Particular significance has been given to the role of discrimination and stigma in leading autistic individuals to seek assimilation to non-autistic norms as a bid for safety. This study explored camouflaging using a qualitative narrative approach to elucidate the lived experience of camouflaging and the impact of the participants' histories and backgrounds.

There has been debate about whether camouflaging should be viewed as an aspect of the "female autism phenotype". Results have shown that people across the gender spectrum camouflage, although a greater prevalence with autistic women appears to remain. As autistic tattoo artist Charl notes:

"I find that being a female I am expected to behave a certain way to fit in socially which is why I have spent so much time masking." (NAS website, 2021).

Camouflaging has also been associated with higher levels of psychological distress in autistic women (Beck et al., 2020). The role camouflaging may play in mental health is of particular concern as research has shown autistic women are more likely to experience depression and anxiety (Lai et al., 2019; Mandy et al., 2012) and have higher rates of suicide than other clinical and non-clinical populations (Cassidy et al., 2014). It has been argued that autistic women have been (and remain) missed by services, as a consequence of camouflaging and male biased autism stereotypes (Head, et al., 2014; Giarelli, et al., 2010). This is particularly relevant to psychotherapists who are likely to meet undiagnosed autistic women seeking support for mental distress, and as a result of mis-diagnosis

(Belcher et al., 2020). Better understanding camouflaging is essential in order to address the lack of appropriate support autistic women face (Gould, 2017).

As an existentially trained psychotherapist, camouflaging can also be seen as an example of responding to the "look" of the other. Seen through this philosophical lens, camouflaging forms part of the tension between becoming defined by others or embracing our essential freedom. This is an anxiety provoking dilemma, that is an essential part of the human experience, and fundamental to our way of relating to others and the world. Consequently, it is important for psychotherapists to understanding camouflaging, not merely as a potential additional "autistic trait" but a crucial part of an individual's lived experience.

#### Research questions:

- How do autistic women, between the ages of 25 and 40 years old, conceptualise and experience camouflaging?
- How does the experience of camouflaging for autistic women, between the ages of 25 and 40 years old, change over time.

This study explores how autistic women experience and conceptualise camouflaging, including how this changes over time. Extending the current literature the study will consider the sociocultural context of individuals, considering the impact of not only gender but other social identifiers on the experience of camouflaging. Furthermore, although the experience of autistic women has recently received greater recognition in academia and the public sphere, the majority of research still centres on the experience of men and boys. The current study aims to address these these gaps within the literature.

The study was conducted during COVID pandemic and consequently interviews took place virtually as well as face to face. Research into the impact of the pandemic has found that for some autistic adults stress levels, sleep disturbance and psychopathological status improved, due to reduced exposure to social and sensorily demanding environments (Lugo-Marín et al., 2021). The participants' experience, supporting that of other autistic researchers and advocates (Cassidy et al., 2020), revealed that the constrictions due to lockdown measures forced employers and services (e.g. health care) to make beneficial adaptations. For example, online therapy, home working, and reduced social interaction, decreased the pressure to camouflage and subsequent stress for some participants. Despite these benefits, the pandemic has also had negative consequences for some autistic people increasing anxiety around access to medication, safety, and social support. The results from this study point to the role camouflaging, and the reduction of camouflaging, in determining an autistic person's experience of the pandemic.

In the following chapters, I will first examine the existing literature on camouflaging, providing context for the study. The next chapter will explore the methodology, including epistemological grounding and theoretical frameworks relevant to the study. I will specifically examine the use of a narrative approach and its relevance to the examination of camouflaging. The findings are then presented in the subsequent chapter, followed by a discussion of their relevance to the research field. Finally, I will explore the limitations and strengths of the study, clinical implications from the findings and possible avenues for future research.

## 2. Literature Review

This chapter will provide an overview of the literature with relevance to autistic camouflaging. Initially, key terminology will be explored, then a brief summary of the history of autism and the current research on prevalence. Following this a literature review of relevant research will be discussed, including the justification for this study's rationale.

#### 2.1 Conventions

#### Abbreviations:

ASD Autism Spectrum Disorder

ToM Theory of Mind

DSM Diagnostic Statistic Manual

CAS Critical Autism Studies

RRB Restrictive and repetitive behaviours

AS Asperger's Syndrome

ADHD Attention Deficit Hyperactivity Disorder

#### Transcript Notations:

... Significant pause

[] Additional material added for context

() Non-verbal communication

## 2.2. Terminology

#### 2.2.1 Autism and Autism Spectrum Disorder

Within the Diagnostic Statistical Manual (DSM-5, American Psychiatric Association (APA), 2013), the term Autism Spectrum Disorders (ASD) is used. However, many autistic individuals find the term "disorder" stigmatising and reflective of a pathologising discourse that negates the natural neurodiversity, of which autism is a part (Bury et al. 2020). Research has also shown (Kenny et al., 2016) that many individuals prefer identity-first terms like "autistic" rather than the person-first language, such as "person with autism". Identity-first language recognises that autism is an essential part of an individual's personhood, rather than a disorder in need of curing (Sarrett, 2012). In recognition of this, throughout the study, the terms autism and autistic person will be used. However, it is acknowledged that individuals vary in how they choose to define themselves, and the terms participants use to discuss their diagnosis will be mirrored by the interviewer and within the transcript.

#### 2.2.2. Camouflaging

Within this study, the term "camouflaging" will be defined to participants as:

"Consciously or unconsciously, hiding your autism from others, for example by using coping skills or strategies during social situations."

This is based upon the definitions used within the literature. Lai et al. (2016:693) describe camouflaging as:

"(consciously or unconsciously) compensating for and/or masking difficulties in social and interpersonal situations".

The word camouflaging is being used (as opposed to masking or compensation) as it is currently the most frequently used term to describe this phenomena in the literature.

However, the appropriateness of this term will be explored later in this study.

#### 2.2.3. Gender and sex

Both the terms gender and sex will be referred to. In line with most academic writing, the term "sex" (female, male, intersex) will be used to denote the biological features of a per-

son (chromosomes, sex organise, hormones); whereas the term "gender" (women, men, non-binary) refers to differing social identity and roles (Schudson et al., 2019). However, it is noted that differing definitions maybe used within the wider literature. One of the aims of this is study is to examine how social and cultural expectations and roles impact autistic peoples lives and camouflaging, consequently issues of gender and gender roles are of particular interest. This is in line with other studies such as Hull et al. (2017) and Livingston et al., (2019b), who explore gender and camouflaging, as opposed to sex.

## 2.3. Definition and history of autism

There are multiple narratives concerning how autism is perceived and defined (Gray, 2001). Historically it has been predominantly viewed within a medicalised paradigm. The word "autism" (an abbreviation of "autoeroticism") was first coined by Eugen Bleuler in 1911 to describe the self-preoccupation in some schizophrenic patients (Tantam, 2013). The term was then adopted by Leo Kanner within his description of "infantile autism" characterised by difficulties communicating and relating to others, and an intense desire for routines and rituals (Lai and Baron Cohen, 2015). In 1944 Hans Asperger also documented a similar pattern of behaviour and abilities, specifically social isolation, social difficulties and idiosyncrasies (Frith, 1991). However, the discussion of children with these characteristics was not referenced in the English-speaking academia till 1962, through the work of Van Krevelen and Kuipers (1962). Wider recognition of the diagnosis then came through the work of Lorna Wing and her description of Asperger's Syndrome (Tantam, 2013). Accordingly, it is only in relatively recent times that there has been any scientific or clinical understanding of autistic individuals. Prior to this autistic people were generally:

"brought to the attention of the medical profession [and] seen either as severely deprived of social stimuli or chronically insane." (Bumiller, 2008:969)

Wing's proposal of the "autism spectrum" was supported by empirical studies in the 1980's highlighting typical autistic features in individuals both with and without intellectual development and language delay (Tantam, 2013; Lai and Baron Cohen, 2015). Wing described the similarities between Kanner's description of autism and individuals with Asperger's syndrome (AS). Both presentations included impaired social interactions, for example impairment in the use of non-verbal communication, difficulty in developing peer relationships, lack of social and emotional reciprocity, and restrictive and repetitive behaviours, such as stereotyped and repetitive motor mannerisms, inflexible adherence to routines and rituals, obsessional focus on particular interests or objects (Attwood, 2006). The distinguishing factor being that those diagnosed with AS had no clinically significant cognitive or language delays (Attwood, 2006). Tantam (1988) further explored the clinical picture of AS, including its association with individuals who desired social relationships but struggled to achieve this due to social and communication difficulties (Tantam, 1988). Furthermore, the greater self-awareness of those with AS often meant a painful realisation of their difference and difficulties relating to others (Tantam, 1988) and subsequent anxiety and depression (Wing, 1981a).

In the latest version of the Diagnostic Statistical Manual (DSM-5), autism is defined as a neurodevelopmental disorder characterised by the following symptoms (APA, 2013); "persistent deficits in social communication and social interaction across multiple contexts" and "restricted, repetitive patterns of behaviour, interests, or activities" (including sensory differences. Symptoms must be present in the early developmental period and cause "clinically significant impairment in social, occupational, or other important areas of current functioning" (APA, 2013). However, for some individuals, it is not until later child-

hood or adulthood that their autistic characteristics are recognised, initiating a diagnostic assessment.

#### 2.3.1. Diagnostic criteria

Within the latest version of the DSM, previous diagnostic subgroups such as Asperger's syndrome, autistic disorder, and pervasive developmental delay not otherwise specified (PDD NOS) have been replaced by the collective term Autism Spectrum Disorders (ASD). This shift was made in part to reflect the position that these diagnoses were different manifestations of the same underlying condition (Sanders 2009). However, many within the autistic community criticised the change, as they felt the separate terminology accurately represented significant differences in the lived experience and could lead to difficulties accessing diagnoses and services (Parsloe and Babrow, 2016). The usefulness and impact of these terminological changes have been much debated (Hughes, 2014), highlighting the difficulty in accurately representing the complex and varied autistic experience.

#### 2.3.2. Aetiology

Initially, autism was classified as a psychological disorder linked to a failure of parental nurturing. However, numerous studies have debunked this theory and since revealed overwhelming evidence of innate factors (Tantam, 2013). Although the aetiology of autism is still unclear, research has indicated it is a multifactorial condition resulting from various genetic factors, neuroanatomical and immune abnormalities (Rynkiewicz et al., 2016). Genetic studies into autism point to mutations that divert from the "typical" neurodevelopment beginning in the womb (Park et al., 2016). There is significant heterogeneity in the genetic variation (and interaction with environmental factors) linked to autism, and some

researchers have begun using the term "autisms" to reflect the possibility that there are different biological aetiologies (Happe, 2019). In some autistic people differences have been noted in the structure of axons and overgrowth in cortical and subcortical grey matter in the early years of brain development (Park et al., 2016). Functional magnetic resonance imaging (fMRI) highlights underconnectivity and decreased activation in neural networks involved in socioemotional processing (Park et al., 2016). For example, hypoactivation in the anterior cingulate cortex, fusiform gyrus and amygdala, which are involved in response inhibition, facial and emotional recognition, and emotional memory (Polsek et al., 2011). An examination of the aetiology of autism is beyond the scope of this introduction but can be read within Tantam (2013).

#### 2.3.3. Neurodiversity

Many individuals find getting a diagnosis profoundly helpful in understanding themselves and their past experiences and gaining access to support and services. As one woman described:

"Autism puts my life into context, and this on its own facilitates self-development." So correct labels matter." (Online blog -Teasperger, 2018)

However, over the last 20 years, autistic individuals, advocates, and academics have critiqued a deficit-based understanding of autism and argued neurological conditions, including autism, are part of natural human variation. The term neurodiversity, coined by Singer in 1998, refers to the variation in individual brain functioning (i.e. learning, attention, mood and other mental functions) that is seen in autism, ADHD, dyslexia, dyspraxia and other diagnoses (Singer, 2017). The term "neurotypical" refers to individuals who's do not have any neurological difference, and who's brain functioning and development aligns with the majority (Owren and Stenhammer, 2013). The Neurodiversity movement has campaigned for the natural variation of neurological conditions, including autism, to be

celebrated (Kapp et al., 2013). Rather than pathologising autism, they argue that individual differences should be accepted and accommodated as with all other aspects of diversity and protected characteristics (e.g. racial or religious differences) (Broderick and Ne'eman, 2008). Furthermore, that there should be a focus on strength-based traits and identities, rather than purely referencing deficit and symptoms (Sarrett, 2012). Those supporting the neurodiverse paradigm often align themselves with civil rights and disability rights campaigns and have developed a wide range of academic literature and popular media content highlighting the importance of this perspective (Bumiller, 2008). This research is based upon the neurodiversity paradigm, whilst acknowledgement the validity and usefulness of diagnosis.

# 2.4. Prevalence of Autism

Prevalence studies suggest that around 1% of the population are on the autistic spectrum (Rynkiewicz et al., 2016). Research into the proportion of autistic individuals with an intellectual disability indicates a mean of 52.6%, although there is some variability in this ratio across studies (Emerson and Baines, 2010). Since the work of Kanner and Asperger, autism has been viewed as a predominantly "male" disorder (Baldwin and Costley, 2016; Rivet and Matson, 2011; Lai et al., 2016), with a general acceptance that males are diagnosed four times more often than females (Whiteley et al., 2010), increasing to between 8:1 and 9:1 in populations with no co-morbid intellectual disabilities (Mandy et al., 2011). Recent large-scale studies, however, have indicated a more negligible male bias (Lai et al. 2016; Rivet and Matson, 2011), most recently suggesting 3:1 (males to females) as opposed to 4:1 (Loomes et al., 2017). It has been argued that women are under-diagnosed because their autism presents differently to men, and diagnostic tools are based on male-biased samples (Gould and Ashton-Smith, 2011; Lai et al., 2016; Tierney and Burn, 2011;

Kopp and Gillberg, 1992). Studies have suggested that females exhibit greater awareness of and desire for social interaction, fewer repetitive and restrictive behaviours (RSB) (Lai et al., 2016; Leekam et al., 2007) and less aggression and hyperactivity (Rivet and Mason, 2011). It has been argued that the less overt presentation, more common in women, leads to under and misdiagnosis (Ratto et al., 2018). It is noteworthy that these studies do not reference whether the participants identify as cis or transgender. More recently, research has begun to explore gender diversity with the autistic population and impact on diagnosis, but this is still in its infancy (Pecora et al., 2020; Warrier et al., 2020). However, academics have argued that there is no specific female autistic phenotype, and this "less overt" presentation of autism can be seen across the gender spectrum (Pearson and Rose, 2021).

#### 2.5. Systematic Literature Review

The growing body of research exploring how individuals camouflage their autistic traits within social situations (Hull et al., 2017) will now be explored. A literature search to identify studies that focused on autism and camouflaging behaviour was conducted. The key terms Asperger\* syndrome, Autis\*, camouflag\*, mask\*, and compensation were used within various databases, namely PsychInfo, Psych articles, PEPWeb and Google Scholar. These search criteria were used on multiple dates to capture the most recent studies as the research progressed; 22/5/2021, 15/2/2018, 4/4/2017. After removing those items from unpublished articles, thesis, or those that did not reference camouflaging, fifty research papers were identified (see appendix x for a breakdown of these studies). Three papers did not examine camouflaging specifically but reference it as part of the discussions. There were twenty-five quantitative studies, four using mixed methods, ten meta-

analysis or review papers, and eight qualitative research studies. Based on this research, the concept of camouflaging and current theories will be examined.

#### 2.5.1. What is camouflaging?

Camouflaging can be viewed as the way a person attempts to disguise characteristics perceived to be socially undesirable when relating with others (Dell'Osso et al., 2020). Adjusting our behaviour and appearance to control or guide the perception others have of us (what Goffman titled "self-presentation theory" 1990) is considered a universal phenomenon. A particular aspect of this has been termed "passing", which refers to altering one's presentation to be seen as a member of an identity group different from ones own (Evans, 2017). For example, individuals with an invisible disability or chronic illness may attempt to pass to avoid stigma and discrimination (Valeras, 2016). Passing involves complex power dynamics that can be difficult to navigate; for example, an individual may experience reactive passing (being mislabelled as something one is not) or active passing (presenting a false image). Passing can involve difficult decisions between the potential benefits of disclosure and safety from hiding differences (Valeras, 2016).

For many years autistic individuals have anecdotally reported "pretending to be normal" and attempting to pass as non-autistic. Hendrickx's (2015) describes, from her personal and professional experience, constantly self-censoring to avoid any social faux pas, hiding routines and rituals and creating "guidance sheets" to help manage social situations. For autistic individuals who struggle to identify and internalise social norms, the experience of adapting their social presentation is even more challenging (Ryan and Raisanen, 2008). What is defined as socially appropriate conduct is dictated by the rules and expectations shared with others (Tantam, 1998). These agreed-upon conventions create underlying

principles around how social actors should behave that can be generalised to novel situations (Tantam, 1998). Although there is variation in individuals' understanding and skill in using these social rules, autistic people generally have difficulties outside the typical range (Wing, 1981a). As Wing (1981a: 116) highlights, the non-autistic social conventions that govern the majority of interactions are complicated, fluid and nuanced:

"These rules are unwritten and unstated, complex, constantly changing, and affect speech, gesture, posture, movement, eye contact, choice of clothing, proximity to others." (Wing, 2018a:116)

Autistic individuals may be aware of their difficulties in understanding these non-autistic social performances, and striving to overcome them can be a primary motivator for camouflaging behaviour (Wing, 1981a).

As research began to explore the female autistic experience specifically, the issue of masking autistic traits was further identified. Baldwin and Costley's (2016:490) study into the general experience of 82 autistic women found participants discussing learning phrases and developing a list of appropriate public responses. Similarly, Tint and Weiss's (2017) research into the service experiences of autistic women found participants describing masking their autistic traits and consequently having their difficulties dismissed or denied. Further exploration into the lives of women autistics revealed individuals hiding autistic traits to appease and avoid conflict, and their distress being missed by professionals (Bargiela et al., 2016).

#### 2.5.2. Definition of camouflaging

Within the academic literature, various terms have been used to describe how autistic individuals may adapt their way of being within social settings; "camouflaging", "masking" (Lai et al., 2016), "compensation" (Livingston et al., 2019b), "compensatory learning" (Frith 1991). These terms vary in definition and emphasis, with the first three most commonly used (Tubio-Fungueirino et al., 2021).

In one of the first studies to specifically explore the issue of autistic camouflaging, Lai et al. (2016:693) used the term camouflaging and described the behaviour as:

"(consciously or unconsciously) compensating for and/or masking difficulties in social and interpersonal situations".

Here camouflaging is conceptualised as a coping strategy used to improve or manage the outcomes in a particular environment instead of a feature of autism per se (Fombonne et al. 2020). This initial definition was supported by Hull et al. (2017), the first qualitative study to look specifically at camouflaging. The findings identified masking and compensation as the key aspects of camouflaging (Hull et al., 2017). Masking was defined as concealing one's autistic characteristics and developing a non-autistic persona to hide behind in social interactions; for example, hiding or suppressing stimming behaviours and adopting or creating a role or character when engaging with others. Whilst compensation was defined as developing methods to meet the gap between autistic functioning and the social expectation of the majority non-autistic environment; e.g. imitating the facial expressions, body language, learning set phrases, rules or guidelines to assist them in neurotypical interaction (Hull et al., 2017). In a subsequent study, Hull et al. (2019) tested the validity of a novel self-report questionnaire for camouflaging, adding a category of "assimilation" (e.g. forcing or avoiding interaction to best fit in with others) alongside masking and compensation as a three-factor construct of camouflaging.

Livingston et al. (2019b) define the construct of "compensation", differentiating this from camouflaging. Compensation is defined as adopting behaviours or cognitive processes to socially perform in a neurotypical (non-autistic) manner (Livingston et al., 2019b). Camouflaging can include compensatory techniques but may also include other behaviours that do not involve an additional process to present as non-autistic, such as putting their hands in their pockets to hide stimming behaviour (repetitive movements, e.g. flicking or flapping hands) (Livingston et al., 2019b).

Livingston and Happe (2017) argued that autistic people might use a range of strategies when relating with others, namely "shallow and deep compensation." The former refers to superficial and inflexible ways of managing social interaction, such as specific rigid behavioural rules, for example, asking lots of questions when getting to know someone or making eye contact. These behaviours can be helpful in social situations but, when applied inflexibly, can lead to misunderstandings and faux-pas (Lai et al., 2019). Deep compensation involves a more sophisticated and adaptable understanding of social interaction and attribution of others mental states (Lai et al., 2019). For example, detail-focused analysis of social situations and other people, including comparison to past experiences (Livingston, et al., 2019b). Livingston and Happé (2017) argue that deep and shallow compensation may reflect differing neural activation patterns. They suggest that research into compensation and potential neural and genetic markers may reduce misdiagnosis and under-diagnosis of autism (Livingston and Happe, 2017). Livingston et al.'s (2019b) study also identified shallow and deep compensation, but then further differentiates "behavioural masking" as regulating existing actions rather than creating new processes, for example, not talking too much or smiling more.

Corbett et al. (2021) divide camouflaging into four components. Masking refers to the regulation (increase or decrease) of social behaviours to lessen the surface appearance of autism (e.g. suppressing repetitive behaviours or giving eye contact). Secondly, mimicry uses novel or adapted behaviours to copy the behaviour of peers (e.g. facial expressions, or rehearsing and scripting conversations). Thirdly, accommodation strategies do not alter social behaviour, instead managing interactions (e.g. using humour) or seeking environments where social skills are not needed. Finally, compensation refers to strategies to make intellectual inferences to indicate the required social behaviour (e.g. pattern recognition to determine social rules).

As research into the area of camouflaging has developed over the last ten years, in some respects, the issue of the definition has become more complicated. One aspect of complexity is how camouflaging may overlap with general behaviour management strategies such as Goffman's (1990) impression management. Many researchers highlight the concealing or modifying of autism-specific behaviours as the key differentiating factor (Lai et al., 2016) between impression management and camouflaging. In Schneid and Raz (2020:4), participants described camouflaging behaviour as hiding autistic traits and linked explicitly to increased internal dissonance and feelings of alienation; whilst impression management was a broader concept that included camouflaging, but also more constructive strategies of communication to achieve social acceptance or status (e.g. using alternative forms of communication).

Robinson et al. (2020) examined compared CAT-Q scores with the Big Five personality traits (openness, neuroticism, conscientiousness, extraversion, and agreeableness) and emotional intelligence (EI) traits, finding differences between the personality traits corre-

lated to camouflaging, with those previously linked to reputation management. The authors argue that negative associations between extroversion and camouflaging and El and camouflaging found in the non-autistic sample but not in the autistic group suggests that camouflaging is qualitatively different from other self-presentation strategies (Robinson et al., 2020). How exactly camouflaging is different to, or overlaps with, concepts such as impression or reputation management is still to be determined (Robinson et al., 2020).

Dell'Osso et al. (2020) theorise that camouflaging may be trans-diagnostic and present within the non-autistic population, although correlated to subclinical autistic traits. The idea of camouflage being trans-diagnostic has also been proposed by Livingstone and Happe (2017), who argue that compensation strategies are used by individuals with neurodevelopmental conditions other than autism. Research (Quinn and Madhoo, 2014) linking the under-diagnosis of attention deficit hyperactivity disorder (ADHD) in girls and women to masking behaviour and lower levels of externalising symptoms provides further evidence of the possible utility of a trans-diagnostic framework.

The research into camouflaging has begun to map out the "camouflaging territory", but the various conceptualisations highlight the need for further exploration to capture and most usefully represent this complex phenomenon (Lawson, 2020).

#### 2.5.3. Discrepancy based approaches to measuring camouflaging

The first attempt to measure camouflaging was conducted by Lai et al. in 2016. The authors used a discrepancy based approach, comparing an individual's internal functioning to external observer-rated behaviour. Within this model, camouflaging is determined by

the degree to which the external behaviour is "less autistic" than the internal score. Lai et al. (2016:693) operationalised the process as:

"discrepancy between the person's 'external' behaviour presentation in social-interpersonal contexts (measured by the Autism Diagnostic Observation Schedule ADOS) and the person's 'internal' status (dispositional traits measured by the Autism Spectrum Quotient (AQ) and social cognitive capability measured by the "Reading the Mind in the Eyes' Test)."

The study examined the behaviour of 60 autistic men and women, comparing the observational measure (ADOS) with a self-report questionnaire of autistic traits (AQ), and the Reading the Mind in the Eyes test which assessed participants' ability to correctly understand the emotions and intentions of others. The test consists of a series of photos of different real faces (although only the eyes are shown) expressing a wide range of emotional states and thinking. It is noteworthy that various studies have shown the validity of the AQ is questionable, and many clinicians would not use it in practice (Fusar-Poli et al, 2020; Lundqvist and Lindner, 2017) The data found camouflaging behaviour in both autistic men and women, although on average, women had higher scores than men. There was substantial variability across the genders and no link between intelligence or age and camouflaging ability. Consequently, Lai et al. (2016) suggest camouflaging may be associated with personality, motivational or contextual factors, or specific cognitive abilities.

Subsequent studies continued to use this quantitive discrepancy based method to examine camouflaging behaviours. Schuck et al. (2019) also compared ADOS and AQ scores (although they did not include the "Reading the Mind in the Eyes" test) and also found more camouflaging in female participants.

#### 2.5.4. Self-report based approaches to measuring camouflaging

Self-report measures have been used as an alternative to the discrepancy model. To date, the most used questionnaire has been Hull et al.'s (2019) 's Camouflaging Autistic Traits Questionnaire (CAT-Q). Utilising data gleaned from their previous qualitative study (Hull et al., 2017) combined with suggestions from autism researchers, clinicians and autistic adults, the authors created a 48 item self-report survey, exploring respondents self-perception of camouflaging behaviours (e.g. "I monitor my body language or facial expressions so that I appear relaxed") (Hull et al., 2019:825). The questionnaire was administered online to 354 autistic and 478 non-autistic adults. The authors reduced the number of questionnaire items to the twenty-five with the highest factor loadings. The findings identified three common factors within the questionnaire; "compensation" (strategies used to compensate for difficulties in social situations), "masking" (strategies used to hide autistic characteristics or portray a non-autistic persona), and "assimilation" (strategies that reflect trying to fit in with others in social situations).

Livingston et al. (2020) used the self-reported strategies of 117 adults (58 autistic, 59 non-autistic, 95 females) to create a 31-item Compensation Checklist. The authors note that whilst the CAT-Q has a compensation sub-scale, this does not capture all the possible strategies and focuses on "shallow" rule-based techniques (Livingston et al., 2020). The Compensation checklist split items into four categories; masking, shallow compensation, deep compensation and accommodation. Masking was defined as actions that involved regulating pre-existing behaviours, for example, smiling or giving eye contact, or decreasing unattractive behaviours such as talking too much. These were simple actions that helped the person to blend into the background rather than support social interaction. Shallow compensation concerned simple imitation without regard for context (e.g. laugh-

ing after joke cues), and therefore often transferred poorly to other situations and could be "seen through". Deep compensation involved complex flexible strategies, such as pattern detection and internal data modelling, to understand others and determine action, which can become automatic (Livingston et al., 2020). Accommodation concerned strategies to mitigate but not necessarily alter a person's cognitive difference, e.g. changing the environment.

The study found that the four strategy types were moderately correlated and that participants reported using a wide range of techniques (Livingston et al., 2020). However, there was low internal consistency within the subtypes, which indicate further examination into the validity of these distinctions in compensation is required. Higher compensation scores were correlated to autism diagnosis, autistic traits and high educational level. However, the link to diagnosis was explained by autistic traits and education level, suggesting that compensation increases with the number of autistic traits a person is aware of rather than a feature of diagnosable autism. Furthermore, the link to educational level suggests that a more extensive compensatory repertoire may be possible with higher intellectual ability, although the link between IQ and education is not straightforward (Livingston et al., 2020). The sample was predominantly female and did not include individuals with intellectual disability, or gender diverse people, limiting the generalisability of the findings and its potential to represent the entire repertoire of camouflaging strategies. Also, the sample only included participants with a diagnosis, potentially missing data from individuals whose camouflaging had prevented diagnosis.

#### 2.5.5. Limitations of methods for measuring camouflaging

Each method has strengths and weaknesses. The discrepancy approach is conceivably more rigorous by operationalising camouflaging and assessing through validated measures (Hull et al., 2019). It also may be better at capturing the unconscious element of the camouflaging repertoire, as it does not entirely rely on self-reporting; however, this has yet to be fully examined. On the other hand, whether proxy measures, such as the Reading Minds in the Eyes (Wood-Downie et al., 2021), are a valid and sufficient representation of internal autistic traits is debated (Hull et al., 2020a). Alternatively, if studies use a self-report measure (e.g. AQ) to establish an internal measure of social understanding, they are limited by the participants' ability to self reflect and communicate (Lai et al., 2016). Furthermore, as previously mentioned, there is debate about the validity of the AQ as a screening tool, particularly in terms of inadequacy in identifying the traits of autistic women (Ashwood, et al., 2016; Murray et al., 2017).

The validity of using observational measures, such as the ADOS is questionable. The ADOS is conducted within clinic based settings and therefore can not evaluate camouflaging in general life (Fombonne, 2020). In addition the ADOS includes items in which assessors rate internal states (e.g. the person's ability to understand the inner world of others), which makes the use of the ADOS as a comparative measure to a separate test of internal autistic characteristics questionable (e.g. AQ) (Fombonne, 2020). Secondly, using observational data to establish external traits may be confounded by other variables, such as the level of anxiety influencing the participants' performance (Lai et al., 2016). Furthermore, the observations may be affected by the identity and biases of the rater (Lai et al., 2016). In particular, there has been criticism that studies overwhelmingly consist of non-autistic researchers analysing autistic participants, and their non-autistic bias may limit or skew the data (Milton, 2012). More recent studies have supported the use of labora-

tory-based cognition assays in future research, rather than the ADOS (Lai et al., 2019). However, there is debate around the generalisability of such data (Morrison et al., 2020). Perhaps most importantly, the discrepancy model is using two separate measurements of the same construct (autism) to assess a new construct (camouflaging); as Fombonne (2020) highlights, it is assumptive to conclude that the calculated difference equates to camouflaging.

The discrepancy model cannot incorporate failed attempts to camouflage, which is critical as autistic people have described that they are not always successful in this exhausting process (Hull et al. 2019). The self-report approach (i.e. CAT-Q) can include failed camouflaging, as respondents are asked about their intention of camouflaging instead of measuring only success. Furthermore, self-report assessments are easy to conduct, gleaning information from various situations (Williams, 2021) and multiple formats (e.g. online Hull et al., 2019). However, questionnaires limit research to those who can reflect on their behaviour and communicate with minimal adaptions from the standard non-autistic research protocols, disregarding autistic people with significant learning disabilities and/or language differences (Hull et al. 2019:830). They also may not capture unconscious camouflaging, which has been repeatedly noted by academics and autistic individuals (Lai et al., 2016).

The CAT-Q does demonstrate reasonable internal consistency and temporal stability over a three-month retest period (Hull et al. 2019); however, correlations between the multifactorial model have been modest (Livingstone et al. 2020; Hull et al. 2019), and more research is needed to ascertain if the CAT-Q truly represents a general score of camouflaging. In addition, correlations with social anxiety scores were higher than with an autism

measure (Hull et al 2019) suggestive of confounding variables (Fombronne, 2020). Further research is needed to differentiate the CAT-Q from other confounding factors (Fombronne, 2020; Williams, 2021).

A fresh approach may be to focus solely on observational methods of measuring camouflaging, avoiding the issue of creating a proxy internal measure, for example, comparing situations where participants are actively camouflaging or not (Hull et al., 2019; Williams, 2021). Depending on the construction of such studies, various limitations still apply, whether participants can overtly control their camouflaging, or the possible reliance on non-autistic observers to determine when camouflaging behaviour occurs, and the generalisability to non-experimental settings. Camouflaging measures are still in the early stages and require a more significant demonstration of construct validity and reliability (Fombronne, 2020; Allely 2018). As Corbett notes:

"Due to the subjective nature of behaviour, the methods used to quantify camouflaging in ASD vary significantly" (Corbett et al., 2021:129).

Therefore, further exploration, particularly concerning conceptualising the phenomena, is required.

#### 2.5.6. Camouflaging and Women

Quantitative and qualitative studies have confirmed that camouflaging can be seen in autistic people across the gender spectrum (Lai et al., 2016; Hull et al., 2019) and from childhood through to adulthood (Dean et al. 2014; Halsall et al., 2021; Cook et al., 2021). However, camouflaging has been particularly linked to autistic women, including being seen as part of a female autistic phenotype (Hull et al., 2017; Kirkovski et al., 2013; Baldwin and Costly, 2016). In clinical observations nearly 20 years ago, Attwood (2006) sug-

gested that the female autistic profile was subtly different, including fewer aggressive behaviours, greater motivation and ability to learn social skills, imitation skills, and more socially accepted specialist interests. Later research supported the theory that women:

"exhibit better expressive behaviours (reciprocal conversation, sharing interests, integrating verbal/non-verbal behaviour, imagination, adjusting behaviour by situations." Lai et al. (2016:14)

Also, various studies have noted that girls have more interest in social interaction and a greater ability to imitate others (Baron-Cohen et al., 2011; Rivet and Mason, 2011). Hiller et al. (2016) found autistic girls had a strong desire to fit in and were more likely to use mimicry to engage socially, including "imitating adult interactions, peer interactions, or social interaction seen on television or in movies" (Hiller et al., 2016:81). Crucially, research has suggested that this socially appropriate behavioural repertoire does not indicate girls have a better understanding of non-verbal cues and social rules (Lai et al. 2016, Hiller et al., 2016). Instead, the findings suggested that cognitively able girls employ these strategies to examine and carefully process social interaction to conceal underlying difficulties (Hiller et al., 2016). Comparative findings from self-report data and parental observation supported the hypothesis that girls were overtly learning these skills but not always putting them into action (Head et al., 2014). Sedgewick et al. (2016) reported that autistic girls had greater motivation to socialise than autistic boys but had more significant struggles in maintaining relationships and managing conflict than non-autistic peers. These findings support the theory that autistic girls may present as socially competent but still experience core social and communication difficulties (Sedgewick et al., 2016).

It is argued that autistic women and girls are able to camouflage their difficulties well enough that others remain unaware of their underlying differences and struggle, leading to under-diagnosis (Kirkovski et al., 2013; Head et al., 2014; Hiller et al., 2014). Dworzynski et al.'s (2012) population-based research into gender differences in the diagnosis of autism in children without an intellectual developmental disorder concluded that girls are less likely to meet diagnostic criteria. Dworzynski et al. (2012) argued that fewer girls are diagnosed because they employ unrecognised adaptive and compensatory behaviours within the assessment process. The study argued that the higher level of depression in girls and poor social understanding suggested that the observed socially adaptive behaviours were due to masking rather than better social skills and understanding (Sedgewick et al., 2016). A review by Kirkovski et al. (2013:2587) noted that girls are more likely to have restricted interests with a social or person-focus, which fit into stereotypes of expected gendered behaviour (e.g. girls being "chatty") and therefore are not recognised as RRBs. It is noteworthy that other researchers have evidence that autistic girls who receive a diagnosis have a higher level of behavioural symptoms than boys (including RRBs) (Gould, 2017), perhaps suggesting that it is not until behaviours are more extreme that they are diagnosed in girls.

Studies indicated that inadequate assessment tools (biased towards male populations) are linked to girls and women being misdiagnosed, denied or experiencing delays in accessing services (Giarelli et al., 2010; Head et al., 2014; Rutherford et al., 2016, Kirkovski et al., 2013). Furthermore, a lack of clinical awareness of the experiences of autistic women and girls (including camouflaging) has been linked to misdiagnosis (Lai et al., 2016; Head et al., 2014). Considering these findings, it is perhaps not surprising that some studies have shown autistic women having significantly higher levels of mental health difficulties (Rynkiewicz and Lucka, 2015) which, in turn, has been linked to the higher use of medication (Howlin and Moss, 2012). Although, it is important to note that research also points

to biological and genetic factors playing a part in gender differences in the prevalence of psychiatric diagnosis (e.g. in social anxiety (Pigott, 1999) and in schizophrenia (Falkenburg and Tracy, 2014)).

### 2.5.7. Gender differences in camouflaging

There is a growing body of research explicitly examining gender and sex differences in camouflaging behaviour. Several studies have reported higher rates of camouflaging in autistic girls. Dean et al.'s (2017) mixed-method study of 96 children (girls, boys, autistic and non-autistic) revealed higher levels of observed camouflaging (e.g. gesture use) in autistic girls in the school playground. Dean et al.'s (2017) 's findings were supported by Rynkiewicz et al.'s (2016) study of 33 autistic girls and boys, using a discrepancy based model comparing the ADOS-2 with a version of the Faces and Eyes test. They found autistic girls using more gestures than boys but making significantly more mistakes on a Faces Test (identifying social communication skills), pointing to girls having poor underlying social skills, but camouflaging through gestures. More recently, Jorgenson et al. (2020) used the CAT-Q to assess camouflaging behaviour in 140 adolescent girls and boys, both autistic and not autistic. Autistic girls had higher camouflaging scores than boys, but only when age and age of diagnosis were not accounted for (Jorgenson et al., 2020). This suggested a more complicated picture of gender differences in camouflaging in children and adolescents. However, the sample size was underpowered, with a disproportionate number of boys to girls. Furthermore, within the sample, the girls were significantly older than the boys, which would impact the reliability of correlations.

This more ambiguous view of gender differences is also echoed in Corbett et al. (2021), who did not find gender differences in gesture use but did report higher levels of vocal

expression and few RRB in girls. Wood-Downie et al.'s (2020) discrepancy based study identified higher levels of reciprocity within girls but equal levels of behavioural camouflaging between boys and girls. The study looked at 84 autistic and non-autistic boys and girls, comparing an interactive drawing task and Reading the Mind in the Eyes Test, and WASI-II, to identify camouflaging behaviour. It is worth noting that most of these studies either assessed camouflaging in laboratory settings (Corbett et al., 2021; Rynkiewicz et al., 2016; Wood-Downie et al., 2020) or observations at school (Dean et al., 2017) and therefore, there will be limitations on what they can tell us about how children camouflage at home, unobserved, and in other settings.

Within the adult population, multiple studies have reported camouflaging across genders but higher levels in women. Discrepancy based research found higher levels of camouflaging in females (Lai et al., 2016; Lai et al., 2019; and Schuck et al., 2019). Lai et al.'s (2019) second investigation into camouflaging again uses a comparison of the AQ and Mind in the Eyes test against the ADOS. They argue the findings support greater camouflaging in autistic females and that there are gender-based neural functioning differences (this is explored further in a later section) (Lai et al., 2019). Comparing the ADOS and AQ, Schuck et al. (2019) also found that camouflaging was more common in autistic women. Furthermore, they noted that in autistic women camouflaging was negatively associated with emotional expressivity, suggesting that women may be more aware of and controlling of emotional displays when camouflaging; however, the directionality of this link remains unclear.

In the first self-reported study comparing gender differences in camouflaging behaviour (using the CAT-Q), Hull et al. (2020) found autistic women scored significantly higher in

overall camouflage levels, notably greater on the assimilation and masking sub-scales, but not on compensation. Of particular interest was the finding that the difference in camouflaging between autistic and non-autistic women was maintained when autistic traits were controlled for, whereas the difference was not maintained between autistic and non-autistic men (Hull et al. 2020). This suggests that being a woman and autistic leads to a greater level of camouflaging than the additive effects of each separately. A subsequent study found women scoring higher on all three sub-scales of the CAT-Q (McQuaid et al., 2021). The research is ambiguous, however, with several studies revealing minimal or no gender differences. Livingston et al.'s (2020) study using their Compensation Checklist reported no sex differences. Cage and Troxell-Whitman (2019) tested 262 autistic people (135 female, 111 male and 12 "other gender", and four who preferred not to disclose gender) using the CAT-Q and also reported no gender differences. However, the data did reveal gender differences in factors motivating camouflaging, with women more likely to camouflage for "conventional" reasons (such as securing employment). The generalisability of these findings is limited, as the participants were predominantly of white ethnicity and therefore may not represent the camouflaging experience of other ethnic groups.

The research also indicates that there may be gender differences in the style and mechanisms of camouflaging (Hull et al. 2020, Schuck et al. 2019). Using a task-related functional magnetic resonance imaging paradigm, Lai et al. (2019) found that in comparison to non-autistic men, autistic men showed reduced activity in the ventromedial prefrontal cortex (vMPFC) and right temporoparietal junction (RTPJ), whilst there was no difference between autistic and non-autistic women (Lai et al., 2019). Also, increased camouflaging in autistic women was related to greater vMPFC neural self-representation response (Lai et al., 2019:1218). The authors argue that this supports sex differences in the social brain

function of autistic individuals, and such differences are linked to higher levels of camouflaging in autistic women. They note that with autistic women, there was an association between camouflaging and vMPFC, but not the right temporoparietal junction (RTPJ), which develops into adulthood with an increasing specialisation for mentalising (Lai et al., 2019). They speculate that this correlation may indicate autistic women camouflage more successfully by using enhanced self-reflection to ascertain how others see their behaviour and how to adapt it appropriately. The authors link this self-reflective camouflaging to the "deep compensation" suggested by Livington & Happe (2017). The potential for neuroimaging studies to explain autistic camouflaging is undoubtedly appealing; however, caution is required. Meta-analyses have demonstrated difficulties with replicating data from fMRI studies, and the assumptions concerning the definition and parameters of the variables measured (i.e. how are they operationalising camouflaging) limit the generalisability of the data (Elliott et al., 2020).

Regarding differences in cognitive functioning, Lehnhardt et al. (2016) study into 215 autistic individuals (71 female and 144 male) found autistic females (in comparison to autistic males) showed higher processing speed and better executive functioning. They argue that these enhanced cognitive processes in autistic women might facilitate the establishing of reciprocal social behaviour and social mimicry skills used when camouflaging (Lehnhardt, 2016:146). However, co-morbid diagnoses (i.e. mental health and other neurodevelopmental conditions) that may have had a contributing or confounding effect were not considered.

The current picture of gender differences in camouflaging behaviour is unclear. As outlined above, some studies have demonstrated gender differences in the level and quality

of camouflaging, but not all, and the nature of these differences varies. Furthermore, most research has not included non-binary and transgender identities, which are particularly relevant due to the higher prevalence in autistic populations (Walsh et al., 2018; Murphy et al., 2020). To date, there has been very little research into non-binary autistic individuals' experience of camouflaging. An online study by Wiskerke et al. (2018) included cisfemale and transgender individuals and found significant levels of camouflaging RRB in both groups, which potentially disputes the theory that there are biological differences that account for apparent gendered variation in camouflaging behaviour. Hull et al. (2020) included non-binary participants and found higher camouflage levels than the women sample; however, this was not significant when controlling for autistic traits, and the sample was very small and likely underpowered. In order to fully understand camouflaging and potential gender differences, more research is needed across the gender spectrum, including non-binary and trans identities (Fombonne, 2020; Hull et al., 2020a)

The emergence of a more nuanced picture of camouflaging and gender supports the need for further research into the female autistic phenotype theory. It may be that higher levels of camouflaging, increased relational interest and internalising traits are representative of an autistic subtype that can be seen across the gender spectrum (Hull et al., 2020a). Alternatively, the variance may represent differing gendered expressions of autism and camouflaging that do not equate to distinct phenotypes (Fombonne, 2020). Other researchers emphasis the role social and cultural context plays in the presentation of camouflaging behaviours, arguing that apparent gender differences can be attributed to these external factors rather than any inherent variation (Pearson and Rose, 2021).

### 2.6.8. Gender and social norms

A crucial aspect in understanding the relationship between camouflaging and gender is the impact of social and cultural factors (Cage & Troxell-Whitman, 2019). The aim of camouflaging is to adapt to social norms (Hull et al., 2017). It is argued that cultural expectations concerning gender-appropriate behaviour place more significant pressure on autistic women (as opposed to men) to camouflage (Lai et al., 2016; Kreiser and White, 2014; Holtmann et al., 2007). Impression management research and social role theory highlight that men and women are subject to differing behavioural expectations (Rudman, 1998; Eagly, 1987). More specifically that women are expected to be more social, passive, caring, polite, whilst men are more assertive and independent (Guadago & Cialdini, 2007). Research into the female modesty effect has found that women are more likely to be modest in public rather than private interactions, and suggest that this is linked to social pressure concerning appropriate behaviour (Rudman, 1998). Furthermore, that women who do not comply with these gender norms are evaluated negatively by others, and suffer socially and within work settings (Singh et al., 2002). It has been argued that women are more constrained by these gender norm as they hold a low social status and more likely to capitulate to observer expectations (Snyder & Haugen, 1994).

Furthermore, for autistic women complying with these gendered social norms is even more problematic. As noted above, these social expectations include women being involved in more purely relational activities, for example, meeting to talk over coffee, whilst for men meeting to engage in a specific activity, or to talk about a particular topic is more common (e.g. playing golf, talking about football) (Aukett et al., 1988). The former is a less structured social situation that is more challenging for autistic people who prefer predictable interactions with predetermined rules and endpoints (Attwood, 2006). Consequently, there may be a greater need to camouflage autistic traits in these social settings.

Hughes (2014:13) notes that "women generally face greater expectations to...be sociable", and therefore autistic women experience more pressure to perform socially than men. Lai et al. (2016) suggested that gender differences in what is considered "normal" social behaviour and in the development of socialisation could be key factors in the increased prevalence of camouflaging behaviour in females.

Dean et al. (2013) specifically highlight the centrality of reciprocal relationships within adolescent girls socialising. Within an increased focus on emotional conversations and self-disclosure compared to boys' more active and structured play. Consequently, autistic girls experience greater pressure to socialise and a more subtle and nuanced social environment to contend with (Dean et al., 2013, Cridland et al. 2014, Holtmann et al., 2007). It has been argued that these gender differences in social behaviour mean there is a greater expectation from parents for girls to be social (Holtmann et al. 2007; McLennan et al., 1993), and therefore autistic girls focus more effort on performing socially, leading to their difficulties being missed (Dean et al., 2013). More recently, Corbett et al. (2021) suggested that differing sex-based expectations may cause greater masking of unusual speech and prosody characteristics seen in girls. Lai et al. (2016) also suggest that gender differences may add to this concealment, for example, non-autistic girls "mothering" autistic girls, in a manner not seen in friendships between boys of similar ages.

In Kanfiszer et al.'s (2017) multi-stage narrative study of adult autistic women, participants described the pressure they experienced to conform to stereotypes such as being feminine, sensitive, caring, or a "good mother" or "good wife." The women talked about their awareness of feeling different to these gender stereotypes, the negative impact of trying to fit in, and social exclusion when unable to. Family, friends and professionals can rein-

force these gender stereotypes, resulting in autistic women being urged to continue camouflaging (Davidson and Henderson, 2010), even though they feel separate from neurotypical women and exhausted by their efforts to comply with these gendered expectations (Haney and Cullen, 2017).

Furthermore, cultural stereotypes have often viewed autistic individuals as quirky male geniuses (Bumiller, 2008) or nutty professors (Attwood, 2006), and these persist. Consequently, autistic women have described feeling doubly excluded, not fitting into female stereotypes nor that of the stereotypical autistic, feeling part of a "subculture within a subculture" (Simone, 2010:13). The experience of autistic women can also be seen within an intersectional framework (Saxe, 2017). Cage & Troxell-Whitman (2019) suggest that camouflaging for autistic women may involve societal, male-biased stereotypes of autism. Furthermore, autistic women are minorities both within the broader predominantly non-autistic population and within the majority male autistic population. How these two factors interlink in terms of camouflaging has yet to be examined. As Cage & Troxell-Whitman (2019:1900) highlight:

"for autistic men, camouflaging may still occur as a response to stigmatisation for being autistic, but they avoid the additional stigma of autistic womanhood."

The same can be said for those autistic individuals who identify as non-binary. How other social-cultural factors, such as race, ethnicity, class, may impact camouflaging has yet to be considered. Research shows that autistic people of colour and people of colour with intellectual disabilities experience greater discrimination and prejudice (Abramov, 2017), and therefore it seems highly likely that other aspects of an individual's identity will influence camouflaging behaviour.

### 2.5.9. Camouflaging, age and diagnosis

The relationship between camouflaging, age, age at diagnosis, and how camouflaging is experienced over time is unclear (Lai et al., 2016; Hull et al., 2017). One study demonstrates that girls' camouflaging behaviour increases over time as they develop skills (Lai et al., 2011). On the other hand, research also suggests that camouflaging strategies breakdown with age due to the increasingly complex nature of the social environment (particularly in teenage years) (McLennan et al., 1993; Mandy et al. 2011; Hughes, 2014; Rutherford et al., 2016 and Dean et al., 2014). Within more recent qualitative research, autistic adults have reported their ability to camouflage, and consequently, their relations with others increased and improved with age (Hull et al., 2017, Cook et al., 2021).

To date, only one study has specifically looked into the effect of age of diagnosis in autistic adults on camouflaging behaviour. McQuaid et al. (2021) studied 502 autistic adults (across the gender spectrum) and found that participants diagnosed in adulthood scored higher on the CAT-Q, specifically on Compensation and Assimilation sub-scales (McQuaid et al., 2021). The authors suggest that the use of compensation and assimilation strategies represents the creation of a "non-autistic social self", which more effectively deters detection than only using masking strategies (McQuaid et al. 2021:7). Potentially, the higher levels of assimilation and compensation and creation of "non-autistic selves" noted within the late-diagnosed group may have a more profound impact on mental health and self-identity. However, more research is required into how camouflaging first develops and changes over time and the impact on diagnosis and mental health (Hull et al. 2020). Whether diagnosis (or self-diagnosis) facilities individuals finding other autistic people and therefore feeling less need to camouflage, also remains unexplored. Research has sup-

ported the impact of autistic relationships and communities (Parsloe, 2015; Jantz, 2011) but has not considered how this may link to the use of camouflaging.

It is noteworthy that this study by McQuaid et al. (2021) is one of the few camouflaging studies that include some participants from non-white ethnic groups, although it is still predominantly Caucasian (82%) and "not of Latin descent" (88%). Commonly, within autism research, there is a lack of representation for black and minority ethnic groups (Matthews, 2019). Consequently, our current understanding of camouflaging, and its impact, is limited.

## 2.5.10. Cognitive Processes

Research has begun to examine what cognitive processes may be involved in camouflaging behaviour. It has been suggested that having a higher IQ and executive functioning (EF) abilities may result in camouflaging strategies being used more often and more effectively (De Lassalle et al., 2021, Livingston et al. 2019b). Studies have also considered whether poor Theory of Mind (ToM), which refers to the ability to guess the mental states of others and is arguably a feature of autism (Baron Cohen, 2001), impairs camouflaging (Hull et al., 2021b). The current findings reveal an ambiguous picture. Hull et al.'s (2021b) study of 58 autistic adolescents found that age, IQ and theory of mind were not correlated with self-reported camouflaging scores. There was a slight negative correlation between EF difficulties and camouflaging total, masking scores, and compensation scores, although only the compensation sub-scale approached significance (Hull et al., 2021b). However, the sample size was underpowered, meaning correlations should be considered cautiously. Furthermore, these are correlations and do not reveal the causal factor, whether, for example, there are other confounding variables (Hull et al., 2021b).

In opposition to Hull et al. (2021b), Livingston et al. (2019a) found that IQ and EF were positively correlated to compensation. However, these two studies operationalise camouflaging differently, with Hull et al., (2021b) using the CAT-Q and measuring theory of mind as a comparison factor and Livingston et al. (2019a) using Theory of Mind within the conceptualisation of camouflaging. There are clear questions concerning what the researchers are trying to measure. Furthermore, the use of Theory of Mind measures to indicate autism is contested by many, viewing it as a separate stage of language development that autistic people may or may not struggle to acquire (Gallagher, 2004; Tantam, 2013). Consequently, its use in explaining the processes behind camouflaging is problematic. On the other hand, further exploration of differing executive functioning processes (e.g. working memory) and how these may affect camouflaging behaviour seems particularly useful.

The nature of identified correlations is currently unclear and require further study; for example, whether IQ enables individuals to camouflage more or whether the ability to camouflage facilitates IQ development (Livingston et al., 2017). There has been one study to date using neural imaging to explore the areas of the brain and brain functioning concerning camouflaging. As previously noted, Lai et al. (2019) studied 119 autistic and nonautistic men and women, using fMRI tests to explore differences in brain functioning linked to camouflaging behaviour. They found differences in brain activation between autistic and non-autistic females and males (Lai et al., 2019). Most notably a lack of impairment in neural self-representation and mentalising in autistic women compared to non-autistic women, whereas there was an impaired response in autistic men. These results could potentially explain differences in camouflaging behaviour and presentation be-

tween autistic females and males; for example, females engage in more "deep compensation" than males, reflected in their differing neural activity (Lai et al., 2019). However, many questions remain; for example, it is impossible to know whether such differences cause camouflaging behaviour or whether these neural functioning differences exist from birth or are linked to the socio-cultural environment (Lai et al., 2019). Furthermore, the study was limited in its scope with a moderate sample size, meaning they could only examine predetermined regions of interest rather than a more comprehensive exploratory approach (Lai et al., 2019).

## 2.5.11. Intentional Camouflaging

Camouflaging has been repeatedly described as both a conscious and unconscious process (Lai and Baron Cohen, 2015, Lai et al. 2016, Hull et al., 2019); demonstrating that how aware an individual is of their camouflaging or how much intention they have when engaging in this behaviour can vary. Hull et al.'s (2017) study found that some autistic people described camouflaging without deliberate intention and desiring more control over their camouflaging. Whilst other participants described deliberately using techniques to hide their autism from others (particularly at work). The understanding of how conscious and unconscious camouflaging occurs remains unclear. In a more recent study, some autistic adults reported camouflaging behaviour beginning with awareness and intention and becoming more automatic over time (Cook et al., 2021). However, other participants only described intentionally camouflaging (Cook et al., 2021). To date, there has been no research explicitly examining the difference between conscious and unconscious camouflaging and how and why individuals might experience camouflaging in this varying way. The research that has explored the nature of camouflaging so far has focused on conscious aspects, or those externally visible to others (Pearson and Rose, 2021)

### 2.5.12. Reasons for camouflaging

The literature identifies multiple reasons autistic people camouflage. In the first qualitative study to explore camouflaging in adults, Hull et al. (2017) interviewed 92 autistic adults via an online questionnaire. The research identified assimilation and "to know and be known" as the main reasons for camouflaging. "Assimilation" (within the study) included wanting to blend into the non-autistic population, ensuring physical and mental safety from bullying and assaults, and enabling social engagement (e.g. work). The second theme ("to know and be known") referenced participants use of camouflaging to increase the opportunity and ease of making connections and relationships with others (Hull et al., 2017). Using camouflaging to facilitate connection and relationships, and to gain social achievement, was also reported in Livingston et al.'s (2019b) qualitative exploration of compensatory behaviour. Cage & Troxell-Whitman (2019) created a questionnaire with 21 reasons for camouflaging and surveyed participants, identifying two main themes, "conventional" (to get by in a formal setting such as work) and "relational" (to get by in relationships). The study also found that avoiding bullying and passing as neurotypical were common reasons for camouflaging. Autistic children and adults are more likely to experience bullying than the non-autistic population (Lung, 2019). Greenlee et al. (2020) found that whilst similar levels of victimisation were experienced by autistic boys and girls, it had a greater impact on anxiety levels in girls. This echoes Sedgewick et al. (2018) research that found autistic girls particularly struggling to manage social conflicts (compared to autistic boys and non-autistic peers), making camouflaging particularly valuable for girls.

Cook et al. (2021) also found connection and relationships as the key motivating factor in camouflaging. Autistic individuals camouflaged to gain social acceptance, minimise being

ostracised for "abnormal" behaviour, and facilitate relationships (Cook et al., 2021). It appears that two interlinking motivational factors emerge; avoiding judgement and negative experiences and facilitating acceptance and relationships. This is supported by recent qualitative research focusing on the camouflaging experience of adolescents, which identified avoiding negative experiences and perceptions, acceptance, and adapting appropriately when obligated as reasons for camouflaging (Bernardin et al., 2021).

There is some research suggesting gender differences in motivations to camouflage.

Cage and Troxell-Whitman (2019) found that women were more likely to camouflage for "conventional reasons" such as managing in work or educational settings; the authors' note that this could indicate the greater marginalisation that autistic women experience. In a study of autistic adolescents, girls were most likely to site avoiding negative experiences (for example, getting into trouble or upsetting others), whilst boys were most likely to name "being appropriate for the situation" as the reason to camouflage (Bernardin et al. 2021). More research is needed to explore gender differences in motivation to camouflage more deeply. Furthermore, the studies noted above had predominantly white, cisgendered participants without an intellectual disability, limiting the scope of the findings. This is particularly pertinent, as the research references factors such as social acceptance and perception, which are greatly influenced by social-cultural identity and background (Matthews, 2019)

### 2.5.13. Camouflaging as a response to stigma

Camouflaging has also been identified as a strategy to avoid stigma and discrimination.

Despite public and government campaigns to promote awareness and acceptance, studies have shown that there is still a high prevalence of negative judgement towards autism

and autistic traits (Cage, Di Monaco and Newell, 2019; Wood and Freeth, 2016). Both identity and traits are stigmatised, which is pertinent to camouflaging, as it means individuals, regardless of diagnostic status, have to adapt behaviour to avoid prejudice. Autistic people are more likely to experience bullying and victimisation (Lung et al. 2019, Griffiths et al. 2012), and camouflaging can be seen through this lens as a response to stigma.

Pearson and Rose (2021) suggested that autism and camouflaging could be examined using the Social Identity Theory (SIT; Tajfel et al. 1979), which posits that our self-perception is dependent on situational (i.e. what is going on) and temporal (i.e. the point in our lifespan) factors. Furthermore, our identity sits on a continuum between our self-perception as individuals and what members of our group grant us about our identity. Individuals may emphasise different aspects of their identity depending on the group and situation and their appraisal of how others view them (Tajfel et al., 1979). Autistic individuals are discriminated against at both the individual and group level, being negatively judged for their autistic behaviours and position within the "group" of autism. Pearson and Rose (2021) argue that to manage these judgements, autistic people camouflage. They differentiate camouflaging from universal impression management strategies (i.e. those used by non-autistic people), arguing that only the former includes concealing identity rather than merely fore-fronting a particular characteristic most appropriate to a social situation (Pearson and Rose, 2021). It is the act of "hiding" aspects of one's identity that negatively impacts mental wellbeing (e.g. depression, anxiety) (Pearson and Rose, 2021). The process of camouflaging is even more challenging for autistic individuals, who may experience increased difficulties in understanding non-autistic social interactions due to social communication differences:

"Autism requires impression management under conditions of external and internalised stigma, with reduced ability to perform such social interaction as well as an increased toll that accompanies it." (Schneid & Raz, 2020:2)

Discrimination from others (and society) can also lead to self-stigmatisation in autistic people (Dubreucq et al., 2020). Studies suggest that a label of autism may increase internalised stigma and consequently the concealment of autistic traits (Botha, Dibbs and Frost, 2020). However, the relationship between social stigma, internalised stigma and camouflaging is yet to be fully examined.

The SIT also proposes that people respond to stigmatisation through individual means, such as dissociating from the group or trying to "pass" as part of a higher status group. Alternatively, people can use group strategies that promote the status of the in-group in broader society, e.g. collective campaigns (Tajfel et al. 1979). Perry et al. (2021) found that camouflaging was significantly linked to both individual and group strategies to manage stigma, suggesting that camouflaging is one of a range of means autistic people use to manage discrimination. Qualitative research by Cook et al. (2021) also identified camouflaging as a "form of stigma management" involving a repertoire of behaviours to portray a more valued social identity. In a recent study into autistic adolescents, participants reported the pressure of social norms and the freedom that they found communicating on social media (Jedrzejewska and Dewey, 2021). The autistic adolescents of both genders camouflaged less online than offline. However, both autistic and non-autistic girls camouflage more online than boys, and the authors note that this could relate to general gender differences in online behaviour as there was no significant interaction between autism diagnosis and gender (Jedrzejewka and Dewey, 2021). The study's qualitative data does

highlight how online spaces can create a feeling of safety, acceptance and community for autistic adolescents (Jedrzejewka and Dewey, 2021).

These initial studies have begun to situate camouflaging within a social context, and they shift focus from the individual and their masking behaviour to a dynamic interplay between self and society. Pearson and Rose (2021) argue that camouflaging may be best understood as an unconscious consequence of stigmatisation and a self-protective mechanism rather than a conscious choice to promote social functioning. As autism is still a stigmatised minority identity, examining individuals' camouflaging within the social context is key to avoiding further pathologising the autistic person. More research is required to examine this relationship, particularly how a person's unique social-cultural and identity status contribute to the development and maintenance of camouflaging behaviour. For autistic people with differing social and communication challenges, understanding and responding to the social-cultural demands of a majority non-autistic population is even more complex.

### 2.5.14. Impact of camouflaging

In recent years there has been growing research into the impact of camouflaging. The "mental effort" required to continually decode social situations and act in a socially appropriate manner has repeatedly been expressed by autistic individuals (Griffith et al., 2012; Lai et al., 2016; Causton-Theoharris et al., 2009). Although camouflaging may lead to fulfilling socially appropriate standards, it frequently results in feeling exhausted (Ryan and Raiseanen, 2008; Davidson and Henderson, 2010, Hull et al., 2017) and the need for social isolation to "re-set" (Hull et al., 2017:2521).

Autistic adults describe "dying of pain" while "pretending to be normal" (Punshon et al., 2009:276). Ryan and Raisanen (2008:136) argue that this constant effort to try and fit in socially leads to ontological insecurity and a profound sense of being "unreal", shame and fear. More specifically, research suggests that camouflaging can harm the development of one's identity (Lai et al., 2016) and can result in individuals "losing" themselves in the "masks" or "roles" they adopt (Hughes, 2014:7). Individuals and researchers have also described a sense of "splitting" between the private and public self (Valeras, 2010) and feeling like they present a fake or false self (Griffith et al., 2012; Kansfizer et al., 2017) that further alienates them from others. Some described the need to stifle their inner self (Hurlbutt and Chalmers, 2002), whereas others expressed a sense of lack or nothingness (Masilamari, 2003 in Kearns Miller, 2015). These experiences have been further illustrated in more recent studies specifically examining camouflaging; participants have described a sense of "who the hell am I?" (Hull et al., 2017:2524) or loss of identity (Tubio-Fungueirino et al., 2020).

Despite the stereotype of the aloof and socially uninterested autistic individual, research has repeatedly shown that autistic people desire connection and belonging (Ryan and Raisanen, 2008; Kapp et al., 2013). Furthermore, this desire to belong often motivates individuals to camouflage their difficulties (Punshon et al., 2009). However, as mentioned, this also produces a tension between the desire to belong and the difficulties experienced when trying to fit in, creating what Causton-Theoharris et al. (2009:84) termed "islands of loneliness". Müller et al. (2008:173) argue that the effort of trying to connect led to feelings of profound isolation, with one participant describing this as being in a "remote abyss" (Müller et al., 2008:179; also see Davidson & Henderson, 2010). Adequately

camouflaging may be successful in that others do not perceive the autistic individual as experiencing problems, but the consequences of managing this remain (Hull et al., 2017).

The intensity and negative impact of camouflaging is seen as one of the differentiating factors between the autistic experience and general impression management (Goffman, 1990). In Goffman's theory (1990) of self presentation everyone adapts their behaviour to a certain degree depending on those they are with, however there are also "back-stage" moments, when it is possible to stop acting and interact without preparation or effort with others. However, as noted above issues of stigma and discrimination mean that autistic individuals are more likely to experience abuse or prejudice whoever they are with (Lung et al. 2019, Griffiths et al. 2012). This intensifies the pressure to camouflage, and potentially means that there are fewer, or no, backstage "safe" spaces. The issue of whether autistic individuals camouflage in intimate relationships has yet to be considered. Furthermore, some autistic individuals camouflage without awareness, and consequently the effort of performing is not something they are able to regulate, exacerbating feelings of overwhelm (Lai et al. 2016, Hull et al., 2019). The research highlighting the greater pressure autistic women and girls feel to socially perform linked to gendered narratives of socialisation (Hughes, 2014), explains why the pressure to camouflage and the actual experience of that performance is more intense, than for autistic men and boys. Consequently, continuing exploring the nature and impact of the camouflaging for autistic women is essential.

Some recent research has suggested that camouflaging leads to higher levels of mental health difficulties in women and girls, and levels of camouflaging may provide clinicians

with a way to recognise individuals who are especially at risk (Beck et al. 2020, Bernardin et al., 2021). However, there is ambiguity concerning the exact relationship between camouflaging, mental health and gender. Lai et al. (2016) found a correlation between camouflaging and depression in men, but not women, and no relationship between camouflaging and anxiety in either gender. One of the few large scale studies by Hull et al. (2021a) using the CAT-Q to assess 305 autistic people across the gender spectrum (181 female, 104 male, 18 non-binary) found a small association between camouflaging and generalised anxiety, depression and social anxiety (the relationship was more significant for generalised and social anxiety), but no difference in gender.

The literature that camouflaging has a significant impact on mental health in the autistic individuals in general is strong. Several studies have specifically examined camouflaging behaviour and mental health indicators, finding that higher camouflaging levels are associated with stress, depression, and anxiety (Lai et al., 2016; Hendrickx, 2015; Bargiela et al., 2016; Cage et al., 2018). Somerville et al.'s (2019) study into self-reported measures of camouflaging, cognitive processes and mental health linked camouflaging with higher levels of stress, anxiety and depression, independent of autistic traits; suggestive that it is the camouflaging, not autistic traits per se that leads to increased distress. Cage & Troxell-Whitman (2019) also conducted an online questionnaire, picking up on the themes of reason, context and cost, outlined in Hull et al., 2017 study. They found that individuals who were "high camouflagers" (camouflaged most in all situations) and "switchers" (moving between camouflaging or not depending on the situation) were more likely to experience poorer mental health than "low camouflagers". There was a more ambiguous picture when anxiety and depression were considered individually, with no difference occurring between low, high, or switchers, which conflicts with previous studies (Hull et al.,

2017; Cage et al., 2018) and highlights the need for further research. This is of particular interest as in a previous study Cage et al. (2018) noted a correlation between camouflaging behaviour and depression. This could be due to the latter study specifically testing for depression and using the CAT-Q, whilst Cage et al. (2018) relied on spontaneous reports of camouflaging. The differing ways studies use to quantify camouflaging and measure mental health impedes identifying potential correlations.

Camouflaging has been identified as a risk marker for suicidality in autistic adults (Cassidy et al., 2018). A subsequent study reported a correlation between "feelings of thwarted belonging" camouflaging and suicidality (Cassidy et al., 2018). Suggesting that the higher levels of autistic traits lead to greater camouflaging, which in turn foster feelings of disconnection and a lack of belonging, resulting in greater risk of suicide; although it should be noted that this study was conducted using a general population and rating autistic traits, rather than diagnosed or self-identified individuals (Cassidy et al. 2018). It is noteworthy that this tool was developed with a non-autistic sample, and it is only recently that an adapted measure for use with autistic populations has been created (Cassidy et al., 2021).

It has also been argued that the continuous cognitive and emotional effort caused by camouflaging exacerbates anxiety and depression (Dell'Osso et al. 2020). On the other hand, camouflaging is also associated with facilitating social relationships and employment, which are linked to better mental health outcomes (Hull et al. 2017, Dell'Osso et al., 2020). Further research (including large scale studies) is required to more clearly map out the connection between camouflaging and mental health and how this might be af-

fected by other factors such as gender and diagnosis (Cage et al., 2018). Cage and Troxell-Whitman (2019) highlight:

"if camouflaging is detrimental to mental health, it is important to understand why camouflaging is still reported by many autistic people" (pp1900).

Answering this question means exploring the broader social, relational, cultural experiences of autistic people, including those of stigma, and how this impact health and well-being (Pearson and Rose, 2021).

### 2.5.15. Summary of qualitative research into camouflaging

The literature search found eight qualitative studies focusing on camouflaging. Four of these studies centred on children and adolescents. Research by Tierney et al. (2016) into the camouflaging experience of ten autistic adolescents found developing friendships was the primary motivating factor, and strategies included imitating peers and hiding autistic traits. Two later studies (Cook et al. 2017, Halsall et al. 2021) explored the experience of autistic girls (alongside a parent) and expanded on the previously identified themes of relationship and camouflaging strategies. Cook et al. (2017) noted that the girls wanted to fit in with their peers but lacked the required social skills. Masking (as termed in the paper) was both a solution for this by aiding social interaction and concealing their autism, but also problematic as it led to later or missed diagnosis. Halsall et al. (2021) also highlighted the girls' desire to find safe, controllable relationships (often with older people or in special educational needs settings). This was a qualitative study of eight girls, their mothers and educators, using reflexive thematic analysis. The data revealed a more nuanced picture of the girls' experience, emphasising how camouflaging varied depending on the situation, clashed with a desire to embrace their autistic identity, and the consequences of late diagnosis, exhaustion, stress and loss of identity (Halsall et al., 2021).

The authors also note that the girls wanted to hide their learning challenges and autistic traits (Halsall et al., 2021); however, as the study had a small sample size with a limited age range (12-15), it may not accurately represent children at different ages and developmental stages.

Four qualitative studies have focused on autistic adults. The first qualitative study examining camouflaging in autistic adults was by Hull et al. (2017). The researchers used an online questionnaire to explore camouflaging within a sample of 55 autistic women, 30 men, and 7 "other gender". The data highlighted factors motivating individuals to camouflage (e.g. connecting and fitting in with others) and the consequences of camouflaging (e.g. exhaustion and a loss of self). Although there was some variance, all genders camouflaged, with more men than women reporting positive consequences of camouflaging, namely achieving socially and making connections with others (Hull et al., 2017). However, the sample did not include autistic individuals who also have intellectual disabilities, limiting its ability to capture the autistic experience across the spectrum. Similarly, only formally diagnosed people were included, arguably leaving out those whose camouflaging had prevented an assessment.

Livingston et al. (2019b) conducted a qualitative exploration of compensation. The study investigated the experience of 136 adults (a mix of formally diagnosed, self-diagnosed and those just reporting social difficulties) through an online questionnaire, with openended questions to ascertain compensatory behaviour. As with previous studies, participants described that compensation was helpful to pass as non-autistic in social situations but was exhausting and not consistently successful. The authors identified different types of strategies used by participants; namely shallow compensation, deep compensation,

and behavioural masking (Livingston et al., 2019b). Significantly, the authors highlighted the effect of external factors (other people, environmental demands) and internal factors (intellect, motivation) on the process of compensation, although they do not explore this in detail. Similarly to studies focusing specifically on camouflaging, the cost of the behaviour was noted, in the negative impact on emotional wellbeing, poor sense of self, and missed or late diagnosis.

It is noteworthy, however, that similarly to Hull et al. (2017) the qualitative study undertaken by Livingston et al. (2019b) was based on a predominantly female and late-diagnosed population, with no individuals with an intellectual disability, and so is limited in its ability to capture the experience of camouflaging within the whole autistic population. However, Livingston et al. (2019b) did include self-diagnosed individuals and those who reported camouflaging without any diagnosis, meaning the findings could be generalised more widely, specifically to the population of autistic people who have missed diagnosis due to camouflaging. On the other hand, the inclusion of participants who report social difficulties without diagnosis or self-diagnosis does raise questions concerning the validity of the data, as it is unclear if their camouflaging (although similar) is qualitatively distinct from autistic individuals.

Schneid and Raz (2020) critique much of the research into camouflaging as being based within the medical-functionalist paradigm where camouflaging is solely seen as a coping strategy to manage autistic deficits. They conducted a qualitative study using semi-structured interviews of 24 Israeli autistic people, using a participatory research approach with autistic co-investigators and co-authors. It is noteworthy that to date, this is the only participatory research of this kind into camouflaging, which may enable previously unrecog-

nised narratives to be revealed. However, as with much of the data on camouflaging, the participants did not include those with an intellectual disability. The autistic co-researchers in this study argued against viewing camouflaging as an inevitable social function and considered social narratives around "normal" and "abnormal" when analysing the data. As with previous research, participants discussed the use of camouflaging to fit in and obfuscate stigma. Participants also described the limited effectiveness of camouflaging in the eyes of society and finding non-neurotypical ways of interacting where camouflaging was not needed (e.g. online and autistic friends). The participants also described feeling pressured and coerced into camouflaging. Crucially the study calls for further research into camouflaging from different perspectives, considering ideas of alternative sociality.

Most recently, Cook et al. (2021) conducted an interpersonal recall study and qualitative interview. Seventeen autistic adults (across genders) took part in a 10-min controlled social task replicating a day-to-day situation and then watched a video of this and had an interview with a researcher. A thematic analysis again identified the desire for relationship and acceptance as key motivating factors, but this was not always successful and led to anxiety and exhaustion. However, unlike previous qualitative studies, they noted that participants would camouflage even when their autistic identity was known, evidencing the stigmatisation of both autistic identity and autistic behaviour, and potentially pointing to internalised stigma (Botha, Dibbs and Frost, 2020). Other key findings included camouflaging limiting their ability to fully engage with the other person, and as noted by other researchers (Livingston et al., 2019b; Schneid & Raz., 2019), the importance of finding authentic ways to socialise. This study involved a novel experimental approach, which facilitated a more detailed examination of the camouflaging process than standard interviewing or questionnaire methods. However, limiting the context of camouflaging to a one to

one interaction with a non-autistic partner within a laboratory setting reduces the general-isability of the findings, particularly as the environment will affect each person's camouflaging repertoire (Schneid and Raz, 2020; Pearson and Rose, 2021).

This qualitative research identified some key themes concerning the experience of camouflaging for autistic individuals. As noted in autobiographical and clinical data, the importance of passing as non-autistic is evidence in the research (Cook et al., 2021; Hull et al. 2017), including in response to stereotypes and stigma (Hull et al. 2017; Schneid & Raz, 2019). However, camouflaging is not simply an attempt to "pass". As noted by Cook et al. (2021), individuals will camouflage with those who know their autistic identity. Understanding the intersection between camouflaging and disclosure of identity is an area yet to be fully explored. The qualitative literature also highlights the influence of camouflaging within relationships. Numerous studies (Hull et al., 2017; Livingston et al., 2019b; Cook et al., 2021) have previously referenced how autistic individuals have utilised camouflaging behaviour to develop relationships, particularly girls and adolescents (Dean et al., 2014; Halsall et al., 2021). However, participants in two studies note that this may not lead to the desired meaningful and authentic relationships (Cook et al., 2021 and Livingstone et al., 2019b). The various ways camouflaging influences relationships and how individuals may change their use of conscious strategies depending on the nature of the relationship and personal goals is unclear. The negative impact of camouflaging is mentioned within all the qualitative studies, particularly noting exhaustion (Halsall et al., 2017; Hull et al., 2017; Cook et al., 2021) and loss of identity (Hull et al., 2017). Although, it is noteworthy that various terms are used to describe the later phenomena, including a sense of "lack" or "nothingness" (Masilamari, 2003 in Kearns Miller, 2015) and loss of self (Tubio-Fungueirino et al., 2020). Further examination into what individuals are experiencing regarding their sense of self and how best to define it is needed. Moreover, how these personal experiences are linked to quantitative findings correlating depression and anxiety levels to camouflaging remains unclear.

The research outlined above provides some insight into camouflaging behaviour and its impact; however, there still remains a paucity of qualitative studies looking at the experience of this complex phenomenon in autistic adult women (Kanfiszer et al., 2017; Allely, 2018).

## 2.6. Camouflaging and existential theory

The discussion of camouflaging both in anecdotal and academic literature has often referred to the concept of authenticity. Autistic individuals spoke of feeling forced to camouflage and unable to reveal their authentic self (Hull et al., 2020b), resulting in a lack of connection to their authentic self (Hull et al., 2017) and a desire for authentic relationships (Cook et al., 2020). The term authenticity is particularly connected to existentialism and to Heidegger, who argued that people shift between authentic and inauthentic ways of being. Authenticity involves understanding and accepting our limitations whilst embracing our possibilities and choosing how to live (Heidegger, 1962). Conversely, inauthenticity is when we obfuscate our freedom and go along with the actions and beliefs of other people and society (Heidegger, 1962). Camouflaging could be seen as a particular example of this inauthentic mode of being, where individuals follow social norms rather than assert their individuality and agency. Crucially, Heidegger argues that both states are necessary, that we cannot constantly live in authenticity, and that there are practical reasons why inauthenticity is sometimes preferable (van Deurzen and Kenward, 2013). This description aligns with the experience of some autistic people for whom camouflaging can be a use-

ful (and essential) way of surviving the social world (Hull et al., 2017). Heidegger views the search for authenticity as a struggle (Chessick, 1996). Autistic writers have also described the challenges when they no longer camouflage, for example, the discrimination they may face (Pearson and Rose, 2021). Exploring camouflaging through an existential lens demonstrates both the universality and specificity of the autistic experience. When autistic individuals camouflage, they are confronted with dilemmas concerning relating, freedom and choice that are familiar to all, although the context of these challenges is unique to the autistic experience.

# 2.7. Summary of literature review

Camouflaging has been anecdotally and clinically noted for some time; however, it is a relatively new concept in empirical research (Lai et al., 2019). Critical questions remain regarding how camouflaging can be best defined and operationalised (Fombonne, 2020). As noted by Hull et al. (2020:312):

"Research into camouflaging using either discrepancy or observational/reflective approaches is still very much in its infancy."

More investigation is needed to ensure current methods of calculating camouflaging accurately capture behaviour and experience (Allely, 2018). As Williams (2021) notes, the limitations of the current methods to measure camouflaging mean we do not yet have a complete picture of what camouflaging is. This includes whether it is best conceptualised as one construct or many (e.g. swallow/deep compensation, masking). It also remains unclear how autistic camouflaging is connected to similar phenomena in the general population, such as impression and reputation management (Lai et al., 2019). Furthermore, how camouflaging may relate to more well-established psychological constructs (e.g. initiation,

introspection and social anxiety) or similar phenomena that have been described in nonautistic individuals.

To date, two review studies have examined the growing literature on camouflaging behaviour (Hull et al., 2020b and Allely et al., 2018). Both reviews concluded that the research indicated camouflaging was a shared experience of autistic individuals without an intellectual disability, although it was not clear how gender impacts the prevalence and expression of camouflaging. Furthermore, additional research into the veracity of a female autism phenotype and whether camouflaging is a distinguishing feature is required (Hull et al., 2020b; Allely et al., 2018). This should include more investigation into the experience of non-binary autistic individuals (Hull et al., 2020b).

The current literature suggests potentially interesting differences in how camouflaging may manifest across gender and sex; for example, differing motivations (Cage and Troxell-Whitman, 2019) and neural mechanisms (Lai et al., 2019). However, at this stage, the information is tentative. Continued research into this area may help differentiate camouflaging from other concepts such as social anxiety and impression management and give insight into impact and outcomes. Moreover, research is needed to determine how camouflaging may vary depending on the situation, life stage, background of the individual (Hull et al., 2020b). This should include considering the impact of age of diagnosis on camouflaging, whether there is any difference in camouflaging across the life span, and longer-term effects (Hull et al. 2020; Allely et al. 2018).

The amount of research examining the critical connection between camouflaging and health outcomes is encouraging. It is evident that camouflaging is tiring and impacts

mental health (Beck et al., 2020; Hull et al., 2021a; Cage and Troxell-Whitman, 2019); however, the exact nature of these connections is unclear with variation in whether camouflaging behaviour, gender and other factors increase depression, anxiety and suicidality (Cassidy et al., 2018). Historically, there has been a tendency to view camouflaging in binary terms, looking for positive or negative outcomes. However, a more nuanced approach is required that examines how individual differences may determine the outcome of camouflaging for a person, and the impact on health and wellbeing, across all genders (Hull et al., 2020a). More recently, several researchers (Pearson & Rose, 2021; Schneid & Raz, 2019) have emphasised the importance of viewing camouflaging within the sociocultural context, particularly considering issues of stigma and discrimination. Fombonne (2020:735) argued that camouflaging "is best studied at the interface between an autistic subject and his ecological niche". These researchers argue that camouflaging is affected by multiple factors, such as gender identity, disability, race and socioeconomic status (Pearson & Rose, 2021; Schneid and Raz, 2019, Halsall et al., 2021). Camouflaging is a "multidimensional fully interactive construct", and exploring how these factors initiate and affect camouflaging behaviour over time is essential (Pearson and Rose, 2021:58). This conception of camouflaging better fits the varied and idiosyncratic expression described by individuals (Cook et al., 2021) and is reflected in the multiple attempts to define the process. Through such investigation, a more accurate and nuanced picture of how camouflaging influences individuals and health outcomes can be achieved, better-informing clinicians how to support autistic people (Allely et al., 2018; Pearson and Rose, 2021).

### 2.8. Research aims

This study will explore autistic women's camouflaging experience to develop a more nuanced and comprehensive understanding of the phenomenon. There has been an encouraging increase in the number of studies examining camouflaging within recent years. However, there remains ambiguity concerning how best to define and conceptualise camouflaging, and repeated studies are required (particularly of a qualitative and exploratory nature). Although research is quite rightly beginning to explore the camouflaging experience of men and non-binary individuals, there is still inadequate information on camouflaging within autistic women, inhibiting the understanding of a potential female phenotype. There has been an increase in research examining the experience of adult autistic women; however, overall, studies have focused on boys and men, and so capturing the lived experience of women is essential (Kourti and MacLeod, 2019)

As the literature into camouflaging has developed, the importance of not viewing the phenomena within a vacuum has been highlighted, however as yet has not be explored through qualitative research (Pearson and Rose, 2021; Fombonne, 2020). This study will specifically pay attention to the social-cultural background of participants and how this impacts on camouflaging. Attending to the idiosyncrasy of camouflaging repertoires and the unique way these may develop, as noted by Cook et al. (2021) and Pearson and Rose (2021). Finally, by focusing on adults and using a narrative approach, this study will consider how participants experience of camouflaging may change over time.

# 3. Research Method and Methodology

## 3.1. Methodology

### 3.1.1. Introduction

This study uses a multi-stage narrative analysis to research the stories of autistic women and their experience of camouflaging. This chapter will outline the philosophical and theoretical frameworks underpinning the study. The chosen methodology will be explored, and the use of narrative analysis discussed.

### 3.1.2. Epistemological Stance

The research process is formed of several conceptual "layers" that orientate the rationale and format of the study. These layers include: epistemology, theoretical frameworks, methodology and methods (Al-Ababneh, 2020). Epistemology concerns the nature of knowledge, how we know what we know, and consequently the possibilities and limits (Carter and Little, 2007; Al-Ababneh, 2020). The epistemological stance is fundamental to the development of the research and how the reader understands the findings. A constructivist epistemological approach views knowledge and meaning as occurring through human engagement with the world instead of a separate objective truth to be discovered (Al-Ababneh, 2020). How people perceive, interpret and reflect on their experiences in the world forms understanding; meaning arises from each person's engagement with the realities of their world (Al-Saadi, 2014). For social constructivists it is through dialogue with others that people gain meaning and understanding (Amineh and All, 2015). The foundation of an individual's knowledge is within the interaction between self, world and other. (Amineh and All, 2015).

Squires et al. (2014:80) note that when examining the lives and needs of individuals from particular groups, a "minimal" social constructivist model can be most helpful. This approach captures the personal sense-making process and uncovers "social-facts" about how people are experiencing their lives. "Weak" forms of social-constructivism argue that it is not the case that there are no objective facts. The social meaning-making process is built upon physical, biological and natural facts. Searle (1995:62) argues:

"To suppose that all facts are institutional [i.e., social] would produce an infinite regress or circularity in the account of institutional facts."

This form of social constructivism does not deny the existence of an objective world but focuses on the process of learning and meaning-making that individuals experience when in dialogue with others and their environment (Taylor, 2018). Consequently, meaning and knowledge are historically and culturally contingent (Taylor, 2018). The social environment plays a vital role in an individual's camouflaging story (Pearson and Rose, 2021). How each person understands the social norms and expectations they are surrounded by will influence how they camouflage. Weak social constructivism allows the examination of coconstructed meaning-making without dismissing the "brute reality" (Searle, 1995:62) of the biological and sensory experience. This study adopts a weak social constructivist approach, as it is particularly relevant when exploring autism which is both a biological and neurological phenomena but also has different meanings and narratives for different autistic people. This is both an experience-centred and socially-oriented approach to narrative, examining each personal experience of camouflaging and how this is expressed within a particular temporal and sociocultural context (Squire, 2016:65).

Within a constructionist stance to meaning-making, the researcher is not separate from the research; the researcher's perspectives will impact the research and the knowledge

acquired (Al-Saadi, 2014). The researcher and participants are co-constructing meaning together (Carter and Little, 2007). As Al-Saadi (2014:4) states:

"the researcher cannot detach him or herself from the research; they inevitably become personally engaged in the research and, as such, findings are influenced by their perspectives and values".

Consequently, reflexivity and acknowledgement of the researcher's position are essential.

### 3.2. Theoretical Frameworks

Part of the rationale for this research was to address the lack of consideration that has been given to the sociocultural and political contexts affecting camouflaging. In addition to the constructivist epistemology, the study is underpinned by several theoretical frameworks: the social model of disability, critical autism studies (CAS), and feminist disability theory. Feminist disability theory, CAS and the social model of disability enable questions of power, identity and discrimination to be brought to the fore through the research process.

### 3.2.1. Social Model of Disability

The social model of disability distinguishes between disability due to "social exclusion" and impairment defined as "personal limitation" (Shakespeare, 2006). Disability is viewed as a disadvantage caused by societal structures that exclude and stigmatise those with an impairment or who differ from the stereotype of a "normal" body/person. The disability model emphasises the role of society in accepting and making adaptions for those with impairment, thus removing disability (Oliver, 2013; Shakespeare, 2006). Disability studies emerged in the 1990s as an academic exploration and response to the medicalised construction of disability (Douglas et al., 2021). Academics from this field are looking to re-

veal and examine the cultural scripts that centralise the non-autistic non-impaired bodies (Douglas et al., 2021). Arguably, such biased social scripts are evident in the very conceptualisation of camouflaging. In particular, the term compensation has been defined using value laden language:

"Compensation is a component of camouflaging in which an individual's observed behaviour is considerably better than actual ability" (Corbett et al. 2021:127)

Some academics highlight the terms such as "better than" inadvertently perpetuate the social norms that pressurise autistic people to camouflage (Pearson and Rose, 2021).

#### 3.2.2. Critical Autism Studies

Informed by critical disability theory, critical autism studies (CAS) developed as an academic field with a specific focus on autism instead of the broader construct of disability (O'Dell et al., 2016). Coined in 2013 by Davidson and Orsini, CAS examines the power dynamics that operate in discourses around autism, questions deficit-based definitions of autism, and investigates "the ways in which biology and culture intersect to produce 'disability'" (Waltz 2014:1337). In contrast to the individualising and pathologising deficit model of autism, CAS affirms the complexity of the autistic person and promotes a "pivotal juncture" when autistic individuals reclaim autism narratives for themselves (Woods et al., 2018:977). The development of CAS reflects the broader neurodiversity movement that advocates for difference in neurology to be seen as a natural variation.

Autistic researchers and writers have long described the difficulty of living in a non-autistic world (Hendrickx, 2015) and the pressure to conform. A study into the experience of children with Asperger's Syndrome described individuals' adopting these social values into their identity, with participants describing themselves as "not normal," reinforced by ex-

periences of bullying and victimisation (Humphrey and Lewis, 2008). The children were aware of the pressure to conform and wanted to "blend in" to social norms, despite the price of a compromised sense of identity (Humphrey & Lewis, 2008). Common metaphors of autism such as "alien," "locked in," perhaps further intensify the sense of exclusion from the "landscape of what is normalcy" (Broderick & Ne'eman, 2008:464).

The non-visible nature of autism means that, along with other hidden disabilities and differences, it inhabits an ambiguous space, as neither able nor disabled. Individuals can experience challenges to the legitimacy of their difficulties, alongside stigma for being outside of the norm, resulting in further isolation and exclusion. Autistic adults have described the experience of "not quite fitting in", being caught between being seen as "not normal" and yet having their difficulties ignored (Portway and Johnson, 2005:66). Some individuals describe being told they are "too social to be autistic" (Hughes, 2014). Such statements demonstrate the difficulty of this "in-between" status. The possibility of "passing" also raises the issue of knowing when and how to hide and when to disclose one's disability status (Davidson & Henderson, 2010). This complex negotiation is even more challenging for autistic individuals who struggle with appraising and reacting to social situations (Davidson and Henderson, 2010; Cox et al., 2016).

Social models of disability are not without their limitations. Some argue that such models perpetuate unhelpful dichotomies between disability and impairment and create restrictive narratives of oppression (Shakespeare, 2006). This is of particular relevance within the autistic community, where some autistic people will define themselves as disabled and find the medical paradigm helpful in understanding and accessing services, whilst any pathologisation would be abhorrent for others.

Anderson-Chavarria (2021) puts forward a predicament model of autism to acknowledge the variation and nuance of individuals' experiences. Predicament is defined as "an unpleasant, trying, or dangerous situation" created through the interaction of the individual with their environment (Shakespeare 2008, 242). In this way, autism can be both biologically based as well as socially constructed. The predicament model has been used to explain the variation of experience and identity within d/Deaf communities, where some see their Deafness as a linguistic difference, whilst other deaf individuals may embrace the term disability. Similarly, autistic individuals vary in whether they view their experience as disabling or merely different.

Furthermore, an individual may want certain aspects of their autistic experience recognised as an impairment that receives support, whilst other parts of their autistic identity are celebrated and seen as only disabling due to the non-autistic bias of society. The predicament model arguably allows this apparent dichotomy to be seen as a common part of an expansive, nuanced view of autism. In this model, the individual is not seen as a "tragic" figure; however, society still plays a role in dealing with issues of access and citizenship (Anderson-Chavarria, 2021). This research will adopt a predicament model of autism that "leaves room for the agency of the actors" to reject or embrace the concept of disability (Anderson-Chavarria (2021:13).

### 3.2.3. Feminist Disability Studies

After the disabled people's campaign grew in the 1980 and 90's some disabled women challenged a tendency within the movement to homogenise the experience of disabled people, obscuring how gender differences affect experience (Bê, 2019). Others chal-

lenged the lack of inclusion of disabled women's stories within feminism, favouring a competent and powerful female ideal (Fine and Asch, 2009), and accepting stereotyped beliefs regarding disabled and older women as dependant by default (Thomas, 2007). Notably, disabled feminists critiqued the distinction between impairment and disability within the social disability model; where the former is seen as personal, and only the latter holds social significance (Bê, 2019). Thomas (2007) argues that disability and impairment are inherently interconnected, as demonstrated by her term "impairment effects", in which she describes the impact an impairment has on an individual's "embodied functioning in the social world" (Thomas 2010:37). For example, physical, sensory differences experienced by an autistic person will have particular consequences for how they perform in the world. However, social expectations concerning acceptable background noise levels inevitably immerse this experience within the social world (Thomas, 2010).

Another feminist disability theorist, Wendell (1996), also disputes the tendency to think of disability and ability in binary terms. She points to those in the Deaf community who refute the term disability, whilst others with invisible conditions consider themselves disabled despite this being unacknowledged in wider society. The emphasis on seeing beyond binaries seems particularly relevant when discussing autism, where (as highlighted previously) there is debate in the autistic community concerning its categorisation.

Proponents of feminist disability studies (FDS) highlight how both female and disabled bodies have been and continue to be seen as inferior, and critically examine how gender and disability affect concepts and societal norms concerning the body, reproduction, physical appearance, and independence (Garland-Thompson, 2005; Ahlvik-Harju, 2016). However, Garland-Thompson (2005) also notes that although constructionist arguments

are useful to emphasises the role of the social world in understanding disability, an individual's embodied experience still requires practical acceptance and accommodation. As with the predicament model, Garland-Thompson highlights the need to see disability as a complex, bio-social phenomenon, crucially giving room for the breadth of individual experience.

Historically, autism was considered a predominantly male diagnosis; however, research has revealed a greater prevalence in non-male individuals in recent years (Loomes et al., 2017). Nevertheless, it is crucial to critically examine the literature, social commentary and experience of autistic individuals through the lens of gender and disability to readdress this longstanding bias.

# 3.2.4. Intersectionality

The experience and understanding of neurodiversity, gender, and disability are complex, "multi-dimensional and cuts across the range of political, social and cultural experiences." (Watson; 2012:194) This study recognises that the participants hold multiple identities and potentially multiple minority statuses that impact their experience. First coined by the feminist Kimberley Crenshaw, proponents of intersectionality argue that an individual's multiple identities lead to a unique experience of discrimination (Kim, 2016). Autistic women are a minority within an autistic minority, which has an extraordinary impact on their lives. Consequently, it is essential to consider the unique way gender, identity, representation, and ability/disability may influence participants' experience (Yee, 2013).

# 3.3. Qualitative research

In recent years, there has been more research into camouflaging; however, only a few studies look deeply into the specific experience of camouflaging for autistic women (Bargiela et al. 2016, Lai et al. 2016, Webster and Garvis 2017). In order to more closely examine the lived experience of this particular group, a qualitative approach will be used within this study. Qualitative research methods can be instrumental when exploring complex phenomena in a natural setting (Howitt & Cramer, 2011), generating rich textured data (Pistrang and Barker, 2012), and searching for meaning (Beaton and Clark, 2009). This is particularly relevant to camouflaging, which by its very nature involves complex interactions with the social environment. Various studies have examined the prevalence of camouflaging using quantitative methods; however, there remains ambiguity concerning the most accurate and helpful way to define and operationalise the phenomena (Fombronne, 2020; Alley 2018). A qualitative design using an inductive approach can help generate a more comprehensive picture of camouflaging (Lowhorn, 2007). As mentioned previously, this study takes a social constructionist stance, in which each person's understanding of reality is influenced by their unique position and interactions with the world. Qualitative research also draws on constructivist beliefs, focusing on capturing diverse personal experiences without determining a definitive truth (Teherani et al., 2015). Crucially, qualitative research allows the participants to describe their experiences in their own words and helping to redress power-imbalances, particularly in marginalised groups such as autistic people (Pistrang and Barker, 2012).

## 3.3.1. Narrative approaches to research

Narrative approaches to research includes a wide range of methods (Erin, 2011). The narrative researcher can respond fluidly and expansively to the evolving phenomena, but this also means that narrative approaches can be difficult to explain (Connelly & Clandinin, 1990; Riley and Hawe, 2004). Narrative approaches can be broadly seen as developing from two branches of academic research; from the humanist tradition in western psychology and sociology, where the focus is on the individual storyteller, and from within the post-modern ontology, which emphasises multiple perspectives and the meaning within narratives (Esin, 2011). The narrative turn, in the 1980s, represented the study of narrative expanding outside of literary specialists, providing a new means of insight across multiple disciplines (Kim, 2016).

### 3.3.2. What is narrative?

The term narrative refers to both a "telling" as well as a "knowing" (McQuillan, 2000). We use the term to refer to the telling of stories, and the knowledge or understanding of a situation or series of events (Kim, 2016). Throughout human history, from myths to movies, and to our everyday moments, we have interpreted our experiences and retold these in multiple ways. Narratives are a profound way of giving meaning to experience (Esin, 2011). Generally, it is agreed that narrative is a telling of events that are organised in a sequence to convey meaning (Kim, 2016:8; Squire et al., 2014). A general definition of narratives would include signs, visuals, acted, and written and verbal data, as the elements making up this sequence (Squire et al., 2014). A story is the detailed organisation of narratives within a structure that may not be chronological (Kim, 2016). Riley and Hawe (2005) suggest that narratives can be identified and revealed through the analysis of stories. Both stories and narratives are subject to interpretation and reveal something about the teller, the audience and what is known (Kim, 2016).

### 3.3.3 Models of narrative research

There are multiple models, or methods, of narrative inquiry, and suitability will vary depending on the nature of the research, for example, the epistemology stance (Kim, 2016). Many researchers have found Polkinghorne's distinction between analysis of narratives and narrative analysis useful. The former finds order, themes, and classification across data sources, creating general understanding based on deductive or inductive inquiry (Kim, 2016). On the other hand, Polkinghorne (1995) described "narrative analysis" as looking for the events and actions to create a plot and a coherent story. The aim is to help the reader understand the how and why of participants by drawing disconnected data to a meaningful sequence (Kim, 2016).

Other narrative models include structural, thematic, and interactional or performative (Esin, 2011). The structural model, first proposed by Label and Waletzy (1967), examines how the narrative is formed and the clauses that form the abstract, orientation, complicating action, result of the story, and subsequently how the individual evaluates this story. Thematic models, most notably Riessman (2008), examine the content and themes within stories, whilst interactional or performative models (Riessman, 2005) focus on how meaning is collaboratively made between speaker and listener. The models most relevant to this study will be explored in more detail later.

### 3.3.4 Narrative Inquiry

This study will use the methodology of narrative inquiry, which prioritises the lived experience of the participant, and getting as close as possible to their subjective experience (Abkhezr, et al., 2020). The focus is on being attentive to the social contexts, cultures, and

spaces that life stories are constructed, lived and told (Abkhezr, et al., 2020). The importance of narratives is in their ability to make human experience meaningful (Polkinghorne, 1988). Humans are meaning-making beings or "storytelling organisms" (Connelly and Clandinin, 1990:2). Individuals create narratives (both real and imagined) to make sense of their experience, express emotions, beliefs, values and identities (Fraser, 2004). Based upon a constructionist epistemology, narratives are the ongoing process of meaning-making through interaction and from which a sense of self is constructed (Phoenix & Sparks, 2008). The question is how the storytellers are making sense of their experience, how they position themselves, and how social interaction affects their stories (Esin, 2011). In opposition to an empirical stance, narrative inquiry aims to capture (without attempting to imitate exactly) the subjective and continually evolving experience of human lives (Clandinin & Rosiek, 2019). However, narrative inquiry is not solely collating and retelling experiences:

"The researcher's role is to interpret the stories in order to analyse the underlying narrative that the storytellers may not be able to give voice to themselves" (Riley & Hawe, 2005:227)

Narrative inquiry focuses on the study of individual "lived experience as a source of knowledge in and of itself that warrants deeper understanding." (Nasheeda et al., 2019:1). It involves studying material, including data already in narrative form, such as film and literature, and creating narrative data through interviews, life storying, journaling, photography (Squire et al. 2014). Narrative inquiry may look at the "narrative structure", what is said, grammar, syntax and what can be deduced for these aspects. Alternatively, researchers may examine the "narrative content", what is being said, or the "narrative context", i.e. where the story is examined within its historical and cultural background (Squire et al., 2014). Researchers could be looking into individual narratives for the plot,

characters, context, and themes (Squire et al., 2014). Alternatively, narrative inquiry can look across many individual stories to find themes within the data and relationships between these, and then employing the data temporally and contextually into a cohesive whole (Polkingthorne, 1995). Analysis can involve looking for themes within and across individual stories, moving between the two in a hermeneutic circle (Squire, 2016).

### 3.3.5. Narratives and Identity

Our sense of self and identity is formed through stories about who we are, the world and other people (Murray, 2015). Riessman (2005) argues that through the stories we tell or encounter, we construct our identities and position ourselves socially and culturally (Nasheeda et al., 2019). When we describe ourselves and our lives, we reflect and (re) construct our identities in ways that impact our emotional and physical well-being (Barker et al. 2020). Riessman & Speedy (2006) argue that in recent years narrative and identity have become more interlinked; due to the increased social freedom within contemporary life, individuals have to construct who they are and how they want to be known. Consequently exploring narratives, and narrative analysis specifically can be a valuable pathway to understanding individuals' identity (Watson, 2007)

The themes of masking, camouflage, identity and narrative have long been closely intertwined (Pollock, 1995; Biggs, 2004). Storytelling can be used to mask (hide/transform) emotions and identity (Murray & Holmes, 1994), and masks can tell stories about identity (Pollock, 1995). Historically and culturally, masks can conceal and transform one's individual and social identity (Pollock, 1995). Consequently, a narrative approach seems particularly pertinent when researching camouflaging, masking, social interaction, and identity. Furthermore, narratives can be beneficial when dealing with distressing or incoherent life

events, such as diagnosis and illness (Carlick and Biley, 2004). Stories can help make sense of such changes and facilitate self-understanding and agency (Frost, 2009). There has been some research into the narratives that people create to understand their autism (Gray, 2001; Jimenez and DeThorne, 2019). Gray (2001) spoke to autistic parents and identified narratives of accommodation (aligned to predominantly medicalised conceptions of "normalcy" and centring on adaption), resistance (rejecting ideas of "abnormality" and embracing advocacy) and transcendence (identifying with faith as a way of meaning-making). Gray's (2001) study exemplifies how narrative inquiry can reveal individual experiences, contexts surrounding them, and the relationship between the two.

Narrative inquiry can examine the individual in context, the situational and the personal. The narrative researcher also welcomes multiple truths and viewpoints, weaving together different strands of experience (Fraser, 2004). Narrative inquiry is sensitive to subjective meaning-making, social processes and how these inform our understanding of self and society (Frost 2009). Exploring what cultural discourses lay behind a person's story, might offer more understanding than what is first perceived allowing for a deeper view of the person's life (Riessman & Speedy 2006). Consequently, narrative inquiry has often been used to explore the identity of new social groups and minority social groups (Frost, 2009; Davidson & Henderson, 2010). It allows consideration of how individuals make sense of their lives within a broader social context (Kanfiszer et al., 2017), including cultural norms around gender, disability, and power (Squire et al., 2014); as well as exploring stories that support dominant social practices and those that contest and critique them (Fraser, 2004). Narrative inquiry is based within a social constructionist ontology and, therefore, can be particularly sensitive to power dynamics within relationships and social structures (Kanfiszer et al., 2017; Squire et al., 2015) and is often used in research applying feminist or criti-

cal frameworks (Kim, 2016). Consequently, narrative inquiry is advantageous when considering the lives of autistic adults who have been identified as some of the most excluded people within society (DoH, 2010).

When working with a minority population, it is even more important to recognise the inherent power imbalance within the researcher-participant relationship (Hoshmand, 2005). Mishler (1986) notes how the interviewer naturally has greater control as they determine and ask the questions. Narrative inquiry emphasises the collaboration and co-creation between researcher and participant (Nasheeda et al., 2019). Squire (2013) highlights that interviewers have an inherent responsibility to uphold interviewee rights. Mishler (1986) argues that to most clearly hear the stories of others interviewers must invite respondents to collaborate. In line with this approach within this study, participants will be asked to comment on a draft analysis of their interview, which will be included in the writing-up process. Narrative approaches also acknowledge that the researcher is more than a mere listener; their presence impacts the co-construction of the narrative (Riessman, 2005). Consequently, reflexive analysis of the role of the researcher will be considered throughout the research process (Squire, 2016; Riessman, 2005), considering how the personal background and cultural discourse may influence the analyses and interpretation of the data.

## 3.3.6. Consideration of alternative methodologies

When considering the methodological approach for the study Interpretative Phenomenological Analysis (IPA) was also considered. IPA's idiographical stance means it can be beneficial when exploring the complex and unique experience of particular groups of people, such as autistic individuals (Smith and Osborn, 2015). Furthermore, IPA's attention to broader contextualised factors makes it a fruitful tool for cultural research and has already been used to explore the lived experience of autistic individuals (Reid, Flowers and Larkin, 2005; Davidson, 2007). IPA's focus on "giv[ing] voice to the concerns of participants" (Larkin et al. 2006:102), through close reading and analysis of the data, assists in uncovering aspects of the phenomena beyond the researchers own perception.

Despite the benefits of IPA, the focus of narrative approaches on how we make sense of our identity and selfhood (Murray, 2015) is particularly relevant when exploring issues of camouflage. Furthermore, narrative inquiry can provide both a voice for autistic adults and potentially uncover social and cultural beliefs and practices that challenge their self-expression and agency. Narrative approaches view the narrative as living within the participant and a co-creation of the dialogue between the participant and the researcher and encompassing the broader reality (Andrews, Squire and Tamboukou, 2013). This approach is advantageous in examining the themes of relationships, social norms, and stereotypes central to this study. Kim (2016:233) highlights how narrative analysis aims to assist the reader in confronting their prejudices and broadening their horizons to "transpose [themselves] into the other's situation". Arguably, the social constructionist basis of narrative inquiry, highlighting how one account can reveal many "interpersonal and societal functions" and values (Harper, 2011:6), is more equipped to present such a social critique in comparison to IPA.

Furthermore, the fluidity of the narrative inquiry enables a more flexible approach which can be particularly useful when interviewing individuals with different communication needs (Gilbert, 2004). For example, narrative researchers may respond with a variety of interview strategies, including a more "give-and-take dialectic" (Polkinghorne, 2005:142),

asking about specific events or materials, or using pictures, video and other media (Andrews, Squire and Tamboukou, 2008). The adaptability of this method is arguably helpful to respond appropriately to the needs of those with varying communication abilities.

### 3.3.7. Narrative studies into autism

There have been a small number of studies using narrative methods exploring the experience of autistic people in recent years (e.g. Kanfiszer et al., 2017; Krieger et al., 2012; Webster & Garvis, 2017). The study by Kanfiszer et al. (2017) explored the experience of seven women diagnosed in adulthood. The researchers used a multi-stage narrative analysis as it enabled them to shift between a broad profile of events and the individuals' personal experiences (Kanfiszer et al., 2017). The authors note that narrative inquiry "accentuates the power and importance of individual voice and variation" to challenge existing dominant discourse concerning this excluded group (Kanfiszer et al., 2017:663). Kanfiszer et al. (2017) began by identifying the stories in each transcript using Labov and Waletsky's 1967 framework of narrative structure, and then these stories were analysed, highlighting patterns of language and salient concepts to create themes that were compared across stories. The data analysis reveals two key concepts of gender identity and social relationships, looking into how women experience and deal with gendered expectations and social situations. Krieger et al. (2012) looked into the experience of autistic adults within the workplace. The authors used semi-structured and open interviews, then analysed the data through Polkinghorne's narrative structure, creating a narrative and then plot each transcript. The participants were able to review and amend the researcher's interpretation of their stories. The second step in the analysis involved looking for meaningful experiences within each narrative; the researchers then assessed the type and structure of the narrative and finally triangulated the different data types to derive the inherent narrative meaning. The researchers noted adaptions they made to the data collection approach (e.g. adapting the environment, having both open and semi-structured interview questions) to adjust to the autistic participants' needs adequately.

Webster and Garvis (2017) interviewed ten autistic women about what had helped them achieve success in their lives. They used a multi-stage narrative approach, namely narrative thematic analysis, followed by Connelly and Clandinin's (1990) Broadening, Burrowing and Restorying (BBR). The data highlighted that internal and external factors were essential to aid the women in achieving success, including the impact of diagnosis on their identity and having support from others. They argued that using this narrative approach facilitates the lived experience of the women being explored and told (Webster and Garvis, 2017).

# 3.3.8. Narrative models of analysis

As demonstrated by Webster and Garvis (2017), researchers can adopt a pluralistic approach to narrative analysis, which utilises the strengths in each model to articulate the participants' voices (Frost, 2009; Kansfizser et al. 2017; Grafanaki & McLeod, 2002). This can result in a more nuanced multi-dimensional understanding of the participants' experience (Frost, 2009). In line with Webster and Garvis (2017), this study combined thematic narrative analysis with Clandinin and Connelly's BBR technique. The former method facilitates examination of the interview's content, and the latter examines the personal and social context. The combination of narrative and thematic analysis to create a "bricolage of methods" has often been used, particularly in psychotherapeutic research (Riessman and Speedy, 2006:430).

Thematic narrative analysis views language as a resource to be mined rather than the topic of the inquiry (Riessman, 2008). It focuses on the "what" of the story and identifying common themes across cases (Ronkainen et al., 2016). This contrasts the structural model (Labov 1972), which focuses on how the story is formed and told, looking for clauses representing time or the narrator's perspective (in Esin, 2011). One of the weaknesses of the structural approach is that it can de-contextualise the narrative, potentially disregarding the co-constructed or social-cultural context of the text (Riessman, 2008). Furthermore, a structural analysis will often look in greater detail at the narrator's speech patterns, word choice, and associated meaning. Autistic individuals may have an idiosyncratic use of language or a difference in pace of speech not due to conveying meaning but difficulties or differences in communication style. Thematic narrative analysis (TNA), on the other hand, does not examine the use of language in such a specific way, instead focusing on the content of what is being said (Riessman, 2008). Esin (2011:108):

"The thematic model is useful for theorising across a number of cases, finding common and different thematic elements between the narratives of different re search participants."

Unlike standard thematic analysis, TNA focuses on the individual story, noting continuity, story coherence, sequences, and exemplary narratives (Ronkainen et al., 2016; Riessman, 2008). TNA also looks across participants stories for meaning and to identify connections between individual narratives and societal structures, such as inequality and power (Riessman, 2008). In this respect, TNA aligns with Connelly and Clandinin's (1990) BBR interpretative techniques, which purposefully examine the broader contextual factors impacting an individual's story. Strongly influenced by the work of Dewey, Clandinin and Connelly (2000), view experience as both personal and social, and individuals need to be understood within the context of their relationships and their environment. Narrative examination of research data involves thinking about the:

"negotiating transitions, negotiating purposes, negotiating ways to be useful, and negotiating transition" (Clandinin & Connelly, 2000:129).

Although Clandinin and Connelly (2000) have primarily concentrated on research into education, their focus on both the individual and understanding the relational and social context is particularly appropriate when exploring identity and minorities.

Furthermore, they view narrative inquiry as a relational endeavour, mindful of the power dynamics between researcher and participant (Clandinin and Connelly, 2000). For analysing data, Connelly and Clandinin (1990) suggest three interpretative tools; broadening, burrowing and restorying. These techniques are also used to "seam together" the narrative material gathered into a more coherent whole (Kim, 2016:207).

# 3.3.9. Broadening, Burrowing and Restorying

The tool of broadening explores the context of the story, the participants' background, the social, historical and cultural milieus (Kim, 2016). General comments about the person's character, values, and the social, cultural and intellectual context or the time are made (Clandinin & Connelly, 1990). Broadening also facilitates the identification of characteristics, circumstances and values across participants' stories. Mishler (1986) describes how through the process of broadening the storyteller's circumstances and general knowledge of the topic can be brought into the analysis; for example, drawing on understanding from previous research into camouflaging, women and autism. Labov and Fanshel (1977) refer to a similar technique, "expansion", where the local and general circumstance of the speaker is brought into the analysis. Broadening enables the social-cultural experience of participants to be included within the study.

The second process of burrowing focuses on capturing the participants' point of view during these life events (Connelly & Clandinin, 1990). This involves a deeper examination of the unique dilemmas, understandings and emotions each of participant (Kim, 2016). Webster and Garvis (2017:6) describe this as:

"listening closely to how individuals connected their life experiences together to make sense of them."

When burrowing, we are questioning why these experiences have led to these feelings and what other factors may link to their origin, similar to narrative therapy (Connelly & Clandinin, 1990). The final stage restorying concerns how the participant retells their story, how they return to the past, present and future in light of this:

"how he or she might create a new story of self which changes the meaning of the event, its description, and its significance for the larger life story the person may be trying to live." (Connelly & Clandinin, 1990:11)

The final narrative lens, restorying, focuses on the temporality of the data. This includes looking at how narratives are temporally situated, as well as how they shift and change over time (Connelly and Clandinin, 1990). The restorying process can include asking participants to reflect on previous interviews or a first draft of the analysis (Craig, 2012). Restorying also incorporates how the researcher retells the data to bring the experiences of the participants to the fore (Kim, 2016). Connelly and Clandinin (1990) note that this restorying process is not simply presenting the data but considering how the inquiry process enables the discovery and construction of meaning. Researchers can use one or all of these interpretative tools (Connelly & Clandinin, 1990).

# 3.4. Process of Data Collection

# 3.4.1. Participants

There are no set guidelines on the number of participants required within qualitative studies. The type of study and research area determine the most appropriate number of participants, aiming to reach data saturation, with enough information to provide a sense of closure (Moser and Korstjens, 2018). Previously, qualitative studies into the experience of autistic people, including through the use of narrative methods, have used relatively small sample sizes. Webster and Garvis (2017) interviewed ten women, Kansfizer et al. (2017) interviewed seven women, whilst Krieger et al. (2012) had six participants. Guetterman (2015) argues that when establishing the sample size, refer to previous literature but remain open to possible changes as the research progresses. Accordingly, and in reflection of previous research, the initial sample size was eight to ten participants, with a final nine participants recruited.

As the population was specific to ensure a well defined and homogeneous sample, purposive sampling was used to identify participants who belonged to this group. Adverts were placed in autistic social groups within London and the South East, including autistic women's groups. Details of the study were also passed to professionals within the National Autistic Society, ALAG and LIMA West Sussex autism service, all of whom support autistic adults in London and the South East. This information was shared online, and consequently, participants from across the UK requested to participate in the study.

### 3.4.2. Inclusion criteria

Participants were required to have a diagnosis of autism spectrum disorder given by a suitably trained psychiatrist, clinical or educational psychologist. Participants also had to provide written evidence of their diagnosis. There were no restrictions on what age partic-

ipants received their autism diagnosis to maximise the potential participant pool as camouflaging has been documented in individuals with early and late diagnoses.

#### Recruitment

Inclusion/Exclusion Criteria:

- Women, 25-40 years. Written evidence of a formal diagnosis of Autism Spectrum Disorder. Fluent in English and attended main stream schooling. Not currently in mental health crisis (receiving crisis support services) Study to be advertised within:
- ASD social groups in London, Surrey, West Sussex and Hampshire. Colleagues and professionals in charities and autism specific services in London, Surrey West Sussex and Hampshire

Potential participants will be given contact details to receive more information on the study.

#### Pre-selection Stage

Participants contact the researcher and are given detailed information on the study

If participants still wish to take part they are asked to complete a short questionnaire on their camouflaging

#### Selection Stage

- Participants that use camouflaging behaviours and comply with the exclusion/inclusion criteria will then be asked again if they would like to take part in the study.
- If participants do not camouflage and/or full study criteria, they will be thanked for their time and given information on services and other research they may be interested in.

#### Consent

- The details of the study and consent process will be reviewed with the participants, including:
- Written and verbal information on the study
- Written and verbal information on the process of consent and withdrawing consent
- Written and verbal information on how confidentiality will be maintained.
- Consent will be obtain from the participants
- Participants were asked when, where and how they would prefer for the interview to be conducted.

#### Data Collection:

- Demographic data; age/ethnicity/age of diagnosis/type of diagnosis/employment/relationship status.
- This will involve a semi-structured interview process (see appendix 1 for interview questions), however it will be adapted to the participants needs, particularly whether they prefer to have more prompting questions
- Written information, communication cards and adaptations to the environment will be considered, see special ethical considerations section)
- Interviews will be audio recorded

#### **Analysis**

- Anonymised transcripts of the interviews will be written up by the researcher
- Multi-stage narrative analysis will be used, specifically
- Stage 1: Identifying themes within the individual transcripts and across the transcripts
- Stage 2: Connelly and Clandinin's (1990) Broadening, burrowing and restorying method of analysis

### Dissemination

- To share the findings through poster presentations at local and national autism events. Including facilitating discussion groups for individuals with ASD on the topic of camouflaging
- Aim for publication in relevant journals, including autism focused magazines.

The sample was limited to women between the ages of 25-40. The literature suggests that changes in the social environment linked to ageing can impact camouflaging behaviour (e.g. development in peer's interactions between childhood and adolescence, (Dean et al., 2017). Therefore, limiting the age to early-mid adulthood aims to increase the homogeneity in the sample. Participants also needed to be fluent in English and to have gone through mainstream schooling. After the participants registered interest in participating they was asked to complete a short camouflaging questionnaire (see appendix v). This initial questionnaire confirmed that participants were currently using camouflaging strategies, and also asked for brief information about where they camouflaged and in what way. This provided written data that was later reviewed in the broadening stage of analysis.

### 3.4.3. Exclusion Criteria

Individuals with intellectual disabilities were not included in the study, as they may have struggled to express themselves verbally within the interviews and to increase homogeneity. Participants who experienced or were diagnosed with mental health disorders were not excluded from the study. There is a high level of comorbidity between autism and mental health difficulties, and therefore exclusion on these grounds would limit the number of potential participants (Tantam, 2013). In addition, as noted in the literature review, camouflaging can lead to anxiety and depression; therefore, exploring mental health difficulties may be a significant aspect of the study. However, individuals receiving support from crisis services were excluded from the study and signposted to further support.

Some individuals wanted to participate in the study but did not fit the criteria, and it was essential to respond sensitively and clearly explain why they could not partake in this research. They were thanked for their interest and signposted to the Autism Research Centre, where autistic individuals can register for a wide range of studies across the UK.

### 3.4.4. Interviews

The method of interviewing is widely used within narrative inquiry (Mischler, 1986). The way an interview is set-up and conducted impacts the participants and influences the accounts of their experience given (Clandinin & Connelly, 2000). When organising the interview, I regularly checked that the participants were happy with the arrangements and our communication style. All the participants responded to the advert via email, and so initial communication continued in this format. Bearing in mind differences in communication for autistic individuals (Tantam, 2013), the participants were given the choice of arranging details by phone if preferred. See figure 1 illustrating the process from advertising to analysis, detailing how participants preferences and agency was acknowledged.

The participants were able to choose the time and location of the interviews, and three participants chose a local community venue they were familiar with and felt comfortable in. However, due to the COVID pandemic, the subsequent interviews were conducted remotely. Participants were given the option of choosing either video calling or audio calling, as it was recognised that there would be differences in communication style and ability. The video calls meant that the participants' non-verbal communication could be observed, bearing in mind that the participants non-verbal presentation may be different in comparison to non-autistic expectations.

One participant requested a phone call as they felt uncomfortable with video calls and struggled to process the visual stimuli. Although this visual data was missing in the phone call, a good rapport was quickly established, and the participant felt at ease and more able to communicate than would have been possible using a video call. Working remotely inevitably affected the quality of the co-created relationship with the interview. For example, when face to face with the participants, I was more aware of my body and making the environment as suitable as possible to their sensory needs. This may have affected the nature of the relationship, and, notably, it was within one of the face to face interviews that a participant referenced my body posture and hypermobility as a source of similarity between us. However, for all the participants, a rapport was quickly established, and issues of embodiment arose in the content. Furthermore, not being in the same physical space may have enabled some participants better communicate and feel more connected to their bodies, as they did not have to cope with numerous novel stimuli.

Facilitating participant choice in terms of the style and set-up of the interview can partially mitigate the inherent power imbalance within the research process (Clandinin & Connelly, 2000; Emerson and Frosh, 2004: 26). Having less restrictive and more open-ended questions is one way of attending to this power inequality, enabling participants to feel in control and freely express themselves (Frost, 2009). For some autistic individuals, however, open-ended questions can be ambiguous and confusing, and therefore inhibit their ability to express themselves (Cridland et al., 2015). Consequently, I created a series of open but specific questions, with follow up prompts that could be used if participants required further clarification. My supervisors reviewed these questions (see appendix vi) to ensure their suitability for the participants and the research aim. I reminded the participants that they could ask me to clarify, rephrase, repeat, or give time for processing at any point.

Some of the participants did query questions, which led to fruitful conversations about the meaning of the questions and their understanding of concepts. Crucially, I was aware of attuning my pace and use of language to match the participant. Participants were also given visual cards to use if verbal communication became difficult and were encouraged to take breaks, use sensory equipment and movement if they needed to.

Riessman (2008) argues that the specific wording is less important than the interviewer's attentiveness and engagement with the participant and the level of rapport and reciprocity created. The semi-structured nature of the interview provided flexibility, and participants were encouraged to speak freely (Erin, 2011), allowing their unique experiences to be explored. I was also careful to minimise unhelpful interruptions and leave silences to facilitate processing (Esin, 2011). Conversely, some autistic people may become fixed on a single train of thought and speak consistently without breaks for a significant period, later reflecting that they did not discuss other subjects that were important to them (APA, 2013). Consequently, with some participants, I asked if they were happy for me to "jump in" and pose a new question or reference a previous point, with the understanding that they could continue on their line of thought if they preferred. Due to these differences in communication style some of the participants "jumped around" when describing their experience, and the order of the questions varied. Providing non-judgemental validation and attentive attuned listening was central to facilitating the participants' voices (Esin, 2011).

### 3.4.5. Ethical considerations

Consideration of ethics is a vital part of all research, most importantly ensuring that participant wellbeing is forefront throughout the process (Koller, 2008). Ethical approval for this

study was obtained from Middlesex University, and a complete ethics application can be found in appendix 1. The ethical dilemmas and actions to minimise the risk to participants will be outlined below. This is based upon the British Psychological Society's Code of Human Research Ethics (BPS, 2021) and the Health and Care Professions Council's standards of conduct, performance and ethics (HCPC, 2121).

### • Risk of harm:

The risk to the participants was minimal; however, it was possible that individuals may feel upset when speaking about their experiences. It was made clear to the participants in the Participant Information Sheet (PIS) that they may find some of the questions distressing, therefore allowing them to make an informed decision before consenting. The participants were also reassured that they were not obliged to answer any questions they felt uncomfortable with and could stop or take a break at any time. The combination of open questions and probes was utilised to allow the participant to have agency over the conversation allowing them to control how much or what they revealed. The participants were encouraged to make themselves as comfortable as needed during the interviews, using sensory equipment or changing the environment to minimise distress. There were also communication cards on hand to signal if they wished to take a break or stop and were unable to verbally articulate at that time. No participants required these systems, and all participants reported finding the interviews a positive and helpful experience.

### Consent

It was essential to gain valid informed consent. To this end, the participants were given a PIS when they first registered interest in the study. They were informed that if they preferred this information in a different format (i.e. verbal, with symbols), this would be pos-

sible. The participants were encouraged to ask any questions about the study and reminded that they could do this in whatever communication format they preferred (verbal, email). Before the interview began, the study details were reviewed with the participants, and they were encouraged to ask questions. They were also reminded that they had no obligation to participate in the research, and not taking part would not affect their care or access to services in any way.

### Confidentiality and anonymity

The participants were informed that their anonymity would be maintained within the transcript and final writing up. This included explicitly explaining the process of this so that participants could make an informed decision. This was explained both verbally and in writing, giving participants a chance to ask questions.

# Debriefing

At the end of the interview, the participants were asked how they felt and given an opportunity to reflect on the interview process. They were also given information on helpful support services if desired, including free autism support organisations. If any participants did require support for an issue of risk or safeguarding, they would have been directed toward the appropriate mental health or social care service.

### 3.4.6. Methodological rigour and validity

Validity within qualitative research refers to the extent to which the findings accurately and legitimately represent the participants' realities and social phenomena (Yardley, 2015). Good narrative inquiry involves seeking trustworthiness and validity while recognising that narrative data are not a perfect record of events (Kanfiszer et al., 2017). There are

multiple ways of viewing qualitative validity, including triangulation, thick description, peer reviews, and external audits (Yardley, 2015). The strategies employed within this study are based on the research's methodology and theoretical and epistemological foundations (Creswell and Miller, 2000).

Yardley (2015) highlights the importance of sensitivity to the context, i.e. that the study allows meaning and patterns that have not been previously specified to emerge from the data. Within this study, sensitivity to the participants perspective was facilitated by including open-ended questions and repeatedly re-reading and questioning the data, enabling meanings to emerge rather than imposed by the researcher (Yardley, 2015). A paper trail of the process from participant recruitment to writing up was also maintained, including records of the coding/theme generation stage, to evidence the accuracy of the findings (Creswell and Miller, 2000).

As the study formed part of a doctoral project with a sole researcher, limited time and resources were available. Consequently, it was not possible to co-produce from conception. Close collaboration and co-production can be extremely helpful in establishing the rigour of the project (Creswell and Miller, 2000). It also aims to stop further marginalising the participants' voice, particularly crucial when researching minority groups (Creswell and Miller, 2000). However, informally, I did discuss the project with members of an autistic women's group to find out their initial thoughts on exploring this topic. Furthermore, "member checking", described by Lincoln and Guba as one of the most crucial processes to aid creditability (1985), was undertaken. Summaries of the initial themes generated from the interview were sent to participants to consider and feedback on how accurately they felt these reflected their experience. These reflections and comments were incorpo-

rated into the final narrative. The participants were also asked if they had further comments about their experience at this later time, enabling a process of triangulation to be undertaken (Yardley, 2015).

Reflexivity is also essential in facilitating validity and transparency. I will outline my assumptions, beliefs, and biases linked to the study, specifically how they may have influenced the data and conclusions in the section below (Creswell & Miller, 2000; Yardley, 2015).

# 3.5. Reflexivity

Narrative inquiry acknowledges the constructed nature of meaning, and therefore reflexively considering my role within this "meaning-making" project is key (Mauthner and Doucet, 2003). My personal narratives inevitably shape the data and findings (Bishop & shepherd, 2011). More than mere reflection, reflexivity requires the researcher to scrutinise themselves as an object or Other and their relationship to the data (Kim, 2016). A reflexive researcher should be aware of what they are bringing to the research and how the findings affect their perceptions (Rinaldi, 2018). This form of self-critique, which challenges the notion of a non-biased researcher, is termed "confessional" or "subjective reflexity" and most commonly used within qualitative research (Kim, 2016:249). The researcher is the primary instrument of the data, with a continual back-and-forth between researcher and data throughout the research process (Watt, 2007; Rinaldi, 2018). Reflexivity is:

"The process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome." (Berger, 2015:2)

The process of reflexivity is crucial in establishing the validity of the research (Creswell & Miller, 2000). Reflectivity is critical to facilitate the participants' voice being central and to create data that is not merely an echo of my inner narrative (Bishop and Shepherd, 2011). Identifying how my biases and positionality may impact the research (and vice versa) allows the reader to more critically understand the data (Creswell & Miller, 2000, Horsburgh, 2003) and enhances the credibility of the research (Berger, 2015). This process of reflexivity is essential throughout the research process, from concept and design, through interview and interpretation of the data (Berger, 2015).

Within this section, I will reflect on my background, beliefs and values and how these may affect the research, and how the research has influenced me. This reflection is informed by personal notes taken through the research process.

I grew up with undiagnosed autistic people in my family. So, whilst there were no explicit conversations around neurodiversity, there was an awareness and acceptance of difference and valuing autistic traits. On the other hand, I also witnessed some of the social consequences of being neurodivergent, such as bullying. I believe this intensified my desire to "fit in" as a child and my interest in how different people engage with each other and the world. Since completing my undergraduate degree, I have worked for over 15 years with autistic individuals in various social and health care settings. In particular, I have worked with late-diagnosed autistic adults without an intellectual disability. As a result of my personal and professional experience, I have heard hundreds of different stories about autism and camouflaging. Themes of hiding and revelation, confusion, acceptance, self-assertion, autonomy and relationality, are all present when I consider what camouflaging means for me. In particular, how camouflaging seemed intrinsically linked to the unique

fabric of each individual's life. This perspective informed my desire to look deeper at the personal experience of camouflaging through qualitative, particularly narrative analysis. My experiences form part of my worldview, in particular the importance of acceptance, facilitating shared understanding, and the impact of social isolation. These stories colour my perception of camouflaging, and I must be mindful of how these will frame and possibly obscure the participants' stories (Mauthner & Doucet, 2003; Berger, 2015).

In order to help identify and bracket (Fischer, 2009) these assumptions, I noted down my reactions, thoughts, emotions throughout the project, as well as aiming to cultivate an "unknowing" stance (Spinelli, 2015). In line with Fraser's (2004) advice for narrative inquiry, this included considering how I felt before, during and after the interview, any insights or thoughts, my sense of the interview and what the participant was trying to convey. I also kept research notes that included ideas and commentary about the content of the research and personal reflections. Writing such notes can facilitate further thought and allow for examination and manipulation from a different perspective at a later time. This can help when identifying biases and how they may affect the research (Watt, 2007). When engaging with the collected data, I continually returned to the transcripts and the participants' words and checked initial findings with the participants. (Berger, 2015).

The other significant part of my personal history was my late diagnosis of dyslexia (another neurodevelopmental condition). I struggled with schoolwork; nevertheless, I worked hard and was considered a good student. As a child, I had not considered that I might be dyslexic but did see myself as careless and "not that bright". It was only when going back to studying at postgraduate level, that I received a dyslexia diagnosis. Dyslexia only relates to a specific aspect of functioning, whereas autism is by definition a condition that

impacts multiple aspects of one's way of being in the world. Consequently, I am incredibly mindful not to equate my experience to the unique and profound challenges autistic people face. However, I was aware that I resonated with some of the participants' stories on an emotional level. In particular, when they talked about the relief from getting a diagnosis and how this changed previous narratives of failure. Also, the experience of hiding difficulties in school, or work, was part of my own story. Some of the participants discussed their diagnosis being dismissed as they did not "look autistic". Kleege (1999) discusses how those with an invisible disability may avoid disclosing their disabled identity to protect themselves from being labelled a fraud. This dilemma is one I could relate to, having heard the "you can't have dyslexia" comment many times. Being aware of how my own story will affect and be affected by the research was essential. As part of my reflections, I noted how I responded when personally familiar topics were discussed and considered how this may impact my reading of the data. For example, noting my own different experience of diagnosis and consciously holding space for participants to have diametric and nuances responses. I used the phenomenological method of horizontalisation during interviews to consider all the information participants were sharing equally, rather than weighting attention in line with my own experience.

Within research, there can be is a binary distinction between researcher and participant, particularly when studying minority identities where the researcher is not part of that group (Rinaldi, 2013). However, my experience is not so static. As noted, dyslexia, like autism, falls within the category of neurodevelopmental conditions (APA, 2013). I decided to only mention my dyslexia if a participant directly asked. This was partly based on my training as a therapist to minimise dominating the agenda (Berger, 2015) and my awareness that dyslexia is very different from autism, and participants may view mentioning it as

irrelevant. I was conscious of finding a balance between resisting giving self-information that would be unhelpful for a participant (Cotterill, 1992) and fostering intimacy and connection through reciprocity (Oakley, 1981). I am also hypermobile, a condition associated with neurodevelopmental conditions, (Baeza-Velasco, 2018). For one of the interviews, the participant chose to sit on the floor. They noticed the way I was sitting and asked if I was autistic; I mentioned I was not but hyper-mobile and dyslexic, and they explained that they were hyper-mobile too and also liked to sit in this way. Potentially this shared experience would help participants to talk more freely with me, in part bridging the divide between participant and researcher (Berger, 2015).

My gender was another area of similarity with the participants and inevitably would impact the data (Berger, 2015). I was particularly aware of moments when there was a sense of shared understanding of the "business of womanhood". For example, when participants talked about assumptions linked to their gender, or discrimination they had experienced, there was a sense that I understood this experience of some level. Our similarity in gender potentially meant that participants were more comfortable sharing experiences with me (Berger, 2015). I was, however, cautious about making gendered or sex-based assumptions, particularly as being gender-fluid or gender-diverse appears to be more common in autistic populations (Murphy, 2020). For example, my previous knowledge led me to wonder whether appearance and gender featured in participants experience of camouflaging; however, I only probed into this area following one participant spontaneously bringing up the experience.

I was similar in age and ethnicity to the majority of the participants. Bishop and Shepherd state:

"Age, gender, background, and self-story, however, were all variables at play dynamically influencing our interactions and the data produced".

(Bishop & Shepherd, 2011:8)

These similarities potentially gave me a "fast-track" into understanding and relating to the participants' experience (Padgett, 2008). Having a similar background can also help participants to feel more comfortable and facilitate honest dialogue (Berger, 2015). For example, being of the same age and background meant I possibly had a sense of the social and cultural milieu of their upbringing. There are also challenges with having a similar position to the participants. There is a danger that shared experiences may mean participant stories that differ from this narrative would be withheld (Berger, 2015). Therefore, it was essential that I deliberately tried not to compare my experience to that of the participants, aiming to give space to the story and not making assumptions.

Despite certain similarities between my background and the participants, there is an inherent imbalance in the power dynamic within the participant-researcher relationship. Reflexivity is crucial in addressing the adverse effects of such a power imbalance and attempting to moderate the potential to dispassionately "other" the participants (Pillow, 2003). Within minority research (such as autism), considering the impact of one's perspective and privilege on the research process is essential (Rinaldi, 2013); it can help to shift the narrative from research about the other, to be for and by the other (Rinaldi, 2013). The term "neurotypical privilege" has been used by some autistic individuals (Nickerson, 2019) to describe the accessibility and power non-autistic people gain from living in a world mainly created for and by non-autistic people. As a non-autistic person, I have not experienced the discrimination, lack of accessibility, or social stigma that autistic and disabled people encounter, I am an "outsider" to this experience (Berger, 2015).

Furthermore, as a non-autistic person, the participants could educate me about their autism, holding an "expert" status (Berger & Malkinson, 2000). However, writers have also argued that researchers outside the chosen group may not conceive of the questions and concepts most relevant to the participants' experience (Berger, 2015). In line with Milton's (2012) double empathy problem, as a non-autistic person, I am potentially limited in my ability to understand autistic people, therefore impacting my research. Consequently, checking in with participants and encouraging honest feedback was vital for the credibility of the research.

My professional experience of working with autistic people may also have exacerbated the power imbalance. Due to the recruitment strategy (i.e. through social groups and autism organisations I have professional links with), most participants were aware that I was an autism practitioner. On the one hand, this may increase the participants' sense of comfort in talking about autism, as they assume I will understand their experience. However, my professional status could also make them cautious about disclosing, particularly considering the negative experiences of services some participants had been through. I attempted to address this power dynamic by adapting my behaviour and demeanour, sitting on the floor if the participant chose to, encouraging open and informal communication, explicitly encouraging the use of stimming toys or fiddles. Crucially, reminding participants that this research was not linked to any services and would not impact the support they receive in any way. I am also aware that due to supporting autistic individuals for many years, there may be a tendency to focus on moments of distress and vulnerability, potentially neglecting positive experiences. Consequently, deliberately watching out for this tendency and how it may bias my point of view was essential (Berger, 2015).

Engaging in the research has had a profound effect on me. Oscillating between moments of identification with the participants' stories, whether from a professional or personal perceptive, and the consciously shifting to a more (but never wholly) objective stance, could be emotional and thought-provoking. A parallel process of "re-storying" was occurring. As I was immersing in and re-storying the participants' narratives, my perspective on my own story was changing. Although my late diagnosis of dyslexia is very different and does not include the challenges and adversity autistic people experience, engaging in this research led me to reflect anew on the times I had hidden difficulties. After being diagnosed, I connected again with the powerful sense of relief and sadness for what I experienced as a child. I found myself being more open about my dyslexia and the current difficulties I have. In one way, the participants' stories of camouflaging, diagnosis, and subsequent adjustments to their self-identity and social behaviour, prompted me to more deeply reflect. This personal experience is one I reflected on but also put aside to view the participants' stories. The interconnection of these life threads, however, is apparent:

structed and negotiated between the people involved as a means of capturing complex, multi-layered, and nuanced understandings" (Goethals et al 2015:82)

On the other hand, the fact that it was only as a consequence of the research that prompted my deeper reflection points to the more powerful position I held as a non-autistic researcher. Arguably I was unencumbered with the stigma and challenges that led the autistic participants to have reflected on their identity and life-story in a much more profound way.

"stories of lived experience of both the subject and the researcher are co-con-

The process of reflexivity will never be "perfect"; it is not possible to fully bracket out our biases, fully know the impact we have on the participants, nor accurately reflect on our

past (Bishop & Shepherd, 2011). This reflexive process is temporarily fixed and, therefore, can only tell a story of the research from the position of my current self.

# 3.6. Illustration of data analytic process

A multi-stage narrative analysis was performed on the data. This enabled the participants' stories to be examined from multiple lenses to create a richer understanding of their experience (Frost, 2008). In line with research by Webster and Garvis (2017), I conducted a narrative thematic analysis, followed by Clandinin and Connelly's (2000) analytic tools of broadening, burrowing and restorying.

# 3.6.1. Stage one: transcription

I chose to transcribe the interviews personally by hand and used the process of "relent-less re-reading", as described by Garvis (2015:6), to get deeply submerged in the data. In line with Riessman's (2005) guidelines, initially, a rough transcription was completed, going through the entire interview noting the spoken words and prominent features (e.g. laughing). Following this, the interview was re-read, documenting shorter pauses and utterances (i.e. um). I reviewed my field notes as part of this process to assist in noting nonverbal or contextual factors that might be relevant (Frost, 2009). The position the researcher takes when transcribing the interview is also relevant (Esin, 2011). Riessman (2008:29) highlights two possible approaches; "co-constructed self", which focuses on the narrative in its given form and the interactional context in the transcript; and the second approach, namely "reflected self", which privileges the participant's speech, removes the interviewer's contribution, and interprets the oral features of the participant (e.g. pitch glides, pauses). The first approach was used within this study, transcribing both partici-

pant and interviewer, including all oral features. The co-constructed approach aligns with the social constructionist approach to the research; furthermore, the interpretation of utterances required in the reflected self method could potentially be erroneous with an autistic participant who may have an idiosyncratic communication style (Tantam, 2013). A pause or emphasising a word may not mean there is new or increased meaning in words being spoken for an autistic individual.

# 3.6.2. Stage two: narrative thematic analysis

Each transcript was read through multiple times to become more familiar with the participants' stories. Then a narrative thematic analysis was conducted (Riessman 2005, Riessman, 2008; Esin, 2011). Each transcript was analysed separately. The first stage was open coding of the data, highlighting meaningful units. Codes were created that described short segments of the data; these could be words or brief phrases that describe that data's content or essence (Riessman, 2008; Esin, 2011). This process was a combination of inductive and deductive, in that it was influenced by my understanding of the theory and the studies conceptual framework, but also allowed for fresh themes to emerge (Esin, 2011). See figure 2 with an example of the coding process.

Transcript	Coding
Participant: Umm, just having to trying to behave in a certain way to fit in with other people's expectations really, often in environments where it feel unnatural or uncomfortable and and kind of trying to blend in[um] and I think really, because I wasn't diagnosed with autism until I was 35 I didn't have a word for that for most of my life, I just thought it was something that everybody (laughs) did and that I was just quite rubbish at certain situations and didn't know why and so I think I put even more pressure on my self to do it (laughs) even though I didn't know what it was (laughs) because it was just "trying to be normal"	"No word for it" Feeling inadequate compared to others
it was just alying to be normal	
Interviewer: So pre your diagnosis, what was "me trying to be normal"?	

Yeah, it was kind of certain things that I knew made me very anxious, that I was bad at, so I would try to to compensate for that. But, for example, the things that most people, if I had to do public speaking or if I have to meet a new group of people in a work situation or have a job interview or things Most challenging like that, are the worst situations, cause it is people you don't know in an situations unknown situation, in an unknown place, having to make small talk with Exhaustion & negative impact of camouflapeople and I would just stress about these things for DAYS and days and days and try to plan what to SAY and how to behave and tried the normal ging Scripting and planstuff that people say, "oh well the more you do these things the easier they get for you, or try going on this course or that course" (said in sarcy way), ning about it, and none of those things helped me at all so, I just had to feel that I have to deal with this huge anxiety and I thought, well maybe other Feeling inadequate people are just better at hiding that than I am and it is just an issue with, "a weakness I have" / like a weakness I have and I have just got to keep trying it until I get better [yeah] at doing these things but I never did, it never did change, it would always be awkward, you know meeting people and trying to chat to peopl you know at work conferences in-between sessions and things, and I would Exhaustion & negative just struggle so much trying to listen to what are they saying and trying to impact of camouflathink what say I say back at at the same time, and it was just totally ging exhausting really and you would just come home and want to sit in silence and collapse (laughs) I think the more that I get to know someone the more Easier with close relacomfortable I am and the less it feels like doing that, but those sort of tionships situations where people say, yeah lets network with all these random strangers, or go and speak to this room of 100 people about something I just it just kills me, its AWFUL (laughs) absolutely awful, I think these days negative impact of now that I know why that is after I got my diagnosis I talked to my boss camouflaging about it and he was really surprised and he was like "oh you" partly Outside autistic steprobably cause women don't generally fit the stereotype that partly also reotype that I have got so used (laughs) to masking that I do that quite well, he Successful masking & used to say to me, you don't seem nervous when you do presentations, bu hidden difficulties whereas from my perspective I was physically shaking and couldn't breath properly, so since then I talked to him and I said I think now I want to focu Asking for & making on the bits of job that I am good at and when these types of things come adaptions up just give them to someone else, I am not going to keep making myself do these things that I know I am, that are just going to make me stressed and I know that I am never going to be good at them [yeah] and now I car Importance of an exforgive myself for that because I have a reason (laughs) rather than keep planation& validation trying to do it [yeah yeah]

Figure 2. Example of the coding process as part of the thematic narrative analysis

Theme 1: What is camouflaging Camouflaging is multifaceted including behaviours, cognitive processes and appearance: "it's everything it's not just what you say it's the whole behaviour I guess"	<ul> <li>Doing specific behaviours, such as eye contact and smiling</li> <li>Hiding certain behaviours, such as stimming, but also the fort of trying to follow a conversation.</li> <li>Cognitive strategies such as planning what to say and how behave, and self monitoring. Also learning ways to act, su as attending courses</li> <li>Adapting your physical appearance</li> <li>A partly unconscious process, and therefore difficult to ge full sense of what "it" is.</li> </ul>		
Theme 2: What is the impact of camouflaging	<ul> <li>Anxiety and exhaustion; before, during and after the social event. This has had a profound impact through her life</li> <li>Has a physical impact that has affected her health</li> </ul>		
Theme 3: Camouflaging changing over time  How her camouflaging has changed over time, particularly due to her autism diagnosis	<ul> <li>Early experience: She describes becoming aware of plann and monitoring her behaviour at school, and this increasin with age. It was something that did not have a label, and assumed everyone did.</li> <li>The perception and experience of camouflaging changes her autism diagnosis. She become more aware of camouflaging, and also a sense of relief and less self-judgement</li> <li>Camouflaging in the future: She discusses her questioning around if and how to stop camouflaging. Crucially the difficulty in know how to "stop masking"</li> </ul>		
Theme 4: Sense of self	<ul> <li>Socialising and self esteem: feeling socially inadequate, increasing the pressure to camouflage</li> <li>Camouflaging and sense of self: Camouflaging as obscuring her sense of self and also prompting questions about one sense of self.</li> </ul>		
Theme 5: Social Pressures	<ul> <li>Being a minority with a non-autistic majority, and consequently the pressure to conform, and the cost/risk if do not do this. Also that this isn't something that can simp changed.</li> <li>Camouflage is a social demand - "forced inauthenticity"</li> <li>The social environment has an impact in everyday interactions. She talks about the qualities of difference situations that impact her camouflaging</li> <li>Gender stereotypes effects the pressure of how to behave particular the unique intersectionality for autistic women</li> <li>Camouflaging as protection from societal prejudice</li> </ul>		
Theme 6: Relationships	<ul> <li>Camouflaging in close relationships, although to a lesser degree.</li> <li>Camouflaging to form relationships</li> </ul>		

Figure 3. Themes and sub themes from thematic narrative analysis of one transcript

These codes were then reviewed, looking for patterns and categories among them (Braun and Clarke, 2006). From this process themes and subthemes were generated for each participant. The generating of themes and subthemes from the coding was done through a narrative lens, noting continuity and coherence (Ronkainen et al, 2016). These themes and subthemes were summarised and sent to the participants for feedback. A summary of the themes and subthemes for Jo is shown in figure 3.

Participants were able to comment on the themes and provide further reflections. Such collaboration is a central feature of narrative approach (Creswell et al., 2007) and served to check the veracity of themes. As the interviews were being analysed, patterns and meanings between participants were identified and noted. Connections across all themes and subthemes, between and within participants stories, were identified (as demonstrated within Phoenix and Sparkes (2008) thematic narrative analysis), leading to the creation of general themes and subthemes.

## 3.6.3. Stage 3: Broadening, burrowing and restorying.

Following this, the interpretative devices of broadening, burrowing and restorying were implemented to create the main overall themes (Webster & Garvis, 2017). I went back to consider each participant individually. The transcript was analysed for themes relating to the social, cultural, historical or political context; for example, references to "autistic culture" were highlighted. I also gathered information from their demographic questionnaire

and the initial camouflaging questionnaire, alongside the context in which the participant found out about and approached the study. This enabled me to create a general picture of the participant and consider the broader social, cultural context in which they were situated, as well as reflecting on the research literature. Examining the participants through this lens drew attention to the impact of socio-cultural background or structural issues such as access to services that affected their stories. Therefore I could "expand' the data to create a more holistic awareness of each participant. The key reflections from this process were noted for each participant (see figure 4 for an example of the notes from this broadening process).

Notes on broadening process for Jo

Jo is a 38 yr old white British woman. She is separated and has children. She is employed full time. was diagnosed with ASC Asperger's Syndrome three years ago. She attends an autistic women's grand found out about the study through this.

Reading through her interview the following aspects for her social, cultural identity and experience noted:

Impact of motherhood on her camouflaging and relationships.

The effect of age on social expectations; in particular, becoming more complex and inaccessible the adolescents

Experience of gender stereotypes and femininity

Struggling to connect and develop friendships with other women

Not fitting into standard female stereotypes of behaviour and preferences

How these stereotypes affect her visibility as an autistic person

The pressure to comply with gender stereotypes

Social expectations within the workplace, and pressure to conform

How her gender and autism interlink to impact how she is seen, how she can progress and the ada she has made at work

Her experience of having no choice but to adapt to social norms, or isolate herself

Camouflaging then becomes a protection to a hostile environment

Her minority status as an autistic and left handed person, and an acceptance of the limitations of the majority to understand these differences

The importance of autistic communities in promoting authentic connection.

The internalisation of social and cultural expectations, and her attempt to consciously shift this.

Figure 4. Notes on the broadening process for Jo.

Next, the interpretative tool of burrowing was used. The individual transcripts were reviewed again to reconstruct key events (e.g. diagnosis, significant interactions with family) from the participant's point of view (Webster & Garvis, 2017). Particular attention was paid to the emotional and moral qualities expressed by the participant (Clandinin and Connelly, 2000). This included noting the use of vivid metaphors by some participants to illustrate a particular experience and how this formed part of their larger story. From this examination, notes were made about each participant; these notes were then reflected on when analysing all the themes across participants.

Finally, the narrative lens of restorying involved highlighting how the participants' stories had shifted, changed, or been retold over time. For example, noting differences in how participants described their camouflaging in childhood compared to adulthood or changes that emerged after the interview when they reflected on their summary of themes. Again notes were made of these reflections for each participant.

The themes and subthemes generated through the narrative thematic analysis were then considered in relation to the reflections that arose from the BBR process, to generate the overall themes and subthemes (Webster & Garvis, 2017). This enabled me to look across all the participants' themes, considering broader similarities and socio-cultural factors, whilst not losing sight of the individual stories and experiences. For example, through the thematic narrative analysis, the theme of different types of camouflaging emerged. When examining this theme and data through the burrowing lens, the personal, nuanced, and

flexible way these multiple strategies were used was fore-fronted. Consequently, generating the overall theme of "camouflaging as a multifaceted and individualised process".

The theme of "diagnosis" emerged in the initial narrative thematic analysis, and was then elucidated through the restorying lens, which revealed the complexity of this transition, how diagnosis changed narratives around camouflaging and led to fresh reflections on the past, present and future. Creating theses final themes is also part of the "restorying" process, as the participants' experiences are reconstructed and retold anew.

## 4. Analysis of Findings

## 4.1. Introduction

A multi-stage narrative analysis was conducted on the data (Frost, 2009; Webster & Garvis, 2017). Initially a narrative thematic analysis (Riessman, 2008), and the interpretive tools of broadening, burrowing and restorying (Clandinin and Connelly, 2000) were employed to create overall themes and sub-themes. Within this chapter each of these themes and subthemes will be explored, and the relationship between them as a representation of the participants stories.

# 4.2. Demographic data

The table below outline the demographic data from the participants.

Participant	Age at time of study	Diagnos- is	Age at dia-gnosis	Ethinicity	Martial status	Employ- ment Status	Other self-reported diagnosis
Yasmin	28 yrs	Asper- gers	15 yrs	White Other	Single	Unem- ployed	ADHD, OCD, endometriosis, anxiety/phoba
Alex	37 yrs	ASC Asper- gers	31 yrs	White Other	Married	Unem- ployed	Depression, anxiety, OCD,
Jess	35 yrs	Asper- gers	25 yrs	White British	Single	Part time employed & student	Depression, anxiety, diabetes, history of single episode of psychosis
Steph	26 yrs	Autism Spec- trum Disorder	24 yrs	White British	Single	Full time employed	Sensory Process Disorder, Anxiety/ Depression.
Holly	28 yrs	Autistic Spec- trum Condi- tion	28 yrs	Gypsy or Irish traveller	Single	Part-time employed	PoTS / hEDS / Mild Sensorineural Hearing Loss /DID - /CPTSD / De- pressive Episodes / Anorex- ia Nervosa
Rachael	40 yrs	ASC Asper- gers	37 yrs	Jewish	Single	Full time employed	ADHD, Dyspraxia
Jo	38 yrs	ASC Asper- gers	35 yrs	White British	Separated	Full time employed	CFS, ME, Anxiety
Sarah	29 yrs	Autism	27 yrs	White British	Single	Part time employed	Anxiety, depres- sion
Naomi	34 yrs	Autism Spec- trum Condi- tion	30 yrs	White British	Single	Full time employed	ADHD, Dysthymia, Anxiety

Table 2: Demographics of the participants

## 4.3. Summary of themes

Four over-arching themes were generated from looking at the women's stories (as illustrated in figure 5). The first theme was "camouflaging as a multifaceted and individualised process", which captured the breadth of each participant's camouflaging repertoire. The subthemes of methods of camouflaging, awareness of camouflaging, and individualised process were identified. The second theme was "camouflaging and relationships", with the subthemes of camouflaging inhibiting and enabling relationships, camouflaging within close relationships, and authenticity versus intimacy. The third theme was "societal pressure", which explored the effect of social-cultural factors on the participants camouflaging. The subthemes were "pressure to conform to a non-autistic majority, camouflaging as protection, and interaction between gender and camouflaging. The final theme was "diagnosis and camouflaging", with the subthemes of pre-diagnosis experience of camouflaging, diagnosis revealing and reframing camouflaging, restorying the past, and future camouflaging. Each of these themes will be explored.

## 4.4. Camouflaging as a multifaceted and individualised process

This theme captures the multiple and nuanced way participants described their experience of camouflaging. All nine participants described using a variety of methods and

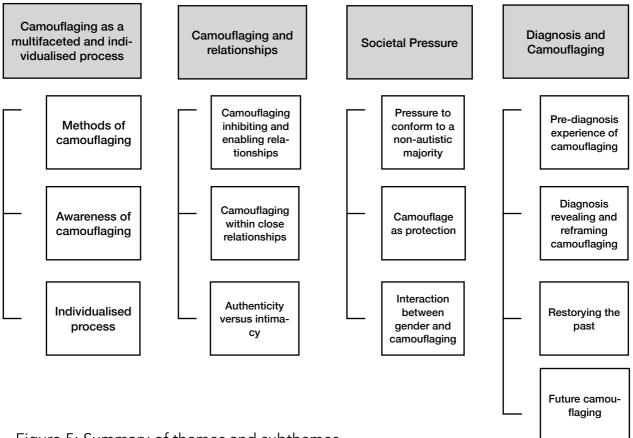


Figure 5: Summary of themes and subthemes

strategies when camouflaging. Although some camouflaging techniques were discussed by multiple participants, the combination and expression of these were unique to each person, forming an idiosyncratic story of their camouflaging. The subthemes cover the different aspects of camouflaging and their variation, methods of camouflaging, awareness of camouflaging, and the individualised process. See figure 6 below.

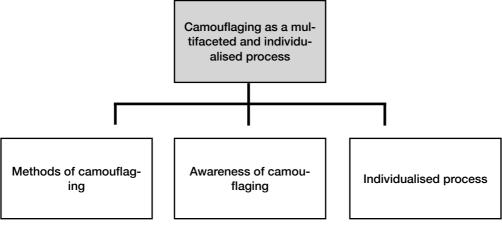


Figure 6. Camouflaging as a multifaceted and individualised process and subthemes

## 4.4.1. Methods of Camouflaging

The participants described their camouflaging as including a range of methods. This involved behavioural strategies (e.g. adopting or hiding specific actions), cognitive strategies (e.g. scripting or analysing), and more wholistic methods such as adopting a role, copying others or changing their appearance.

All participants described using behavioural strategies as part of camouflaging. Six participants specifically discussed adopting non-autistic mannerisms, in particular eye-contact and facial expressions, when in certain social situations:

"I pretend what would it be like to be a normal person, so I pretend, and I put on nice clothes and I make eye contact and I speak slowly and I answer nicely and I smile and I give them what they want and I am good at that". (Rachael, para 4)

"I am always like I should probably nod, when people you know are talking about something, and I will look at my manager". (Steph, para 29)

"I struggle with eye contact but because I see it as an appropriate thing to do and people do it, and I suppose you have to or you can come across as rude, so I learnt how to do this by taking the following the lead of the other person, so counting the seconds of the other person and so I followed them." (Jess, para 2)

"I think I have just like learnt to give the eye contact." (Holly, para 8)

"So yeah how to look at people, how to talk to people, when to smile at people" (Jo, para 14)

"You are obsessing about "am I making the right facial expression, do I look sympathetic" (Naomi, para 10)

As well as performing certain behaviours, six of the women reported hiding autistic behaviours, in particular stimming. Yasmin talked about hiding her stimming behaviour from everyone including her family:

"With the flapping and the stimming all that, there are some things I do that I only do when I am on my own" (Yasmin, para 53)

Eight of the participants described hiding anxiety, and meltdowns as part of their camouflaging. Steph reported how she consciously hid her feelings of overload when at work:

"I am better at bottling it up and not making it show during the day, if I do get too overwhelmed I will just go and sit in the toilet at work." (Steph, para 63)

#### Naomi also stated:

"That was my experience of masking and hiding mental illness and hiding anxiety and trying to look calm" (Naomi, para 8)

Jess specifically described hiding their distress to avoid making other people upset.

"I do hide some, like if I was feeling a bit down or anxious, I do hide that cause I don't want to worry them". (Jess, para 18)

Five of the participants reported trying to be "inconspicuous" (Sarah, para 2) or "anonymous" (Jess, para 56) as a way of camouflaging, as opposed to hiding specific autistic behaviours, such as rocking or stimming. Jess described:

"I was, tried, to be kinda of anonymous, nothing, and then like they wouldn't notice me, people wouldn't notice me, so I wouldn't have kind of definition.

(Jess, para 6)

Holly stated:

"I am quite quiet in social situations and that is probably a bit of a camouflaging thing, because I feel like if I say nothing I won't stick out for any reason". (Holly, para 8)

Three of the participants also talked about deflecting attention away from themselves, as a way of managing social situations and part of their camouflaging repertoire. Steph stated:

"I don't like drawing attention to myself or the topic being on me, so when, like, people ask how are you, I am someone who will deflect that kind of thing." (Steph, para 31)

Whilst Holly described using her interests and activities as a way of deflecting attention:

"I have things to show them like my art work and that kind of thing to take the focus off." (Holly, para 28)

All the participants described using at least one form of cognitive strategy when camouflaging. For example, preparing and mentally rehearsing scripts or learning "generic stock phrases" (Yasmin, para 63). Jess stated:

"I feel like I have to rehearse, cause if I am on the phone I have to rehearse my introductory speech." (Jess, para 16)

Whilst Alex reported: "I am constantly writing these scripts in my head." (Alex, para 51)

Six of the participants described consciously analysing and decision making whilst speaking or engaging with others as part of camouflaging. Steph explained that:

"Sometimes when people are chatting I have this whole monologue going on of

"oh you should"." (Steph, para 6)

Alex recounted having "mental drop down lists" and "flow charts with the diamonds and stuff" (Alex, para 55) when speaking with others to help them decide what to say next.

Naomi explained how she is "monitoring everything I say to make sure that I am voicing appropriate opinions." (Naomi:4)

#### Jo noted:

"So there is this constantly internal, trying to make sure the meaning you are taking is the right one, which then once that thought process starts going, the masking has to come in to cover the fact that you are distracted by trying to process what is going on and what to do." (Jo para, 60)

Two participants also reported that this analysing and ruminating continues even when they have ended the social interaction. This "post-hoc" analysis last for hours impacting their mental state, Holly stated:

"I often worry and run over things that have happened in that interaction...usually I start blaming myself and then I feel the need to apologise to that person." (Holly para 30)

Steph described "I will come home and still overthink things and stuff I have said" (para 14) and later on noted:

"I worry if like my eye contact was too much or too little or if spatial awareness wise I was giving off weird vibes." (Steph, para 21)

When describing how they camouflaged seven of the women reported copying other people, either specific behaviours or someone's whole way of being. Four participants described copying the opinions, interests and preferences of others. Sarah reported "I was trying to make my interests aligned with other people" (Sarah, para 14). Participants also described copying the whole behaviour of peers or family members:

"I always felt like I got adopted by people and then moulded to them, I think that is part of camouflaging, especially for girls, this kind of imitation of a more confident friend, who adopted me" (Naomi, para 10)

For five of the participants copying the physical appearance of others, namely through clothing and make-up, was also a part of their camouflaging. Some described copying the appearance of others in order to fit in with the social norms better. Rachael described:

"I would put on lots of make up and a dress and look like a normal person... I guess that is a kind of camouflaging cause you want to fit in and look normal." (Rachael para 14)

Holly described how she did not care about her appearance, but would put makeup on as a way of aligning with peers, and also a way of facilitating conversation:

"I also found that I used to do a lot of nail art because it used to be a talking point." (Holly, para 62)

Naomi also reported adapting her appearance to blend in with her work environment:

"So I can use clothing to distract attention from me and I think it works on a lot of NT if you kind of look the part, because they kind of, especially at work if you look professional" (Naomi para 41)

She also recounted how she will dress in ways that are unusual:

"Because I feel way more confident being and maybe drawing looks, for a reason that I chose rather than cause I am walking funny or not making eye contact or just looking really shy" (Naomi, para 41)

This demonstrates the complex relationship the participants had with their appearance and camouflaging and the variation in how they used their physicality to manage social situations. Furthermore, Yasmin also described consciously using her appearance to manage social interactions, but differentiated it from camouflaging:

"I just want to go through things smoothly, I want to not stand out in anyway like not in a bad way, I want people to look at me and see that I am capable of picking a good outfit as well, because that is another social skills thing, I don't want people to see that I am unfortunate, so it is not quite camouflaging but it is another thing I do to ease my path through life, even though it takes me ages to do my make-up" (Yasmin, para 92)

In addition to adopting the appearance or behaviours of others, some of the participants described taking on particular social roles as part of camouflaging. Holly described deliberately adopting a helping or expert role at university and work in order to navigate social situations without others realising she was different in anyway. She reported:

"Maybe the fact that I have always focused on roles that, or being in roles where I am a support to others, that might be a masking technique." (Holly, para 88)

She also discussed how her job (working with children) was an extension of this, as focusing on the needs of another.

Sarah described how having a caring role within a family setting meant that there was little choice but to camouflage, as engaging with others in a non-autistic manner was required for the well-being of others and there was no one else who could take this role:

"Around my mum I just have to pretend that I can sort it out cause she can't and so someone needs to." (Sarah, para 26)

In addition to be a helper, Holly also described being perfect in work and other social situations as part of her camouflaging. By adhering to the rules, and completing all tasks set:

"The idea of being really efficient like yeah she keeps to all those rules, she doesn't do anything wrong so how can there be anything wrong." (Holly, para 92)

In contrast to these accommodating ways of interacting, Yasmin reported consciously adopting an extroverted role of a class entertainer. She reported not being able to align to her peers' way of socialising, and so acting in humorous and rebellious ways to gain approval:

"I couldn't be normal, so I decided I would make it my thing to be weird and erm, I was basically the class clown and I did end up with a lot of friends because I took a lot of effort to entertain them and also I would, I was really daring, and also I was naughty at school". (Yasmin, para 17)

In addition to describing the different facets of their experience of camouflaging, three of the participants described camouflaging as more than just isolated strategies. Alex explained that for them "it's a whole package really, its not just your behaviour" (para 35). Whilst Jo stated: "it's everything its not just what you say, it's the whole behaviour I guess" (para 6). Jess explicitly noted how camouflaging is more than a technique it is part of your way of being:

"In a way it is my personality and so I don't really like, cause it kinda sounds like it is on a limb in a way, and it's not, it's more central to myself" (Jess, para 94)

## 4.4.2. Awareness of camouflaging

The topic of awareness and consciousness was present in varying ways in all of the women's stories. When describing their experiences of camouflaging five participants described camouflaging as principally automatic, explaining that they were not fully aware they were adapting their behaviour. Jo described:

"For me it has certainly become so second nature, it is part of who I am, I am those behaviours, are automatic so that is the bit of it that is really weird." (Jo, para10)

Holly also expressed a lack of awareness: "It is probably so ingrained that I don't think about it." (Para, 74). This was echoed by Naomi: "Actually I am not consciously doing that, it is kind of habit" (Para, 27).

Two participants described the complexity of being aware of their camouflaging, but unable to control their behaviour: Steph reported:

"I know that's kinda a waste of effort and energy, but I don't know it's kind of hardwired into me." (Steph, para 14)

### Similarly Alex stated:

"I am constantly having to do this all the time, and I don't know if I am ever going to be able to stop doing that, I think it is too engrained at this point."

(Alex, para 51)

The women's stories highlight how the experience of camouflaging is affected by levels of awareness and control. Two participants described a process of initially overtly learning techniques, that now feel automatic. Yasmin reported "after training myself all these years, it's so automatic I couldn't not do it" (para, 46). Similarly, Jo stated "they are so ingrained from decades of having to do this" (para, 10).

In contrast, Rachael discusses her camouflaging as a conscious process, and consequently distinct from effortless non-autistic interaction:

"I think that they [non-autistics] are doing all this stuff subconsciously, that they are not aware that they are doing all this stuff whereas autistic people are thinking about it all the time and it is exhausting." (Rachael, para 6)

Yasmin also differentiated her experience from non-autistic people in terms of the awareness and effort involved:

"like a slower way of working it out logically...I just can't do it automatically, like immediately and intuitively like other people can." (Yasmin, para 9)

In her follow-up feedback Yasmin further explains that whilst camouflaging is a conscious and effortful act, it is her only way of responding:

"My camouflaging may have been deliberate, but I couldn't have chosen otherwise, because I didn't have the emotional intelligence to rationally choose. It depends what you mean by "conscious"."

#### 4.4.3. Individualised Process

The participants' terminology to describe camouflaging varied. Many used masking or camouflaging, but how accurately they felt these terms captured their experience differed. Whilst others used alternative words, or preferred to avoid specific labels all together. Participants explained the use of language reflected the particular strategies they used and their personal intention in using them.

Two of the women delineated between the terms masking and camouflaging, explaining that for them the former representing hiding from others, whilst the later captured the desire to assimilate. Steph reported:

"I would usual refer to it as masking, because it is like putting on a mask, putting on an act, I see that as a visual thing, whereas I see camouflaging, I don't know, it to me feels more hiding, whereas masking feels more putting on something, putting on a front." (Steph para 104)

Holly identified with both terms, but primarily with "masking" and linked this to her personal experience. Her use of the terms "masking" and "armour" illustrate the importance of camouflaging as a protective strategy:

"I probably related more to masking, because I think camouflaging is like blending in to your environment and that is not what I kinda want to do, I want to get through unscathed! So it is a full mask or putting on body armour or putting a wall up... yeah probably more like masking armour and putting up a wall is more how I would describe it, a bit of a disguise." (Holly para 78)

Rachael used the terms "subtle" and "overt" masking to represent how differing abilities impact the camouflaging process:

"There are some people who need that, and that's overt masking, and they need that masking to have social interaction and then other people who are very verbal and good at social interaction, and that might be a more subtle masking". (Rachael para, 37)

The impact of personal ability is also referred to by Naomi, She explained that due to her ADHD she was not able to hide her stimming behaviour and "blend in with everyone

else" and so preferred the term masking, as this more accurately reflected how she adapted her behaviour:

"I like masking more than camouflaging cause I am not really, I have never been able to disappear into the background, cause I talk too much and I am too fidgety." (Para, 55)

Naomi goes on to suggest the novel terms "filtering", "negotiating", and "mirroring", partly because she feels they more accurately represent the strategies she uses and partly due to a concern that "masking" implies deception:

"Mirroring that's a term that I actually really like, I guess that is a form of masking but lot of my experience is just being hyper vigilant about what the other is saying and trying to mirror it, that sort of person and an identity chameleon." (Para 55)

Later on her hesitation in finding a preferred term aptly demonstrates the difficulty in defining this complex experience:

"I don't really like the idea of being deceptive...I don't know how to word it! Negotiation maybe or err filtering of..." (Naomi, para 57)

Sarah also specifically chose language that distanced her from suggestions of deception:

"Masking can sound like you are being fake and I don't think it is necessarily being fake, I think it is more about having less of a clear idea of your own identity and therefore just sort of thinking, this is what I am supposed to be like, so I will be like that, and feeling like you have to work and make effort rather than you having to hide being a part of you, so I think camouflaging is a better word to describe it" (Sarah, para 64)

Two of the women rejected all the current terminology used. Jess described that the use of a specific term felt at odds with her experience of camouflaging:

"I don't think I would describe it as camouflaging, because I wouldn't call it anything I would probably break it down into bits and erm, so just give an example of what I am aware of what I do, but in a way it is my personality and so I don't really like cause it kinda sounds like it is on a limb in a way and it's not, it's more central to myself." (Jess, para 94)

Whilst, Yasmin created her own term that more accurately described her experience, in particular emphasising that she was not masking her autism:

"I would say rather than camouflaging, I would say whatever word could be used to say doing literally just...doing what everyone else does...i can't think of a good word, camouflaging isn't quite right but...it's not masking, it's not, it's just a real conscious effort to, it's...consciously effortful social interaction" (Para, 87)

Although there was variation in how the participants described their camouflaging they all described it as exhausting, causing anxiety and distress. Steph states this as:

"I think like we said before there are positives and negatives to camouflaging but I think there are probably more negatives in that, it does take a lot of effort and it is draining and I think it does affect me a lot" (Steph para, 99).

Three of the participants attribute mental health crises to their camouflaging, and two as leading to and/or exacerbating long term physical health conditions. Sarah:

"I could go and camouflage five days a week in an office in a job but it was so draining, and like I couldn't do it long term, I did it for two and a half years, and I completely broke down." (Para, 34)

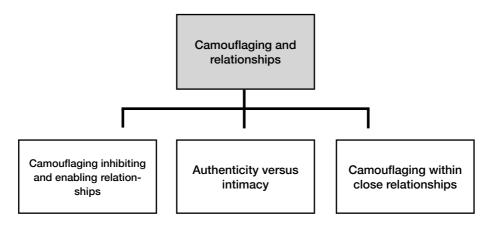


Figure 7. Camouflaging and relationships and subthemes

In her follow-up written feedback Yasmin emphasised the effort that was involved, in particular in the cognitive aspect of camouflaging:

"The main reason it's tiring is the effort involved. It involves a lot of educated guesses and assumptions that lead on to more guesses and assumptions. I think by worrying if I "got it right", I didn't mean anxiety, I meant that if any of these assumptions/guesses are wrong, it will have a knock-on impact on the success of my social decisions. Therefore, I have to constantly think, to maximise the chances of my guesses/assumptions being correct."

## 4.5. Camouflaging and relationships

All the participants described how camouflaging affected their relationships. Their narratives were divided into three subthemes; camouflaging inhibiting and enabling relationships; camouflaging in close relationships (i.e. family and partners); and intimacy versus authenticity. This theme and its subthemes are depicted in figure 7.

#### 4.5.1. Camouflaging inhibiting and enabling relationships

Eight participants reported camouflaging as both essential in enabling relationships to develop, and inhibiting relationships from deepening. Several participants described having to camouflage when initially beginning a relationship, as people expect non-autistic communication and are unlikely to initiate an interaction without this. Naomi:

"In the early stages, I guess, of socialising, cause if not people don't give you the time of day because they find you so strange" (Para, 33)

Jo also refers to this and her experience of social isolation without camouflaging:

"I don't want a really lonely life like I used to have, so I want to know people and you can only know people by getting through that stage of doing those things in a social sense, sometimes it has to be gone through, in a, it's it's really hideous." (Para, 54)

Rachael described how she likes socialising and meeting people, and camouflaging is helpful in navigating these social situations. Furthermore, that even within longstanding relationships, such as some social groups she goes to, it is necessary for her to camouflage to not upset others and avoid being excluded:

"So yeah I will continue to camouflage in the future because if I go to choir it annoys people if you talk which I understand". (Para, 30)

Steph describes how camouflaging is essential in enabling her to manage her relationships. Without camouflaging social situations would become too overwhelming and she would have to withdraw or avoid them. For her camouflaging also provides a protective barrier that enables connection:

"I think definitely situations where it is more than one or two friends like a thing or an occasion where I will have to put on this front or I will have to withdraw." (Steph, para 67) However, this camouflaging is exhausting and she will need to recover at home afterwards.

Holly talked about how camouflaging enabled her to build relationships that were functional and useful, for example at work or university:

"I felt like it [camouflaging] was something I had to do to get by but if I was honest it felt like an annoyance...and it was good that I was able to find people say if we had to do a group project." (Para, 22)

The participants also reported that camouflaging inhibited relationship building. Several participants described how after using camouflaging to initiate a connection they were unable to deepen the relationship. Holly reported using hair and makeup to engage with others, but then the relationships remain in this surface "camouflaging" level:

"I felt like I did manage to maintain some friendships, but it felt a bit superficial" (Para, 64)

#### Naomi also stated:

"I have quite a few polite acquaintances that don't develop in to friendships even if I would quite like them to, and the other person would quite like them to, because I get stuck in the camouflaging sphere." (Para, 8)

Naomi goes on to explain that the reason she thinks it is difficult to deepen the relationship:

"There is quite a big gap between who I am, and what is socially acceptable, so it is kind a big adjustment to take a friend through." (Para, 12)

As well as inhibiting the deepening of relationships some participants talked about how camouflaging increased the likelihood of unbalanced or unhealthy relationships. Alex described how they had camouflaged to develop friendships during their childhood. Following their diagnosis they identified that part of their camouflaging had included acquiescing to their friend, subjugating their own needs, and consequently that their friendship was "toxic" (Para, 57)

"One of the things that happened after I got diagnosed was that I did lose some friendships because I feel like I realised what real friendship was as opposed to toxic relationships." (Alex, para 57)

Rachael reported how the combination of camouflaging and struggling to understand social interaction meant she was confused about to what extent she should allow people to make fun of her when camouflaging in social situations:

"It is really hard to know what is acceptable, cause sometimes people say things that aren't acceptable, but you are told to find it acceptable "like this is banter"." (Para, 12)

Holly also explained that her camouflaging led to unbalanced relationships:

"People don't have a sense of who I am, and relationships become unbalanced and I think because I often have the kind of "I am fine routine" and so I become a source of help for others, but then they are perhaps not as thoughtful about my needs, and that kind of thing so yeah it probably has affected my relationships." (Para, 56)

The focus on the needs of the other person is described by several other participants.

"I am willing to mask with someone I care about to make them comfortable, cause it's not just about my comfort." (Alex, para 59)

Yasmin described that part of her purpose in camouflaging is: "to make the other person, as best as I can, feel comfortable." (Para, 5) Whilst discussing eye contact Jo noted:

"cause you don't want to stare them out either and make them uncomfortable."

(Jo para, 6)

Conversely, Naomi discussed that camouflaging inhibited relationships because you were too focused on self rather than the other person:

"It does affect your relationships, because you are focusing more on what you are thinking than on what they are experiencing and they are communicating and you are missing all kinds of stuff." (Para, 10)

In addition to difficulty in deepening interactions, and the potential for unbalanced relationships, Sarah described that the exhaustion that came from having to camouflage, with even close friends, made her hesitate to see people. In discussing the impact of lockdown she said:

"I would love to see my friend again but at the same time like it makes me anxious to think that things are going to go back to the way they were and I would have to camouflage more again, because like I have been less like drained and overwhelmed and exhausted." (Para, 42)

## 4.5.2. Authenticity versus intimacy

The women also described the dilemmas between feeling authentic in relationships and the need to camouflage. Four participants described the tension between wanting to be yourself and wanting relationships. Sarah stated:

"If I don't camouflage I won't get close to people, but if I do it I am inhibited from authentic connection." (Para, 8)

#### Rachael reported:

"You are always asked to camouflage, everything that you are asked to do that is not natural to you is camouflage, they are like "can't you just not say that and I am like, "no, I want to be myself", but it is a conflict because I want to be myself and honest, but I want people to like me and for people to think that I am normal, so I think that is an autistic thing that is a constant conflict of those two things." (Para, 22)

## Rachael goes on to explain that:

"They think that you don't care, and they don't understand, of course I care, I want people to like me, but I also don't want to be fake and not myself, and act in a way that isn't natural to me." (Para, 32)

Steph also described this sense of not being herself socially:

"I think well actually, I have never really been myself outside my home environment and it does get me a bit sad to think that I can't actually really be me." (Para, 99)

Holly noted, that due to camouflaging she was conscious that "people don't have a sense of who I am." (Para, 56)

Two participants discuss having relationships where they can experience intimacy, whilst also feeling able to be themselves. Rachael described how this involved effort and carefully choosing her friends:

"I really try and be myself, like now I have the best friends I have ever had...so I think that I choose people to be my friends who do like me." (Rachael, para, 22)

Jo reported that the ability to be more authentic grew with time:

"The more that I get to know someone the more comfortable I am and the less I feel like doing that [camouflaging]". (Para, 4)

## 4.5.3. Camouflaging within close relationships

Eight participants described having to camouflage when with family. Both Alex and Holly explained that their camouflaging was partly due to their parents' difficulty in accepting their autism. Holly noted: "She [mum] perceives that autism is something that is wrong with me." (Para, 36)

Similarly, Alex described: "She [mum] would be just frustrated by some of the more aspie aspects of me" (Para, 31) and then also stated their camouflaging means "She [mum] loves this idea of a person that isn't real" (Para, 75)

Three participants reported having to camouflage, because a parent was undiagnosed but on the autistic spectrum. Holly explained:

"I am also aware that my mum is probably on the autism spectrum, but is very like stand-off-ish and doesn't want to go there." (Para, 36)

Similarly Alex described their relationship with a male family member:

"I think he has a lot of internalised self hatred about that and one of the things that will set him off and set off his anger is when he sees himself in me, particularly an autistic thing, so sometimes I have to be quite guarded with him." (Para, 26)

Rachael also reported that she has to camouflage with family, and links this to her father being undiagnosed autistic. She described having to camouflage:

"all the time, I told you my dad is much worse, and my mother does not understand it at all and so she finds everything I do annoying and thinks I should be quiet and well behaved." (Para, 34)

However, Rachael did mention since her diagnosis her mother is more understanding.

This modification of behaviour in order to adapt to the needs of family members was also reported by other participants. The impact of having to consider and care for the needs of family was particularly mentioned by Sarah. She reported that: "My family don't know that I have been diagnosed so I still do it [camouflage] around them." (Para, 4). She described having to care for both her mother and grandmother, and camouflaging is a necessary part of this:

"They will looked to me for answers, cause they will ask my mum and she won't be able to answer it properly, and so whereas with my closest friend I will need her to answer for me cause I can't do it, whereas somebody has to do it with nan, cause she can't breathe so she can't answer, and erm my mum can't like sort anything out - so I will." (Sarah, para 26)

Yasmin also talked about hiding her autistic behaviours from her family in response to their difficulties, highlighting how she camouflages with her family, and in addition has to attend to their needs:

"I try and hide them or whatever, but she [mum] is the one I camouflage least with, because my dad and brother are mentally ill, so basically it's not just camouflaging, its trying to not aggravate them in anyway." (Para, 78)

In these situations there were specific reasons for camouflaging with family. However, Jo reported camouflaging with family because this was her only way of relating:

"I think that I do it in all situations because it is just how I have learnt to be" (Para 56)

Steph was the only individual who described not needing to camouflage with her family:

"I think I can definitely be more myself at home." (Steph, para 45)

"As we have gone along we have learnt more about autism as a family, so yeah I think they are quite understanding." (Steph, para 47)

Two of the women discussed camouflaging within partner relationships. Alex stated that the closest relationship with the least camouflaging was with their partner. Whilst, Naomi described camouflaging at the initial stages of a relationship:

"Autism has shown itself in relationships in terms of how people want to get out and do things and I feel like a drain and a burden on the relationships so I always try to be more enthusiastic and outgoing than I might feel." (Para, 16)

She goes on to discuss the difficulties of reducing her camouflaging as the relationship continues:

"In romantic relationships I have had the feedback of "who are you" you are a completely different person, from when I first met you, I think part of it is that mask coming off a bit." (Naomi, para 12)

Rachael also discussed being mindful of the neurotypical stereotypes of what was attractive, which included attending social events and small talk, but how challenging this was to achieve.

Only two of the women had children so it was not possible to explore how camouflaging may relate to the parent-child dynamic. However, Jo described her concern about possibly camouflaging with her children:

"The idea that I might be doing that even with my children is something that worries me, actually, I very much hope that I am not but it is a difficult one to untangle." (Para, 56)

### 4.6. Societal Pressure

All the participants described the pressure they received from society to conform to stereotypes and behavioural norms, and the discrimination and prejudice they receive when breaking these expectations. Three subthemes emerged within the data: pressure to conform to a non-autistic majority; the interaction between gender and camouflaging; and camouflage as protection. See figure 8. below.

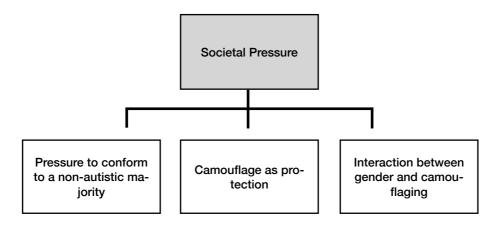


Figure 8. Societal Pressure themes and subthemes

### 4.6.1. Pressure to conform to a non-autistic majority

All of the participants specifically reported the pressure they feel to adhere to neurotypical standards, and the negative consequence they experience if they do not. Jo describes:

"I know it is inauthentic, but I also know that is the only way people are allowed to behave in those situations, so it is forced inauthenticity and the only way to not do it is to not be in those situations, but sometimes they are not avoidable." (Para, 50)

### Sarah stated:

"to fit in and to be liked and to be able to achieve things, like work like I wouldn't be able to do my job if I behaved like this at it, like to be able to access things."

(Para, 50)

She then went on to describe a distressing experience when trying to access therapeutic support. Sarah struggles using video calling with people she does not know, so instead of camouflaging she asked for an initial telephone call to help her build a genuine relationship in a gradual way. However, the service were not able to facilitate this and discharged her. She explained:

"That is the first time that I ever properly tried to not mask or camouflage or whatever and all it meant was that I got denied access to a service, so I won't try that again!" (Sarah para, 44)

## Rachael talked in-depth about this issue:

"I think masking is just like telling the autistic person to act like they are not autistic, I think that is what it is and society expects that of you cause if you don't, act like you are not autistic, people just have a go at you all the time and your life would be worse than if you pretended to be normal." (Para, 8)

She went on to recount her experience of getting a vaccination. She explained that despite having an advocate to help her, and asking in advance for adaptations (e.g. being able to leave straight away, having minimal verbal communication), the medical staff still expected her to behave in a non-autistic manner:

"This is the staff, never mind the public, this is a reasonable adjustment, he [advocate] told her [nurse] and she still behaved like that, people think that you should just not make a fuss." (Para, 10)

Rachael also explained that this pressure is implicit:

"No-one *says* put a mask on, no one *says* that, but yeah of cause you are told the whole time to behave in a normal way." (Emboldened to highlight participant's emphasis) (Para, 10)

Furthermore, that because camouflaging is not visible, others do not recognise the pressure she is under: "So all of that is camouflaging all the time, people do not see that."

(Rachael, para 28)

Four of the women described accepting the expectation to adhere to majority non-autistic standards, and consequently that camouflaging was necessary. Rachael explained:

"But no one made me do, like if I said to my mum, I don't want to go, she wouldn't have made me, but I felt that I should do it cause it is what normal people did."

(Para, 4)

Alex reported an acceptance of adjusting her behaviour including camouflaging:

"I am willing to do some, you know because we are going to have to get along, it is not an autistic world and I don't know that I would really want it to be." (Para, 59)

Yasmin, echoed this preference for a non-autistic world:

"Cause I don't believe that autism is just different and is perfectly normal, I believe that the non-autistic way of interacting is normal". (Para, 7)

Jo described her willingness to adapt to a majority non-autistic, as an extreme version of her experience as a left-handed person: "Things will always be set up in an unintuitive way for you, and I think it is that [being left handed] on steroids, the entire world is, and that is fair enough it would be set up for what works best for the majority, I suppose what would be nice is if there was a little bit, if people were a little bit more flexible in what they think is normal." (Jo para, 54)

## 4.6.2. Camouflage as protection

The women all described camouflaging as a way of protecting themselves from the societal pressures, discrimination, and bullying. Several participants talked about using camouflaging as a form of protection against bullying as children:

"I used more scripts when I got into secondary school, cause it was a rough school and I had more riding on getting it right." (Yasmin, para 25)

Alex explained that camouflaging for them:

"is kind of a safety thing and maybe cause I was bulled so much as a kid my default response is still to behaviour neurotypical when I am out and about."

(Alex, para 73)

Six of the participants described camouflaging as a necessary form of protection against a vulnerability they felt in everyday life. Yasmin (para, 47) stated "my feeling is that it is something necessarily...it's something I have to do." Jo (para 96) echoed this view:

"so it is a bit of protection because you are hiding the bits of yourself that make you feel vulnerable."

This sense of vulnerability is mirrored by Alex:

"I don't think that is something I am ever going to fully unlearn and or even if I should its not a safe place for autistic people." (Alex para 3)

Whilst Holly also reported this fragility:

"there is a sense of having a weakness that they might take advantage of me in some way, and like if they spot something like that or if they humiliate me" (Holly para, 44)

Holly goes on to say: "I see it as a bit of a masking as protection and not wanting to be vulnerable." (Para, 86)

The centrality of camouflaging as protection is clearly noted by Steph:

"it's [camouflaging] my only real form of protection unless I have someone with me who knows me, so it is the only thing that will kind of get me through a social situation or a journey or something like that, that is the only thing that is protecting me from the public, because I, if not I think I would be quite vulnerable if I was out and about." (Steph, para 77)

Jess' use of language and metaphor reiterate this concept of camouflaging as defensive: "remind[s] me of my army colours and being in the army and in that way it does, cause it is like survival." (Jess, para 94)

The use of "war" language can be seen with other participants also, for example Holly talks about "armour" and putting up a "wall" (Para, 78)

Two of the women specifically described camouflaging as a protection against social judgement and criticism. Sarah noted camouflaging was "like protection from being judged for being different" (Para, 2). Whilst Rachael stated:

"[I] Think all of it is camouflaging cause if you didn't do that, people just have a go at you all the time." (Para, 4)

Steph describes camouflaging to protect her from infantilisation from others:

"I think they would think that I am less able to do things and I worried that they would change these tone of voice and requests and maybe talk down to me a bit more, treat me a little more childish." (Steph, para 93)

Holly described her feelings of vulnerability when she did not camouflage effectively:

"I have slipped up there the mask has come down and it makes me feel quite vulnerable in a way." (Para, 40)

However, two participants highlight the limitations of camouflaging as a form of social protection. Rachael explained:

"I have had experiences like that of being emotionally unsafe, as much as you try and camouflage and mask that still happened." (Rachael para, 28).

She goes on to describe how there is a cost to this process:

"an autistic person literally can't mask themselves out of everything because it will hurt you but also it won't work." (Rachael, para 28)

Alex described camouflaging as providing protection, but also reducing social visibility of their difficulties and disconnection from others:

"I don't think I could let them [camouflaging] down completely unless I, this is where I get so lonely sometimes." (Alex para, 79)

### 4.6.3. Interaction between gender and camouflaging

Seven of the participants described the increased pressure on autistic women to camouflage in comparison to men. Holly suggested there is a greater expectation on women: "It seems like that's the way, society and its expectations, and I think more so with women, about how you behave and that kind of thing, so I perceive it as inevitable in order to fit in society without ending up in too much distress or conflict."

(Holly para, 74)

## Jo reported:

"There is this constant thing of trying to, how you navigate this extra set of social expectation that comes to you just because you are female, which I really don't understand." (Jo para, 77)

This experience of an additional layer of social pressure due to gender is echoed by Sarah:

"Really ingrained sexism, that like men are sort of told like from kids you can be whoever you want to be, and so don't necessarily feel like they need to fit in as much." (Sarah para, 60)

Naomi described the pressure she experienced growing up to socialise and how this affects her adult presentation of autism:

"I have, seem, less autistic than autistic men do because I have had the socialisation through the hand clapping games and hair braiding and the increase expectations to respond in that way and to be caring and show empathy, and not to sit on your own and join the group and play with the dolls and I did all those sort of things." (Naomi para, 37)

It was noticing this expectation to play and act in a certain way as a young girl that Naomi first became aware of rules around how she was supposed to behave, and the fact that she would have preferred to deviate from these. She went on to describe the increased pressure adult autistic women experience to be social:

"As an adult I think it gets hard to pass because people are more understanding of autism in men, it makes more sense to them, a man has trouble anyway being empathetic or coming up with the right emotional support responses, whereas women are expected much more to come up with that naturally, to do that well and so I think there is less patience for getting it wrong." (Naomi para, 9)

Two participants demonstrated the increase pressure they felt to camouflage by telling personal stories of their treatment in comparison to male peers. Rachael described a male peer at a youth camp, who as equally chatty, extroverted and assertive as she was, but "his behaviour was so much more tolerated because he was a boy" (Para, 12)

Jo described a male relative who she believes is on the autism spectrum, but unlike her:

"he has never had to pretend, and never felt the need to, even though he wasn't

diagnosed, if you see what I mean, because it was perfectly acceptable for a man

to be a computer geek and that's it, he just won't, but I can't imagine I would have

got very far with that attitude." (Jo para, 73)

She also talks in more detail about the specific expectations on women to be "friendly". In particular in the work place she noted:

"if there is any sign of you being rude or whatever, the expectation is that you have to be friendly and lovely and chatty." (Jo para, 75)

Jo outlines the stereotypes that increase the pressure on women to be polite and socially compliant.

Several participants did mention that they were able to use gendered stereotypes about the appearance to their advance. They described how altering their appearance through make up and clothes could be a helpful addition to their camouflaging repertoire. Naomi explained:

"that is probably one of the benefits of being female autistic, is that you literally do put on a mask, I think a lot of women do that, whether you are autistic or not actually." (Naomi para, 49)

## Whilst, Holly stated:

"I also found that I used to do a lot of nail art because it used to be a talking point, like people would ask you about it and that kind of thing and that was quite easy and it helps me to kind of fit in and in some way it does feel like...a bit of a mask and I think it does help in some ways in that putting on a full face of makeup helped me to distinguish between work mode and home mode, but probably it does feel like I have got a bit of a mask on and then I can go home and take it all off...that seemed to work quite well!" (Holly para, 62)

One participant described the increased prevalence of camouflaging in autistic women as both due to increased social pressure, but also as an innate ability:

"Definitely for women, it's something that comes more naturally and it's definitely a learnt behaviour of just wanting to fit in and I can see why it is more a girl thing." (Steph, para 79)

She also noted that this involved having to suppress emotion and experience "as girls we get on with it and bottle it up" (Steph:79)

Jo also suggested that women were better able to camouflage:

"I think women feel more pressure to fit in anyway but I think perhaps we have more awareness of when we are getting it wrong, so even if we are not getting it right we are trying very desperately to do it." (Jo para, 73)

It is noteworthy that five participants described a fluid or diverse experience of their gender, even though they still called themselves female for social or official purposes and felt impacted by stereotypes and pressure concerning women. Holly described:

"I don't really have gender issues or anything like that, but I don't really identify as really being a woman." (Holly para, 68)

## Rachael explained:

"I never felt a pressure to behave in a girls way, like this whole gender things, I mean what is that, what is a women, I mean I don't identify as female or whatever, I just am female." (Rachael para, 2)

Jo also described this lack of innate connection to her gender, but camouflaging was a way of fulfilling social expectations:

"So there is nothing innate about any of this it has no connection to me, but somehow these things have an impact on me and I have to somehow try and if you want to camouflage into stuff you have to camouflage into this assigned role to you as a female person." (Jo para, 77)

Similarly, Naomi did not feel connected to her gender identity:

"I don't have any problem accepting that I am female, I don't have any dysphoria about it, but I don't have any sense of real identity of as a woman, I only recently heard the term "assigned female at birth" and I was like yes and that is exactly what it is." (Naomi para, 37)

Naomi goes on to talk about the distance this created between her and other women:

"So there is quite a gulf that has been built up between me and women who don't have any problem being women and being in the world at large and stuff."

(Naomi para, 43)

Jo explained that only now, in her mid-thirties has she developed friendships with other women, after many years of not being able to fit in to these gendered social settings.

The existence of gendered stereotypes meant that gender as well as autism could be felt as a performance. Alex explained:

"So yeah even gender is masking, for me, either one, people are like what pronouns are you and I am like, well they are all wrong, I am me, it's a very abstract thing." (Alex para, 33)

This experience of "playing with" or "performing gender" was echoed by Naomi who also reported:

"Nowadays I play with it [gender] a bit more but it still feels like a performance." (Para, 37)

However, four participants pointed to a sense of freedom due to being outside both gender and neurotypical boundaries. Alex reported that their autism, and identifying differently to traditional gender norms, meant they were more able to recognise and avoid negative gendered social pressure:

"I think that maybe because I am autistic maybe I can see through it, and I don't have time for it." (Alex para, 71).

Also several participants discussed playing with gender stereotypes deliberately to their advantage. Holly stated:

"I have feminine interests and that kind of thing that that is a way, you know that works in my favour I can blend in a little bit." (Holly para 70)

In addition to defying gender stereotypes, participants also reported falling outside of stereotypes around autism, and how this led to lack of recognition, minimisation, and misdiagnosis. Alex noted:

"its weird people say autistic people can't be sarcastic and I am like...have you met me?" (Alex para, 47)

Sarah described not fitting into stereotypical conceptions of autism and consequently struggling to get diagnosed:

"I had said to my person there, "I don't think it is the right diagnosis" and she was like "yes it is don't be silly"." (Sarah para, 40)

This dismissal of their experience continued post diagnosis, Naomi reported a situation at her work where she was advocating for the experience and needs of other autistic people, but was dismissed because she did not conform to their stereotyped view of what autism looked like:

"Ultimately it was quite demoralising because people constantly conceive of autism as an impairment and that if you are like piping up with ideas and saying that is not what it is really like to be autistic then people will say that you are not autistic enough." (Naomi para, 22)

Two of the participants explained how not fitting into prevailing stereotypes was linked to their gender. Jo noted the disbelief she has experienced when telling people:

"He was really surprised and he was like "oh you", partly probably cause women don't generally fit the stereotype." (Jo para, 4)

Holly also explained how her autism has gone unrecognised because she did not present a stereotypical male profile:

"Cause more people associate autism with being overt and in men, so yeah seems easier to miss and especially because I have kinda feminine interests and that kind of thing that that is a way, you know that works in my favour I can blend in a little bit." (Holly para, 70)

Rachael specifically connected the experience of misdiagnosis with the lack of understanding of camouflaging:

"That is again why women are so misdiagnosed because they [clinicians] don't understand about masking they don't understand about, they will look at you (not me because I had a good assessment) but some people, because the person is making eye contact as an effort to mask, cause they are used to doing it, they will look at them and go you are not autistic you make eye contact." (Rachael para, 36)

These experiences speak of a double minority status for some, being marginalised both due to their gender and neurodivergence. Alex described feeling doubly vulnerable in social situations due to both gender and autistic: "In addition to being scared because I present as a woman, I have that [being autistic]." (Para, 73)

The intersection between different social identity statuses was further discussed by five participants, who reported how other aspects of their identity affected their experience.

Rachael described how her assertive and expressive way of being was linked to her Jew-

ish heritage and identity, and defied typical white non-autistic female stereotypes. She explained how the combination of her Jewish and autistic identities, alongside camouflaging, increases the difficulty, and her vulnerability when socialising:

"Getting in trouble with horrible men, think that I am flirting with them when I am not, because my behaviour is not, because English girls are not like this, English girls are more reserved and quiet, Jews are really loud and whatever, but then again because people don't know I am Jewish or that I am autistic, my normal behaviour of just being friendly and speaking to people, and masking." (Rachael para, 12)

Alex reported the intersection between their nationality and autism, describing how they have to mask more in their home country because of greater social expectations around small talk and emotional expression (Para, 45). Two of the women talked about the crossover between gender, autism and motherhood. Jo described having to navigate the social expectations of being a mother in addition to gender and neurodiversity (Para, 85). Whilst, Alex noted their difficulty in fitting in with neurotypical women in the mother and toddler groups.

Four of the participants described how the difficulty and pressure to camouflage increased with age, as social expectations calcified:

"So I think that the older you are the more that you do it [camouflage] cause you are meant to behave in a certain way when you are older than when you are younger." (Rachael, para 30)

Jo noted: "I don't think it was an issue when I was a very small child because kids are far more accepting of other kids." (Para, 12) Later on she described: "I found people increasingly baffling as I got older and got more complicated." (Para, 32)

Naomi reported that for autistic girls it is easier to camouflage as there are specific social setups that force non-autistic socialising, but with age these situations diminish. She goes on to explain that gendered stereotypes of autism in adulthood exacerbate the pressure to conform:

"whereas as an adult I think it gets hard to pass because people are more understanding of autism in men." (Para, 39)

Holly (para 20) and Yasmin (para 49) explained that as they have got older the pressure to camouflage, and the complexity of the social situations they are facing, have become so overwhelming that they try to avoid socialising.

These descriptions highlight how varied and nuanced the participants' experience of camouflaging was; influenced by issues of gender, ethnicity, age, other disabilities. Yasmin vividly illustrates this when discussing how appearance, autism and camouflaging interlink. She explains how being unattractive is more problematic because she is already disadvantaged by her autism. Consequently, camouflaging, make-up and clothes are extremely important for her:

"I feel like cause I have really bad skin and without my make-up I am a bit unfortunately looking, I feel like I can't get away with both like you know what African Americans say 'pick a struggle'." (Yasmin, para 90)

# 4.7. Diagnosis and Camouflaging

The fourth theme examines how the participants' autism diagnoses influenced their camouflaging. The theme also reveals how the participants' camouflaging narratives have changed over time, in particular how they have re-storied their understanding of camou-

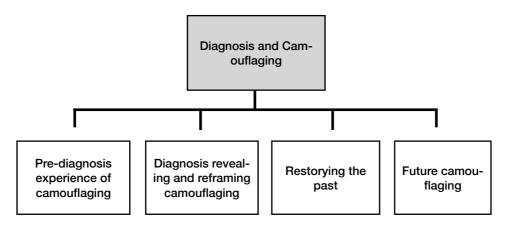


Figure 9. Diagnosis and camouflaging theme and subthemes

flaging following their diagnosis. The theme is divided into four sub-themes: pre diagnosis experience of camouflaging; diagnosis revealing and reframing camouflaging; re-storying the past; and future camouflaging (see figure 9).

## 4.7.1.Pre-diagnosis experience of camouflaging

Although they did not have the conceptual framework of autism or camouflaging prior to diagnosis, all of the women spoke about "hiding" and "fitting in". The women's stories revealed that they made sense of this experience through several narratives. Most notably a self narrative of difference and deficit, but also a lack of self, and being a fraud. Six participants described feeling different to other people and consequently attempting to hide their perceived atypicality. Yasmin stated:

"My whole life I have always known I was different...but didn't get why some things were embarrassing or abnormal." (Yasmin para, 57)

Jess also described having this awareness at an early age:

"The first memory I have was when I was three and I remember being in a playground we were taking it at turns, all the children to slide down this slide and I remember thinking that I didn't feel right, I didn't feel part of the group, and I was aware of my individuality." (Jess para, 48)

## Steph explained:

"I just wanted to fit in and so it is hard to try not to come off as a bit different or odd, and so I think that is what I mainly worry about." (Steph para, 21)

### Holly reported:

"I was aware that I was different and that I wasn't interested in the same things they were, like I didn't care about my appearance." (Holly para, 18)

However, she goes on to report that with age the pressure to hide this difference and assimilate with others increased and she began copying the appearance and activities of others.

Rachael described how other people reinforced her inner experience of difference, and the impact this had on her sense of self:

"You are told all the time you are different but you don't know how to be different and then you try and be different and people still comment on it, and then of course it would impact your sense of self." (Rachael para, 20)

This is echoed by Jo who also spoke about how feeling different negatively influenced her self-esteem: "I just always felt like an alien (laughs) and didn't really belong there." (Jo para, 16)

### She goes on to say:

"These feelings of being alienated to everything, is quite corrosive to your self-esteem over the years, so [I started]putting on this barrier, this face." (Jo para, 96)

The other prevailing narrative when describing their pre-diagnostic experience of camouflaging was of personal failure or deficit. Six of the participants described feeling that, unlike everyone else, there was something intrinsically wrong with them. Naomi stated "you are something you have to hide and not socially acceptable." (Para 27)

Prior to her diagnosis Yasmin reported "I believed there must be some internal script that I was lacking" (Para, 13). She then talked about copying others and hiding behaviours as "I don't want to be the one, to be noticed as someone who is lacking". (Yasmin para, 98)

Alex described thinking that they were failing at coping with difficulties everyone else could manage:

"I remember thinking that everybody went into the bathroom to cry and everybody's clothes hurt that much and I was just shit at dealing with it." (Alex para, 33)

Alex also described intense self criticism about this, saying to themselves: "what the fuck is wrong with you, why would you do that?" (Alex para, 18)

Rachael also reported this narrative of deficit:

"I didn't know I was autistic, it would have been very helpful to know that cause I didn't know that, and I just thought there was something wrong with my brain and everyone else was normal." (Rachael para, 16)

Similarly, Jo described this internalised sense of defect in comparison to others, and how this motivated her to attempt to match the behaviour of other people:

"I have just got to keep trying it until I get better at doing these things but I never did, it never did change." (Jo para, 4)

Sarah reported how her literal use of language exacerbated the experience that it was only her who struggled with these social interactions:

"I always thought that everyone else found everything just as hard, but managed better with it, but particularly from saying like life isn't easy, and like people say "life is difficult" and I always thought that like people found life just as difficult but managed better and coped better, so I just, well I still do, beat myself up a lot for not being able to cope as well as others were." (Para, 12)

She went on to describe how this lead to a global sense of being a "bad person" (Para, 20).

Several participants reported that, prior to their diagnosis, camouflaging lead to an ambiguous sense of self. Jess talked about being "anonymous" and a "nothing". Similarly Sarah stated:

"I don't think it is necessarily being fake I think it is more about having less of a clear idea of your own identity." (Sarah para, 64)

#### Later on she described:

"I think probably like intertwined with it all, because I guess the more you camouflage the more you have time to develop less of an identity, but I guess the less of an identity you have the more you camouflage." (Sarah para, 68)

Rachael spoke about confusion she felt trying to copy other people, and how this effected her sense of self:

"It is really hard to be yourself I don't know what that is, it's like you are pretending to be a grown up." (Rachael para, 6)

Naomi described the process of hiding and assimilating for so long felt like an "identity dysphoric experience" (Para, 31) particularly when around other people:

"It has a damaging effect on your sense of identity over time because you don't feel like you are known by anyone and also probably yourself because you are something you have to hide and you are not social acceptable." (Naomi para, 27)

Alex described a movie that they felt depicted their experience of hiding and assimilating for so many years. In the film the protagonist has always been told how to behave and had no idea of what she actually wanted or felt, even what type of eggs she liked to eat.

Alex stated:

"So it took me a long time to figure out who I was, because that was always decided ed for me." (Alex para, 35)

In contrast to this feeling a lack of self, Steph described hiding an inner sense of self: "hiding your true self to fit in to a situation" (para, 2), and that this inhibited relational connection (as discussed in the camouflaging and relationship theme).

Two of the women explained that camouflaging left them feeling fraudulent. Sarah described:

"It sort of like almost makes me feel that I am faking who I am with different people, like, I always worry that if people different people spoke about me they would feel, like, I was being fake with them." (Sarah para, 70)

Naomi also reported feeling deceptive:

"You give them the social acceptable answer they are looking for and you are going to feel deceptive and that is going to make you feel guilty." (Naomi para, 25).

### 4.7.2. Diagnosis revealing and reframing camouflaging

The participants' stories revealed how diagnosis led to a different understanding of their previously unlabelled camouflaging behaviour. For eight of the women, diagnosis prompted greater self-awareness and self-acceptance, while for three participants it resulted in more confusion. Three women also described the diagnosis as pathologising their behaviour. All of the women spoke about their post-diagnostic camouflaging in pragmatic terms. This subtheme explores diagnosis and how it reframed camouflaging for participants.

Four women explained how it was through their diagnosis that their camouflaging behaviour was revealed. Consequently, bringing more awareness to this previously nameless experience.

Jo reported how having specific language enabled her to more fully recognise her lived experience:

"I didn't have a word for that for most of my life, I just thought it was something that everybody did." (Jo para, 4)

Naomi also explains the importance of having language and a term for camouflaging, and the difficulties of understanding her experience without it:

"I suppose I must have been doing it but I never really had a word for it because I wasn't diagnosed until I was." (Naomi para 32)

She goes on to say:

"Masking wasn't something I ever thought I was doing, I just thought I was trying to "fit in". (Naomi para 53)

Alex vividly describes the impact of the diagnosis, and the importance of having a narrative to explain their autism and camouflaging; seeing the latter now as a mask:

"I finally had this framework for who I was and why I was the way I was and I am trying to, I always struggle for the words for it, but it was like having a literal mask, I can literally visualise it, having this literal flesh mask ripped off and having these horrible stitches in my skin and this really raw glistening skin underneath, but at lest it was real." (Alex para, 37)

Steph also explained the importance of her diagnosis, and specifically her camouflaging being identified:

"I have to camouflage there so it can be quite draining to come home and just kind of drop that act, if that makes sense, so it's something I do with my friends, none of my friends know my diagnosis, so it is something that I am quite good at without kind of really meaning to be, it is something that comes quite naturally to me now, which I think I didn't realise until I kind of sat down and talked to the assessor, and she was like 'people don't usually do this [camouflage], its not a normal thing to do', and that was quite interesting to me because I don't realise I am doing it sometimes, but it can all get on top of me when I come home." (Steph para, 4)

She goes on to explain how validating is was for her to have this new label and language through which to see herself and interact with others:

"I have something concrete, I have something that backs up, whereas before I didn't really have anything to go on and I just thought you know, it's for me to do." (Steph para, 87)

Two participants specifically commented on how the diagnosis helped them to become aware, or more aware, that they were camouflaging:

"I think I am more aware of myself doing it now that I have read some stuff about masking, that made me able to identify it." (Jo para, 46)

Steph reported how she used to "get on with it" and was not aware of the camouflaging she was doing:

"I was just good at getting on with things and assuming that was what everyone else did and just coping." (Para, 79)

She stated that having the diagnosis:

"I have become more understanding and I can like recognise especially when I am out and about and things are overwhelming, I can label it better and be like, 'this is probably why'." (Steph para, 51)

This process of diagnosis and identifying their camouflaging was within a medicalised setting, and two participants specifically refer to this new narrative of being pathologised.

Jess described:

"I never really thought of it [camouflaging] as being, I don't know, pathological, like it was part of a symptom or part of autism, cause I didn't really know about autism then, cause I was diagnosed when I was 25 years old, not when I was a child." (Jess para, 2)

For Yasmin her autism was abnormal and camouflaging was her way of mediating this:

"I don't believe that autism is just different and is perfectly normal, I believe that the non-autistic way of interacting is normal." (Yasmin para, 7) Eight of the women expressed how getting their diagnosis reframed their perception of themselves, from feeling deficient to having greater acceptance and compassion for themselves:

Jo reported:

"now I can forgive myself for that because I have a reason rather than keep trying to do it." (Jo para, 4)

Naomi described: "I have got this sense of compassion towards myself now." (para, 47)
Holly noted: "it has made a difference to me in that I am not as hard on myself." (para, 54)

Sarah explained that now she able to put less pressure on herself:

"I realise that there is an alternative and I don't have to make myself so drained all the time." (para 34)

Two participants spoke about their camouflaging with a sense of pride and acceptance. Jess noted how her camouflaging skills have improved over time. Yasmin clearly articulated a sense of acceptance with her camouflaging: "I am fake but that is natural and that is authentic" (para 63).

In contrast to this three participants spoke about the confusion they had felt about their camouflaging following their diagnosis. Having the label and concept of camouflaging led them to question their sense of self. Jo felt that her camouflaging was "second nature, it is part of who I am" (para, 56), however she also describes camouflaging as:

"Obscuring who you are even from yourself and not knowing how to be genuine I don't know how to remove these layers of acceptable cloaking that I have built

for such a long time I am not even sure what is underneath them and what is real anymore." (Jo para, 38)

She described how it was the revelation of her previously unidentified camouflaging that left her feeling bewildered: "it starts off all these questions in your head then about what is really me." (Jo para, 10)

Rachael also described a similar experience and how she would now like to learn more about herself and her camouflaging:

"It is hard to know what is camouflaging and what is masking, I think learning about the autistic sense of self would be good, what is your self, what is masking what is camouflaging?" (Rachael para, 37)

Yasmin, also spoke about struggling to define herself and camouflaging as exacerbating this feeling, however, in contrast to the other participants she accepted this and embraces it as part of her identity:

"It doesn't matter if you can't define yourself, who cares? No one needs to know, just go with the flow, and I am fake, but that is natural and that is authentic and it would be more, it would be way more fake to try and curb that at this point and it really doesn't matter, if you are making things easier for yourself and other people." (Yasmin, para 63)

She specifically differentiates herself from some other autistic people questioning their camouflaging and identity:

"They are struggling with their own identity, and I do too, I don't struggle with it, I don't have one just the same as them, but I basically just don't care, cause I have bigger problems, and I just think that they are navel gazing and complicating things" (Yasmin, para, 65)

Two other women specifically differentiated their camouflaging behaviour from narratives of fraudulence or deception:

#### Sarah stated:

"camouflaging, as like a chameleon and they don't do it to be malicious, they do it to protect themselves, whereas you wear a mask to deceive people."

(Sarah para, 64)

#### Naomi noted:

"It's more about filtering out stuff than adding stuff in, most of the time for me, cause I don't really like the idea of being deceptive" (Naomi para, 57)

All the participants talked about how since their diagnosis they still felt camouflaging was necessary and pragmatic. This was partly due to the social benefits camouflaging could facilitate, for example Rachael explained how since her diagnosis she is wanting to camouflage less but in order to engage socially finds it a necessity:

"I want to be myself and I want to feel more confident in myself, but you still have to adapt to what is acceptable behaviour." (Rachael, para 30)

#### Naomi echoed this:

"Yes internally it has made a difference but I still feel that I have to do the masking thing to remain socially acceptable." (Naomi para, 33)

Sarah described how camouflaging was essential in managing work and family settings:

"So I perceive it as inevitable in order to fit in society without ending up in too much distress or conflict." (Sarah para, 74)

Alex noted they had to continue camouflaging "cause we don't live in a place where people don't care yet." (para, 61)

Jess stated: "I think it is a survival thing, a way of getting by, so I do think I would have to do that in the future." (para, 80)

Eight participants described camouflaging was necessary and practical because, despite their diagnosis, it was not something they could "switch off" (as noted in the subtheme awareness of camouflaging). For example, Yasmin described the necessity of masking, but also her acceptance of this as part of her identity her "true fake self":

"I will never stop doing it and unless I could magically be cured, cause, you know they go on about "not masking" and all that crap, that would be more masking for me cause I do it automatically so to not mask would actually be more fake, and I always say I am my true fake self...after training myself all these years, it's so automatic I couldn't not do it and it would be more effort not to do it." (Yasmin para, 45)

#### 4.7.3. Restorying the past

Six of the participants specifically referred to thinking differently about their past camouflaging, in light of their diagnosis. Alex described becoming aware of how they were:

"so busy trying to be this constructed person I couldn't tap into sort of my true creative voice." (Alex para, 67)

Alex also described being angry at the pressure there had been to camouflage:

"So angry, that this thing had been put on me and I had no say in it."

(Alex para, 37)

Alex goes on to say:

"I don't know if I am ever going to really get over it, that's it's like my life has been wasted and I wondered how it would have been different." (Alex para, 43)

Rachael explained how helpful it would have been to know that she was autistic as she thought "there was something wrong with her brain" (para, 16). Later she described the pressure to perform as non-autism as abusive: "forcing non autistic behaviours on autistic people is very abusive." (para, 36) The diagnosis has enabled her to see this behaviour as no longer her deficiency, but there was a sadness that this was only revealed when she was an adult.

Jo also described that her diagnosis resulted in reframing previous narratives of deficit:

"It was mainly a huge relief because I just felt there was so much wrong with me
and I am so weird in so many ways." (Jo para, 40)

Holly reported looking back after receiving her diagnosis with a fresh sense of being unsupported as a child and young adult:

"Part of me felt let down in a way, like I could have been better supported and understood, but at the same time I think that over time it was like, it [camouflaging] is going well, this is working in a way." (Holly para, 72)

This quote also reveals her sense of achievement about her camouflaging and how it was "working" in a way that enabled her to manage socially.

Sarah described several stories where at the time she was trying to fit in and camouflaging, thinking her difficulty was due to her own failure, but now sees that her needs were being missed. She talked about how both her family and school did not intervene, and wondered about the impact support would have made:

"I think I would have answered if someone had asked me directly but I never would have asked for help or said that I was finding things hard." (Sarah para, 10)

## 4.7.4. Future camouflaging - taking off the mask?

All the participants discussed how their diagnosis also affected how they viewed the issue of camouflaging in the future. They also explained the factors that will influence their future camouflaging. Two participants reported having a deeper sense of self understanding and acceptance that lead to a desire to camouflage less:

Naomi talks about camouflaging less and hoping to continue this in the future, and also that ageing influenced her attitude to camouflaging:

"I think this maybe happens with age as well, more self-acceptance, less spoons to pretend with people, I think a lot of people experience that as they get older you know more self-acceptance and less need to pretend, so hopefully my aim Is to pull down the mask." (Naomi para, 47)

### Similarly Alex stated:

"I think I am much better at being straight up with people I get close to, I will be like these are the issues I have and if you don't think you can handle that that fine and I won't be offended but that's like where I am at and I need you to meet me with this and if I get the sense that that is not something they are willing to do then I will just ease back or ghost them or whatever, you know I am getting old and tired." (Alex para, 55)

Two women discussed the idea of "taking off the mask", referring to the recent neurodiversity campaign that encouraged autistic people wanting to reduce their camouflaging.

These participants noted that reducing camouflaging was a complex issue. Rachael stated:

"I think yes so the term masking and camouflaging is useful but it is not helpful just to have bloody hash-tag campaign saying take the mask off because, if you did that you would get abuse all the time." (Rachael para, 36)

#### Whilst Yasmin stated:

"You know they go on about "not masking" and all that crap, that would be more masking for me cause I do it automatically so to not mask would actually be more fake." (Yasmin para, 45)

As previously mentioned, they all described how camouflaging was necessary whether for practical or safety reasons, but most reported masking less and wanting to mask less in the future.

#### Jess described:

"I think it's a survival thing, a way of getting by so I do think I would have to do that in the future, in certain situations but not as much as in the past." (Jess para, 80)

Three participants described a new sense of assertiveness and advocacy for themselves and other autistic people, as they think about the future. Holly talked about being able to camouflage less at work as a consequence of their diagnosis:

"I think now I can explain there is a reason why I might need to know certain things whereas before I was worried that I couldn't say that." (Holly para, 54)

Alex described wanting to find their "true creative voice", including:

"I wanna be able to give clothes or designs to other people that are a bit not typical or give them the freedom to be who they are." (Alex para, 35)

They also talked more broadly about their attitude towards not camouflaging within a broader social context:

"I am in an oppressed group and if you want me to shut up so you don't have to deal with me fuck off!" (Alex para, 73)

Similarly, Rachael explained her desire to express her autistic self:

"We need the courageous people who aren't quiet and don't just put up with stuff yeah that again is seen as argumentative and causing conflictive."

(Rachael para, 26)

The women discussed the external factors that impacted their ability to change their camouflaging in the future. Four noted the importance of adapted, accepting and accessible environments being available.

Jo described how:

"Any situation where there can be unexpected curveballs automatically kicks in the masking because you have to mask the actual coping with it." (Jo para, 60)

She goes on to say that with people who are "friendly", "kind" and non-judgemental the pressure to camouflage is lessened (Para, 63).

Steph also talked about the impact of her work environment:

"I think if work could give me that sort of accommodation I would be a happy person and I would be a less emotional person when I got home." (Steph para, 110)

Steph and Holly both described how due to the pandemic they were working online, which meant not having to camouflage when going to an office (e.g. hiding the impact of

the sensory overload, or making small talk). Holly mentioned being able to fidget between Skype calls, or use sensory toys whilst online, and how helpful this was. This demonstrates how environmental changes can reduce the pressure to camouflage.

Describing the influence of wider social factors, Jo talked about the need for less discrimination against women for her to be able to reduce her camouflaging:

"So if over time society changes, say there is less prejudice about women shouldn't be assertive, then if that was removed, I might feel able to drop more parts of it [camouflaging]." (Jo para, 87)

Five of the participants also discussed how post diagnosis they were reevaluating and renegotiating relationships and personal boundaries in order to reduce their camouflaging. This included asserting their needs in a way they had not previously done, instead of camouflaging. Sarah described how she now asks for her best friend to adapt for her:

"So now I will like tell her which table and which side of the table I want to sit at whereas before I would be like "I just have to deal with it." (Sarah para, 32)

Alex discussed how they withdrew from harmful friendships after receiving their diagnosis and understanding themselves better. Whilst Holly explained how since her diagnosis she has been actively seeking out relationships where she was accepted and valued:

"[I have] a neurodivergant staff network and that has been really good in terms of just feeling as though you have a space where I can relate to others and feel a bit more comfortable." (Alex para 48)

Jo reported the importance of prioritising her well-being, rather than camouflaging and focusing on others' experiences and needs:

"Not overbooking all my time, free time with stuff to do and just have some, erm, if I feel like I need to just spend the time just lying in bed then I let myself do it, rather than feeling like it is lazy." (Jo para, 42).

She later described how previously her camouflaging included:

"Giv[ing] myself a hard time, that I need to do this and I need to do that, and that is the bit that I am trying to back down and not really care what other people think." (Jo para, 85)

Jo's diagnosis and the revelation of her camouflaging was key in this new stance of greater self-acceptance.

Rachael explained that following her diagnosis she is careful about who she builds relationships with; finding those who are accepting and understanding:

"I really try and be myself, like now I have the best friends I have ever had, so I think that I choose people I can be myself with." (Rachael para, 22)

The participants' stories also highlighted that this process of understanding and reframing their camouflaging, re-storying their past and considering their future, was ongoing.

Rachael highlighted how the interview itself was helping her to reconsider her understanding of her camouflaging, and in particular to be more assertive about her needs and opinions as an autistic person:

"so actually this [the interview] is helping me, because I am trying to be like this more, I need to not care what people think." (Rachael para, 36)

Three of the participants described only recently being diagnosed, and how current this process of self-understanding and re-storying was. Jo reported:

"I am still trying to process this really cause it is only 3 years ago, actually almost to the day that I was diagnosed, cause it starts off all these questions in your head then about what is really me." (Jo para, 10)

Sarah explained how she is still trying to understand her autism and camouflaging:

"I have only been diagnosed for a year and a half, when I have been undiagnosed for like 27 years." (Sarah para, 54)

Alex vividly described how they became aware of their camouflaging as a consequence of their diagnosis, using the metaphor of a mask being ripped off and sensitive skin being revealed. Initially this was an emotional and raw experience, but overtime they became more comfortable and confident:

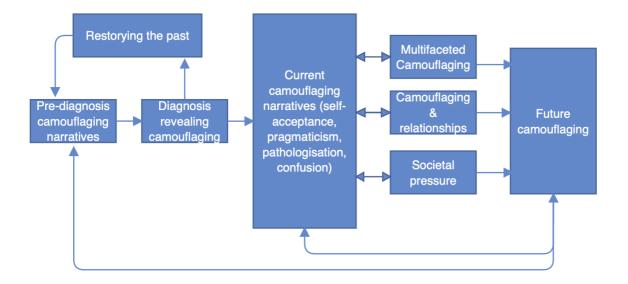
"Not quite so sensitive anymore, as it was before, you know if someone doesn't like who I am I can kinda take that." (Alex para, 67)

This metaphor captures the change in their experience and understanding of their camouflaging pre and post diagnosis.

## 4.8. Dynamic interaction between themes and subthemes

The final theme of diagnosis highlights how the participants' narratives and use of camouflaging have changed over time. Figure 10 illustrates these changes and how the themes and subthemes interact. The participants described their diagnosis as revealing or reframing their camouflaging, making them reflect and reformulate their past narratives; in figure 10 this is demonstrated by the arrows linked back to "pre-diagnostic camouflaging narratives". Participants also discussed how their diagnosis influenced their current con-

Figure 10. Dynamic interaction of themes and sub-themes



ceptualisation of camouflaging, describing stories of greater self-awareness and acceptance, pathologisation, pragmatism and confusion, as depicted in the large central box. These current camouflaging narratives both effect and are affected by social pressures, personal relationships, and their personal camouflaging repertoires (the strategies they use). These three areas are identified within the themes of "societal pressure", "camouflaging and relationships", and "multifaceted camouflaging". The current camouflaging narratives, influenced by the unique individual, relational and social context of the person, affect their view of future camouflaging. The participants also revealed that this is an ongoing process, with their attitudes and experience of their past, present and future camouflaging influencing each other, represented in the arrow sweeping from right to left. Figure 10 is by no means a summary of the participants' experience but a visual signifier for the complex and dynamic nature of the participants' experience of camouflaging.

## 5. Discussion

## 5.1. Introduction

This study explored how autistic women understand and experience camouflaging. Nine women were interviewed, and their data were analysed using narrative thematic analysis and the tools of broadening, burrowing and re-storying (Clandinin and Connelly, 1990). These narrative threads were woven together to "thicken" understanding (Bruner 2004:702) and revealed four main themes, each with subthemes. The first theme was "camouflaging as a multifaceted and individualised process", with the subthemes of methods of camouflaging, awareness of camouflaging, and individualised process. The second theme was "camouflaging and relationships", with the subthemes of camouflaging inhibiting and enabling relationships, camouflaging within close relationships, authenticity versus intimacy. The third theme was "societal pressure", with the subthemes of pressure to conform to a non-autistic majority, camouflaging as protection, and interaction between gender and camouflaging. The final theme was "diagnosis and camouflaging", with the subthemes of pre-diagnosis experience of camouflaging, diagnosis revealing and reframing camouflaging, restorying the past, future camouflaging. This chapter will consider the limitations and strengths of the study and discuss the findings with reference to relevant literature. Implications for clinical practice and future research will also be explored.

# 5.2. Strengths and limitations of the research

The study adds to the small but growing body of research concerning camouflaging in the autistic population. Although there have been various studies looking into camouflaging, the majority have been quantitative, and this study provides valuable information into the lived experience of autistic women. Furthermore, narrative thematic analysis allows a closer examination of how social and cultural factors influence camouflaging behaviour, which has been highlighted as requiring deeper examination in more recent literature (Pearson and Rose, 2021; Perry et al., 2021).

The participants' autism diagnosis was confirmed by submitting official assessment reports, ensuring that the results can be considered reflective of diagnosed autistic women. Some studies have included self-diagnosed participants, arguing that this enables examination of individuals whose camouflaging may have been so effective that they have not been identified for assessment. However, due to the small sample size within this study, homogeneity was prioritised so the participants' stories could be examined together to find general themes (Lubrosky et al., 1995). Again, an age range between 25-40 years was chosen to facilitate homogeneity in the sample. This does mean that the findings can not be generalised to women outside of this age range, and there is a paucity of research into the experiences of autistic older adults (Venus et al., 2021). However, there were no criteria regarding age at diagnosis; this was partly due to the difficulty in obtaining participants if the criteria were too narrow and to facilitate exploration of the potential impact of age of diagnosis. Interestingly, most women had been diagnosed as adults, with only one being diagnosed in late adolescence. This aligns with previous research that women are more likely to be diagnosed in adulthood (Gesi et al., 2021) and that late-diagnosed individuals are more likely to camouflage (McQuaid et al., 2020).

There was a focus on making participants feel relaxed and comfortable. This included the women choosing a community venue they felt comfortable meeting, emphasising that

they could use sensory equipment or take breaks if they wished. As a consequence of the COVID pandemic that began partway through the study, participants were given the choice of doing interviews via a video call format or telephone, and several found this format easier than a face to face meeting. However, the change in interview format may have impacted the quality of the discussion and data generated. Due to the inherent communication difficulties and differences for autistic people, participants were encouraged to ask if they were unsure about the meaning of a question or were struggling to communicate. Several participants did query the broader open questions; consequently, the prompts and examples were used to facilitate understanding (Nicolaidis et al., 2019). However, the use of a semi-structured interview, and additional prompts, may bias the direction of the material discussed. This was partly mitigated by a written summary of themes being sent to each participant following the interview, giving the participants time to review the content and correct or add information they felt was missing. Several of the participants noted that they liked this written communication. A narrative study using written data may be a valuable way of exploring participants' experiences for future research. Due to the limitations of this project being conducted by a sole researcher, it was not possible to conduct participatory research, involving participants from inception and holding ownership throughout the research (Chown et al., 2017). However, participatory and emancipatory research is vital and should be facilitated whenever possible.

The study was limited to participants without a comorbid intellectual disability (ID). This is particularly noteworthy as, to date, no study has examined camouflaging within participants who are autistic and have an intellectual disability, and so the data concerning autistic camouflaging is skewed. On the other hand, the qualitative nature of this study with a small sample size means that including a range of participants with and without ID would

extend the heterogeneity, making it more difficult to draw overall conclusions. The majority of participants were white British, so the results are limited in their ability to highlight the experiences of individuals from different ethnic groups and cultural backgrounds. This is important as the results highlight the impact of social and cultural expectations in determining and experiencing camouflaging behaviour, which will vary depending on different cultural backgrounds. Furthermore, there is a general paucity of research into the experience of autistic people of colour (Matthews, 2019), and in future research it is essential that efforts are made to readdress this balance. Furthermore, the study gathered demographic information on employment, relationship status and ethnicity, but not sexual orientation, whether participants had children, or religious status, which could also impact the social expectations determining their experience of camouflaging.

The study was specifically focused on autistic women; however, on reflection, a short questionnaire (in addition to the demographics questions) exploring participants' attitudes and identification in terms of sex and gender could have been helpful, as the interview data revealed that participants had a varied and fluid interpretation of their identity as a woman. Saxe (2017) cautions against any use of binary gender identities in research, as it may discourage participants who do not identify in this way or led to participants signing up as a particular gender to take part in a study that interests them. Further qualitative research exploring the experience of camouflaging across the gender spectrum would address this issue.

Previous research using Clandinin and Connelly's burrowing, broadening and restorying technique has used multiple interviews to collect data (Zhu, et al. 2020; Wei, 2021). In line with other studies, in this research one interview was conducted and participants further

reflections were collected using written methods (Webster and Garvis, 2017; Connelly and Clandinin, 1990). This was due to awareness of the potential pressure multiple interviews may place on participants (considering that social interaction is inherently more energy-draining for autistic people) and the limited resources of the one sole researcher. In the future, an online questionnaire (or journaling) platform that participants could log into at different time intervals, maybe a valuable way of collecting narrative data from larger populations of participants, without increasing stress levels through multiple interviews; although this would again likely restrict the sample to individuals without an intellectual disability.

## 5.3. Discussion of results

The next section will examine the four themes generated from the data, reflecting on relevant literature.

## 5.3.1. Camouflaging as a multifaceted construct

In line with previous research, the participants described camouflaging repertoires that involved multiple strategies (Livingston et al., 2019b; Hull et al., 2017; Schneid and Raz, 2020). This included masking behaviours (e.g. hiding stimming), shallow compensation strategies (e.g. learning scripts), deep compensation (e.g. using logic to determine appropriate responses), and accommodation (e.g. choosing environments that would minimise perceived differences). However, with the exception of one person, the participants did not distinguish between these strategies nor suggest they were linked to different levels of exhaustion and intention, as implied by Livingston et al. (2020).

The participants reported all of the camouflaging techniques covered in the CAT-Q (Hull et al., 2019); however, they also described behaviours not captured in the questionnaire. Several women spoke about becoming passive or quiet in social situations or purposefully deflecting attention away from them to other people or topics. Although the CAT-Q has one item that refers to "avoid[ing] interacting with others in social situations" (Hull et al. 2019:827), this does not reflect the strategies used to deflect attention, nor the holistic nature of the technique that participants described. In particular, one of the women described trying to become "nothing", "having no definition" when in social situations, which may significantly impact her sense of self and wellbeing. The Compensation Checklist by Livingston et al. (2020) does capture this aspect more closely, including items exploring the holding back of thoughts and opinions, being present but passive in social events, and avoiding situations where you would stand out.

The Compensation Checklist also refers explicitly to "helping others" as a camouflaging behaviour, which is again not covered in the CAT-Q. Several of the participants mentioned looking after the needs of others and being helpful as a part of their camouflaging repertoire. Despite shifts in implicit and explicit stereotypes around gender and caring behaviours (Charlesworth and Banaji, 2021), there remain assumptions concerning women taking more helping roles (Cudé and Winfrey, 2007; Grady et al., 2008; D'Cruz, 2000). Helping and caring behaviours could be a gendered expression of camouflaging, influenced by these cultural stereotypes. The participants also discussed using make-up and clothing as a form of camouflaging strategy, in which they consciously enlisted gendered stereotypes. These behaviours are not included in either the compensation checklist or CAT-Q, which indicates that the present conceptualisation of camouflaging within the literature

does not adequately represent autistic individuals' lived experiences. In particular, that gendered expressions of camouflaging are not yet operationalised.

The majority of participants included concealing their emotions as part of their camouflaging. This strategy is also not mentioned in the main camouflaging questionnaires, although the Compensation Checklist (Livingston et al., 2020) refers to hiding thoughts and opinions, and the CAT-Q notes adapting facial and body expression and generally "putting on an act". One study by Schuck et al. (2019) explores emotional expressivity and camouflaging behaviour, finding a negative correlation between camouflaging and emotion expressivity (in particular positive emotions) in females but not in males. However, the authors cannot determine the directionality of this correlation and wondered whether it is due to females inhibiting emotions as part of camouflaging or a reduction in expressivity as a consequence of camouflaging. The participants' stories in this research would support the former idea that individuals suppress emotions as part of camouflaging. Research has associated suppression of emotions with both negative mental and physical outcomes and impairing social interaction (Ellis and Cromby, 2012; Peters et al., 2014); and therefore examining the connection between camouflaging and emotional suppression is pertinent.

Understanding how camouflaging impacts mental wellbeing is still unclear, with studies finding differing correlations (e.g. Lai et al., 2016; Hull et al., 2021a). Examining how different camouflaging strategies may impact depression, anxiety or difficulties with self-concept has yet to be fully explored. Hull et al. (2019) found that only the assimilation sub-scale was linked to poorer mental health outcomes. The participants' stories suggest that a more nuanced examination of camouflaging may help explain mental and physical

health correlations. For example, if individuals are suppressing emotions as part of their camouflaging repertoire, what impact does this have on wellbeing? Alternatively, examining what the specific consequences would be of adopting passive, helping or "perfect" roles as part of one's camouflaging, may reveal correlations to mental health outcomes. Furthermore, the data highlights how other aspects of an autistic person's identity may impact their camouflaging (i.e. gender, nationality). Examining negative consequences of camouflaging through an intersectional lens is essential, particularly bearing in mind the relevance of the stress minority model and its connection to poor mental health outcomes (Botha, Dibbs and Frost, 2020).

#### 5.3.2. Awareness of camouflaging

A central aspect of how the participants spoke about their camouflaging was the level of awareness or intention. Some participants described it as an automatic process that was "hard-wired" and over which they did not have control. Others described it as a deliberate effort that differed from the unaware and effortless experience they observed in non-autistic people. Crucially, most participants described their camouflaging as being both with and without awareness. Although much of the previous literature references that camouflaging can be "conscious" and "unconscious" (Lai et al., 2016), there has been minimal exploration of why and how this occurs. The findings from this study support those in Cook et al. (2021), where participants also described camouflaging beginning with awareness and becoming more automatic over time. Several of the women within this study described beginning to adapt their behaviour in childhood, and that this process continues, building a repertoire of strategies that become more habitual over time. Consequently, their current experience of camouflaging contained aspects that they felt able to moderate and some that they did not.

Other participants (e.g. Naomi) described only becoming aware of their camouflaging following their diagnosis. This supports Lawson's previous research:

"rarely is it [camouflaging] done deliberately. In fact, it's only as I talk together that I realise I have been doing this over many years". (Lawson, 2020:522)

Lawson (2020) suggests that camouflaging, or using Lawson's preferred term "adaptive morphing", can be thought of as part of a survival response to a perceived or actual threat, alongside the fight, flight, and freeze reactions. In this model, camouflaging can be seen as a partly embodied unconscious mechanism. However (extrapolating from Lawson's work), we could argue that like other survival mechanisms, someone can be, or become, aware of their camouflaging, and even deliberately use it (like they could deliberately choose to run), and yet there is still an aspect that is unintentional. Understanding this nuanced aspect of camouflaging is important for several reasons. Firstly, some previous research has suggested that unconscious deep compensation is less exhausting (Livingston & Happe, 2017) than conscious shallow compensation or masking. However, this is not noted in other studies, and the participants in this study did not differentiate their camouflaging in such terms. Secondly, levels of awareness and intention may affect a person's experience of agency and sense of control over their camouflaging. This was something mentioned by several participants, specifically when describing how they would like to "take off the mask" or camouflage less, but the automatic nature of their behaviour prevented them. This experience and perception of control may significantly impact their mental wellbeing. Research has linked greater self-efficacy and internal locus of control with better mental and physical wellbeing for many years (Malhotra and Suri, 2017; Najafi and Foladjang, 2007). Exploring how camouflaging and the experience of control and wellbeing may be interconnected would be helpful to develop a better understanding of

the consequences of camouflaging and what type of support is most beneficial. Several studies have suggested that promoting individual agency over camouflaging is helpful (Schneid and Raz, 2020; Hull et al., 2017); greater insight into the levels of awareness and intentionality involved will assist clinicians in supporting individuals develop self-awareness and efficacy.

It is notable that despite the variance in how the women described and defined their camouflaging, they all reported experiencing exhaustion. This is in line with previous studies that link camouflaging with exhaustion (Hull et al., 2017; Cook et al., 2021). In addition, several of the participants discussed the physical impact of their camouflaging and associated this to causing or exacerbating long term physical health conditions (in particular CFS). There is a growing interest in the prevalence of chronic conditions (e.g. Chronic Fatigue Syndrome and Ehlers Danlos Syndrome) in autistic populations; however, the research is unclear (Bileviciute-Ljungar et al., 2018). Camouflaging may impact physical health, both through increased exhaustion and stress, and as forming a broader "mask" that includes hiding physical symptoms (as well as autistic traits) to fit into socially accepted norms (Samuels, 2003). The connection between camouflaging and physical health has not been explored but may significantly impact an individual's quality of life.

## 5.3.3. Developing the conceptualisation of camouflaging

Livingston and Happe (2017) suggested a trans-diagnostic framework for understanding compensation within neurodevelopmental conditions. They describe compensation as processes that contribute to a neurodevelopmental condition's apparent improved presentation, despite underlying differences remaining; for example, an autistic person learning social skills, or using other cognitive abilities (e.g. IQ) to offset difficulties; or someone

with developmental dyslexia developing alternative neurocognitive pathways to manage phonological processing deficits. One of the participants (Naomi) explicitly notes that their ADHD diagnosis means hiding their stimming behaviour (a camouflaging strategy often referred to in literature; Hull et al., 2017; Lai et al., 2016) is not possible due to her hyperactivity and impulsivity. Consequently, their camouflaging repertoire is influenced by their complete neurodevelopmental profile. A more helpful way of understanding an individual's camouflaging repertoire and experience would be to look across their diagnoses and how this impacts their cognitive and physical functioning (Livingston and Happe 2017). Corbett et al. (2021:138) also states:

"a more nuanced consideration of camouflaging using compensation models to reveal subtle differences in cognition, behaviour and affect that may reflect underlying profiles of challenge and strength in youth with ASD."

A fuller understanding of camouflaging can be obtained by seeing it within the context of an individual's neurodevelopmental profile, physical health profile, and sociocultural background and identity.

The participants had differing views on what terminology best defined camouflaging. This demonstrated the variation in how each person conceptualised camouflaging and their relationship to it. For example, the term "masking" was more fitting for some, as it better represented the performative nature of the experience; as Steph states, it is "putting on an act". Whereas for others, the term "camouflaging" more accurately described their experience as they most closely resonated with "blending into the background" (Rachael) or assimilating with their surroundings. Several others felt the terms currently used in the literature did not sufficiently capture their experience. More specifically, participants disliked the terms camouflaging and masking as they emphasised the concealment of autis-

tic traits, which was not part of their intent or experience. This supports previous findings by Cook et al. (2021), where participants also defined camouflaging not as a process of concealing their autism but aligning to the majority of non-autistic people they wish to connect with. Lawson's (2020) also argues that the terms masking and camouflaging are inaccurate and unhelpful as they suggest a level of agency and deliberate deceit that is not experienced by all autistic people. Indeed, several participants were concerned that their camouflaging would be considered deceitful and that others would negatively judge them. The participants' concern around being perceived as deceptive highlights the importance of considering how camouflaging is discussed both within academic and general discourses and the impact this may have on the lives of autistic people (Lawson, 2020); particularly as the phenomenon is now discussed more often in public and academic spheres.

The participants' diverse use of language reflects the academic debate concerning terminology (Corbett et al. 2021; Tubio-Fungueirino, 2020). Generally, camouflaging is defined as hiding autistic traits, which, as noted above, is not the experience of many autistic people. Furthermore, although there is general agreement about the nature of camouflaging (for example, various methods used), there is disagreement about how best to term and delineate various aspects (e.g. differentiating between shallow and deep compensation, masking or camouflaging). Lawson (2020) highlights the importance of language within research, as it attempts to represent the participants' experience and can become part of the broader social narrative. All the participants within this study had thoughtfully considered the terms they use to denote their camouflaging. One participant noted that the current terms mainly used, masking and camouflaging, are too metaphorical and do not specifically reference their experience (Jo, para 89). Their use of language

further demonstrates an individualistic experience of and relationship to camouflaging and may be helpful when considering how best to define the behaviours. Perhaps, Lawson's (2020) novel term "adaptive morphing" or a similar phrase such as "adaptive repertoire" more accurately represents the phenomena, as it removes assumptions around deception, concealment of identity and level of awareness.

Many participants also defined camouflaging as a "whole package", an immersive experience that impacts one's general sense of self. The holistic description of camouflaging from many of the participants within this study concurs with McQuaid et al.'s (2020) theory that late-diagnosed people construct a non-autistic persona, in contrast to those diagnosed in childhood, who are more likely to hide certain behaviours in a piecemeal way. This suggests they may be different camouflaging "profiles" that influence the type of strategies used. Furthermore (as suggested by Corbett et al., 2021), these different camouflaging strategies or profiles may also be associated with different mental health outcomes.

## 5.3.4. Camouflaging and relationships

The participants discussed the connection between camouflaging and the development and maintenance of relationships. The experience of camouflaging, and its consequences, affected the participants initial and intimate relationships. Camouflaging was part of the relational dynamic and affected how they thought about and navigated their relationships.

In line with previous literature, many participants described camouflaging as essential to gain acceptance and initiate relationship building (Cook et al., 2021; Cage and Troxell-

Whitman, 2019; Hull et al., 2017). The women emphasised the importance of camouflaging socially undesirable traits at the initial stage of interactions when they experienced less tolerance for any unconventional behaviour. Cook et al.'s (2021) study also noted that impression management was crucial in these initial stages, where unfamiliar social partners are more likely to be critical of behaviour outside of social norms. Most people want to give a positive first impression (Pearson, 2010); however, for autistic individuals, this performance is generally more effortful, leading to negative consequences such as exhaustion and anxiety (Tantam, 2013). Participants within this study similarly discussed how difficult it was to tolerate this initial stage of interaction that required strict adherence to social norms.

Supporting previous research (Cook et al., 2021; Hull et al., 2017), some women described feeling less need to camouflage within their most trusted and intimate relationships. However, other participants continued camouflaging within established relationships to avoid being rejected for not adhering to non-autistic norms. Some participants described the consequence of camouflaging in this way as being "stuck in the camouflaging sphere" (Naomi, para 8), which limits intimacy and inhibits the relationship deepening. This echoes Cook et al.'s (2021) findings that camouflaging inhibited intimacy by preventing genuine connection. Autistic individuals may find themselves in a "catch-22" situation, where either they choose to camouflage to initiate relationship development and then feel stuck in unsatisfactory inauthentic relationships or risk losing the other person by seeking greater authenticity through camouflaging less. Being "stuck in the camouflaging sphere" can increase loneliness, which has been linked to poorer mental wellbeing within autistic populations (Hedley et al., 2018). The findings from this study provide evidence for Bernardin et al.'s (2021) theory that lack of authenticity could be a crucial factor in ex-

plaining the relationship between camouflaging and higher levels of anxiety and depression.

Previous research has highlighted that difficulties with social skills mean that many autistic individuals struggle to develop close relationships. However, findings from this study suggest a distinction between not yet having the understanding or skills to deepen a relationship and camouflaging (due to fear of rejection) inhibiting relationship development (although an individual may experience both). Hiding stigmatised identities of any kind can increase loneliness and impair intimacy (Newheiser & Barreto (2015). In addition, moving out of the "camouflaging sphere", revealing your autistic identity, in a way that will be understood and well received by others is a highly complex social act. Similarities can be drawn to the process of "coming out" within the LGBTQIA+ population, where individuals also have to consider how cultural and relational factors may influence the response they get when disclosing their identity (Griffith and Hebl, 2002; McLean 2007).

Furthermore, disclosing your autism diagnosis may not be sufficient to ensure you can camouflage less without negatively impacting the relationship. In previous research, autistic individuals describe the need to camouflage after disclosing their diagnosis, as their autistic traits (distinct from autistic identity) may be received negatively (Butler and Gillis 2011; Botha, Dibbs and Frost 2020; Pearson and Rose, 2021). Participants within this study also described the need to camouflage with people who knew they were autistic. Unlike sexual minorities, outness in the autistic population has been associated with higher levels of psychological distress due to negative responses from others (Botha, Dibbs and Frost, 2020).

#### 5.3.5 Camouflaging in intimate relationships

Some participants mentioned the difficulty of camouflaging whilst trying to develop romantic relationships. The role of camouflaging within romantic or sexual relationships has not been previously explored in the literature. The women's stories revealed the dilemma of developing an authentic connection whilst also camouflaging to comply with acceptable and attractive behaviour stereotypes. This was particularly difficult as norms concerning acceptable behaviour for women can clash with autistic traits (e.g. directness, high sociability). On the other hand, one participant (Alex) described their intimate and authentic relationship with their spouse, with whom they no longer had to camouflage. This supports previous research noting that autistic people can feel less need to camouflage in close relationships (Cook et al., 2021).

The study identified that camouflaging could inhibit the development of healthy, balanced relationships. Some of the participants had stories of tolerating hurtful behaviour from other people as part of their camouflaging. This included hiding their needs and emotions and laughing along with bullying behaviour in order to fit into the social environment. Autistic individuals are more likely to be victims of bullying and abuse (Little 2002; Baldwin et al. 2014), and autistic women are more likely to be victims of sexual abuse and violence (Roberts et al., 2015). There is very little research into domestic abuse amongst autistic people, but one study points to a higher risk level for autistic individuals (Hwang et al., 2020). Similarly, the role camouflaging may play within abusive relationships has not previously be noted within the literature. However, common camouflaging strategies such as hiding emotions and copying the behaviour or speech of others could make it more difficult for individuals to speak out or protect themselves against harmful behaviour.

Participants within this study also described various stories of adapting their behaviour to make the person they were with comfortable, even at the cost of their own comfort. Previous research has indicated that autistic individuals are partly motivated to camouflage to reduce distress and help others around them (Cook et al., 2021; Livingston et al., 2019b). Participants also spoke about deliberately adopting roles of being "the helper" within relationships, which has been described in other studies (Livingston et al., 2019b). Performing such roles may include subjugating themselves, increasing the potential involvement in harmful relationships and negatively impacting mental wellbeing. Exploring the impact of camouflaging within romantic and sexual relationships and links with unhealthy and abusive relationships is a crucial area of study.

All but one of the participants described moderating their behaviour with their families. The experience of camouflaging within the family has not been previously examined. Cage and Troxell-Whiteman's (2019) quantitative research included an item concerning home and romantic relationships, but there is no further exploration of the topic. Most of the women from this study spoke of starting to camouflage with their families when they were children and continuing as they moved into adulthood, including after family members knew their diagnosis. The literature concerning children and adolescents with minority gender and sexual identities highlights the negative psychological impact of hiding one's identity with family and the benefit of acceptance (Ryan et al., 2010). As an undiagnosed autistic child, camouflaging at home may have a similar impact on wellbeing and identity development. This formative experience may also partly explain the higher levels of adult camouflaging in late-diagnosed people that McQuaid et al. (2020) identified.

The findings revealed that some participants camouflaged out of concern for their family members' welfare. Some women mentioned camouflaging in order to care for the mental or physical ill-health of family members. The needs of family members also determined the camouflaging strategies used, for example, having to suppress difficulties in making telephone calls to arrange medical appointments for family or hiding emotions when dealing with the mental health issues of others. Some participants were aware that their family members struggled to accept their autism diagnosis and camouflaged to minimise further distress. Furthermore, family members were generally unaware of the autistic person's needs and how they were camouflaging. Previous studies have briefly mentioned that camouflaging is linked to concern for others or avoiding others' discomfort (Livingston et al., 2019b), but there has not been an examination of how this manifests. The participants' stories describe how this combination of camouflaging and caregiving can begin in childhood and continue through adulthood and the resultant stress and isolation. Pearson and Rose (2021) draw on Hochschild's Emotional Labour theory to argue that the unconscious aspect of autistic camouflaging is synonymous with "deep acting", where one's emotional state is adapted to comply with the social situation. The description of many women in this study suggests that it may be helpful to view some aspects camouflaging in terms of the Emotional Labour model. The women are hiding or suppressing their own emotions to help, care for, or reduce the distress of others, in particular within the family home but not exclusively. Pearson and Rose (2021) argue this may be another link between camouflaging and autistic burnout described in various studies (Hull et al., 2017; Livingston et al., 2019b).

Camouflaging within the family and intimate relationships diverges from Goffman's impression management. Goffman (1990) distinguishes between front and backstage; the

former denoting situations such as work and our social sphere where we manipulate how others perceive us, and the latter referring to the occasions where you can "drop" the performance and may include a small number of people with whom you can be intimate. Arguably, autistic individuals who camouflage within the family and intimate relationships have less time "backstage" and only when alone. This is particularly pertinent as it is generally acknowledged that autistic children and adults may display more distress and characteristically autistic behaviours at home as they recover from managing the intense and unpredictable environment outside (Simpson et al., 2020). Therefore, camouflaging within the home setting and not having the opportunity to "take off the mask" may be detrimental. Cage and Troxell-Whitman (2019) study found that "high compensators" who compensated in all settings (including home life) had the highest level of anxiety and stress. Pearson and Rose (2021) also distinguish between the contextual identity shifts that are considered a part of all social interaction and performance, and camouflaging, where the autistic person is not amplifying particular aspects of their identity but continually "hiding" aspects of self. The latter having a more profound impact on mental wellbeing and self-concept (Person and Rose 2021). Many of the participants in this study mentioned that despite camouflaging at home, having safe spaces with other autistic people was extremely important, supporting previous research (Cage and Troxell-Whitman, 2020; Jedrzejewka and Dewey, 2021). The specific impact of camouflaging at home and whether this can be mitigated by accepting spaces outside the home or family would benefit from further exploration.

#### 5.3.6. Camouflaging and social pressure

Participants spoke eloquently about the pressure to conform to non-autistic social standards and the role camouflaging played in fulfilling these norms. The women described varying and sometimes conflicting beliefs about these social expectations. For some participants, the pressure to conform to non-autistic standards felt oppressive, and camouflaging became a tool of this oppression; as Jo stated, camouflaging was "forced inauthenticity". They described how the consequences of not camouflaging are so severe that to engage in society and stay safe, their only option was to conform. Furthermore, for some women, the pressure to camouflage and adhere to social norms exemplified society's rejection of autistic people and the autistic identity. This perhaps elucidates Perry et al.'s (2021) study, which found that camouflaging did not mediate the negative relationship between stigma and wellbeing. If camouflaging is seen as an enforced social expectation, any protective benefits may not translate into positive wellbeing.

Furthermore, the participants' framing of camouflaging within the context of social pressure aligns with the more recent studies by autistic researchers. Lawson (2020) and Pearson and Rose (2021) (both included autistic researchers) forefront the role of the socio-cultural environment, in particular holding a stigmatised identity, in the development of camouflaging repertoires. The women's stories reveal that even for late-diagnosed individuals, who have experienced much of their life without a label, non-autistic social standards have nevertheless been influential. Several participants directly refer to the implicit nature of this social pressure; Rachael (para 10) stated, "no one told me to do it." Consequently, the discrimination they experienced and the pressure to camouflage was unacknowledged by those around them and made seeking understanding and support more difficult. The invisible nature of these social pressures is pertinent, as autism is itself an invisible disability (Neely and Hunter, 2014) and camouflaging is generally unseen by oth-

ers. Individuals with invisible disabilities, such as autism, are exposed to the same ableism and discrimination as visible disabilities (Kattari et al., 2018). The psychological impact on autistic people caused by not being seen in these various ways would be worth exploring. Particularly as research suggests that hiding a stigmatised identity can increase poor physical and mental health (Newheiser & Barreto, 2015).

It is noteworthy that although there is evidence of greater autism awareness and acceptance within society in recent years (Dillenburger et al., 2013), the participants still described experiencing discrimination and stigma. This includes several women telling stories of struggling to get health care support after disclosing their autism and not camouflaging. This exemplifies the mixed messages autistic individuals can receive from society in general and health care in particular. Explicitly encouraging disclosure and adaptations and implicitly pressurising individuals to camouflage, as some of the women described.

The participants gave a nuanced response to their experience of social pressure and expectation. Although some described it as stressful and discriminatory, others accepted it as a reality of social existence. Several participants spoke about their awareness that they lived in a majority non-autistic world and therefore felt adapting their behaviour (having to camouflage) was a reasonable expectation. There was a sense of "fairness" in adapting to non-autistic environments. Furthermore, some participants saw their camouflaging in contradictory ways, as oppressive and as a helpful tool. Social expectations were both resisted and accepted. These descriptions help explain the previous findings by Perry et al. (2021) and Botha, Dibbs and Frost (2020), in which participants demonstrated both inter-

nal and external responses to stigma, i.e. camouflaging autism, and advocating for autistic rights.

Some participants did use normative language; for example, when Yasmin (Para, 5) stated the "non-autistic way of interacting is normal." Here camouflaging is more than an accepted consequence of living in a non-autistic majority; it is considered a more effective and objectively superior way of relating. Some researchers have discussed autistic individuals internalisation of external stigma (often during childhood) (Botha, Dibbs and Frost, 2020). They argue that due to the impact of social rejection, individuals internalise beliefs about the unacceptability of their behaviour and identity (Botha, Dibbs and Frost, 2020; Bachmann et al. 2019). However, to attribute autistic individuals acceptance of camouflaging as merely a form of self-stigma minimises their agency. Some participants within this study were explicit in their desire to adapt their behaviour to facilitate connection with the non-autistic majority; in this way, camouflaging can be seen as a strategy that provides social power. Literature on invisible disabilities has also pointed to the multiple narratives an individual can have concerning their diagnosis, including internalised ableism, alongside narratives promoting disabled identities (Kattari et al., 2018). Bachmann et al. (2019) note that the experience of self-stigma will be affected by the cultural context and how each autistic persons' social and cultural identity affects their experience of discrimination. Exploring an individual's unique experience of vulnerability (including social discrimination) may be extremely useful in minimising the negative psychological impact of stigma and facilitating agency over the experience of camouflaging.

#### 5.3.7. Camouflaging as protection

In line with previous literature, many participants spoke of using camouflaging to protect against social judgment and discrimination (Pearson and Rose, 2021). This was a strategy that developed in childhood, before diagnosis, and continued into adulthood. The participants use of language (e.g. "vulnerable", "weakness", "humiliate") highlights the fear they felt concerning the potential actions of others. Whilst, terms such as "wall" and "armour" were used when describing camouflaging. These visceral descriptions concur with Lawson's (2020) argument that camouflaging equates to a threat response in stressful social situations, similar to "fight, flight, and freeze". The participants' descriptions echo the necessary and automatic aspects of camouflaging. The women's "protection narratives" frame camouflaging as an individualised response to stigma (Perry et al., 2021) rather than purely as compensation for individual deficits (Lai et al., 2016).

The participants' stories also support the work of Botha, Dibbs and Frost (2020) who frame the experience of autistic individuals within the minority stress model, evidencing links between having a stigmatised social identity, discrimination, concealment (camouflaging) and poor health outcomes. Camouflaging is the protective response ("adaptive morphing" (Lawson, 2020)) to negative social experiences. Camouflaging as a protective act means that "taking off the mask" increases feelings of vulnerability and danger. As Steph stated:

"that is the only thing that is protecting me from the public, because, if not I think I would be quite vulnerable if I was out and about." (Para, 77)

Disclosing one's autistic identity may not be enough to stop the pressure to camouflage; even if there is overt acceptance of the autistic identity, implicit expectations for people to conform to non-autistic standards continue. As demonstrated by the participants' sto-

ries, this means that the pressure to camouflage continues even in settings that may overtly seem welcoming. As Botha, Dibbs and Frost (2020:9) note:

"participants expressed being caught in a double bind, recognising that both disclosure and the failure to disclose resulted in negative consequences."

This echoes previous research into mental health and sanism, which notes the dilemma individuals face in "coming out"; either disclosing their diagnosis and facing stigma or not coming out and experiencing the negative consequences of this (Kattari et al., 2018; Yuksel, Bingol and Oflaz, 2014). However, there is perhaps a "triple bind" that autistic people experience because others can judge camouflaging as deceptive behaviour (Lawson 2020), something noted by participants within this study. Consequently, autistic people are stigmatised for disclosing their autism, stigmatised for not disclosing and presenting autistic behaviours, and stigmatised as being "deceptive" through their camouflaging, with the latter potentially becoming more pronounced as misinformation about camouflaging increases in the public domain.

The participants' stories highlight the complex nature of the discrimination and social pressure they experience. Most of the women had not been diagnosed until adulthood; consequently, much of the pressure to conform was experienced without any label of autism being ascribed to them. Sasson and Morrison (2019) found that first impressions were less favourable for autistic individuals, both when labelled as autistic and when given no label. This highlights how the autistic behaviours themselves are stigmatised (Butler and Gillis, 2011). The findings of this study suggest that the pressure to protect oneself through camouflage exists pre-and post-diagnosis, although the narrative concerning this act may change.

#### 5.3.8. Gender and camouflaging

In line with previous research, many of the participants reported experiencing greater pressure to camouflage because of their gender (Kansfizer et al. 2017, Lai et al., 2016). They described the disparity between what was expected of them (and the judgement they received for not fulfilling these social expectations) and what was expected of men in similar situations. They could not "get away with it" in the way men around them did;

"it was perfectly expectable for a man to be a computer geek, and that's it, he just won't, but I can't imagine I would have got very far with that attitude."

(Jo, para 73)

This had consequences socially, relationally and within employment; for example, navigating sexism within a non-autistic workplace. This provides context to previous research by Cage and Troxell-Whitman (2019) that found women were more likely to camouflage for conventional reasons (such as work advancement) than men. This difference could be an example of the interaction of camouflaging and gender, with continuing sexism in the workplace (Gender Equalities Office, 2019) exacerbating social pressure and increasing the need for camouflaging. This meant having to decode and comply with two sets of social expectations and tolerating double the pressure from others. Furthermore, several of the women described how their direct, assertive autistic way of being contradicted the pressure they felt to "perform womanliness". Violating these gender norms led to criticism from others in work and social settings, which aligns with the "backlash effect" described by Rudman (1998) that suggests individuals are punished if they contradict gender norms. However, the participants in the study highlight the particular tension between autistic traits and female social norms. Leedham et al. (2020) also noted the prescriptive gendered attitudes autistic women experienced, leading to self-doubt, shame and negative self-image, all of which were experienced by the women in this study.

Many participants described an awareness of gendered social expectations from child-hood, reinforcing previous literature demonstrating gender differences in children (Dean et al., 2014; Kourti and MacLeod, 2019). Furthermore, some participants described that from childhood, their awareness of their difference was gendered; they were aware both of not complying with general (non-autistic) behaviours and not fitting with stereotypically female behaviours. Many women reported mindfully learning and adopting behaviours externally labelled as feminine and using these to enable social interaction.

In line with recent research (Haslall et al., 2021), the participants described that it was in later childhood and adolescence where camouflaging became particularly present, as the social pressure they experienced to engage in highly social gendered interactions increased. Recent longitudinal research (data from the Avon Longitudinal study of parents and children, possible 14901 children) found in late adolescence the gender ratio of autism symptoms switches, with girls exceeding boys (Riglin et al., 2021). It may well be that unable to cope with the increased pressure to camouflage and perform socially, girls autistic traits become more evident. The study also found three distinct symptoms trajectories: low (a consistently low level of autistic traits), declining (symptoms reduce over time), and late-emerging. There were no significant gender differences in the late emerging group, although there was greater association between boys in the declining group. Further research into the reasons behind the switch in ratios and the existence of late-emerging autism is required; however, the impact of gender differences in social expectations during adolescence and changes to parent and teacher scaffolding should be considered.

Some of the participants described adopting gendered behaviours as a part of camouflaging. In this way, the more prescriptive social norms concerning the behaviour of women were seen as beneficial, as they provided a fuller "performance" that could be adapted to assimilate socially. The participants' stories of camouflaging and gender were nuanced. On the one hand, being identified as a woman leads to greater pressure and constriction; on the other, they had a female costume (including clothes and make-up) that could be played with for their benefit, one that was less available to non-female identities. This also demonstrates how gender identity and roles can affect the type of camouflaging strategies a person uses. Further research with a larger sample size to explore gendered expressions of camouflaging repertoires and how this may influence outcomes would be of interest, particularly because gender performance has been previously linked to negative mental wellbeing (Landstedt et al., 2009; Dhejne et al., 2016).

The prevailing stereotype of the "male aspie" meant some participants continued to feel defective both as a woman and as an autistic person. This doubled sense of difference or minority within a minority status has already been identified in academic and anecdotal accounts (Hendrickx, 2015). In addition to not feeling a connection to external stereotypes about womanhood, many participants described a more fluid experience of their gender or less connection to their gender, even though they felt comfortable identifying as a woman within official, social and practical spheres. Participants spoke about the benefit of being able to 'step outside' of gender norms more easily than non-autistic women, who were viewed as more closely enmeshed within gendered social expectations. This was partly connected to how their autistic traits conflicted with stereotypical "womanly traits", such as greater sociability. The participants' fluid experience of gender, and pressure to adhere to gender stereotypes, can be seen to support the theory that gender dif-

ferences in camouflaging repertoires are linked to different social expectations (Pearson & Rose, 2021), as opposed to innate sex differences in the expression of autism (see Hull et al., 2020b for a review).

Some participants talked about the difficulty in developing women friends and the importance of finding autistic women's groups where they were able to explore and express their autism and their gender expression and identity. Research indicates a greater prevalence of non-binary and trans people in the autistic population, but there may also be a rich and varied experience of gender within those autistic people who identify within the gender binary (Murphy, et al., 2020; Kourti & MacLeod, 2019, Warrier, et al., 2020). It is interesting to note the participants' childhood stories of a growing awareness of gender expectation alongside an awareness of non-autistic behaviour, even before they had a diagnosis or language for this. How camouflaging may impact gender expression and what effect this has on autistic peoples' inner experience of their gender would be an important area to explore. Kourti and MacLeod (2019) suggest that autistic people have a unique experience of gender and womanhood that, as yet, has not been fully understood. The stories of the women within this study would support this idea and that camouflaging may obscure the expression of this aspect of womanhood.

Some academics have begun to analyse the autistic experience through a 'neuroqueer' framework (Walker and Raymaker 2021; Egner, 2019). The neuroqueer project is a collaboration of academics, bloggers and activists, who disidentify with both the medical model discourses of normality and cure and the counterculture identities (Kleekamp, 2021). Unlike intersectionality, neuroqueer thinkers do not simply want to combine multiple identities; they argue that a radical rejection of the identity categories is required, and

identity as malleable and fluid needs to be made central. Many participants within the study describe their experience of being outside of the standard categorisation of gender. To date, the research into camouflaging has looked at participants either in binary (men/women) or on several occasions, including "non-binary" identity. However, arguably, this still sits within a non-autistic heteronormative view of gender. As demonstrated by the participants in this study, the issue of camouflaging should also be examined through a more fluid understanding of gender, stepping outside typical categorisations.

#### 5.3.9. Social identities, intersectionality and camouflaging

Gender was only one aspect of the participants' identity that affected their experience of their autistic self and camouflaging. Several participants spoke about how age, ethnicity, nationality, and motherhood impacted their gender and their camouflaging. Up to this point, the literature has focused attention on how gender affects camouflaging but has not considered this within an intersectional framework. Although Livingston and Happe (2017) briefly mention that an individual's compensation behaviour will be impacted by social-economic statuses, such as ethnicity or home-life stability, this is not discussed further.

There has been some change in the general autism discourse, with articles specifically referencing the need to expand past the "White Male Pale" stereotypes (Garcha, 2021, title) and the need to explore the experience of non-male, non-white autistic people (Matthews, 2019). Within the study, Rachael described how her gender, Jewish identity and autism intersected and affected her social experience and camouflaging. As Saxe (2017:155) notes it is the combination of gender and neurodivergent status that impact the lived experience:

"The interaction of both of these identities that results in a qualitatively unique experience of oppression."

It is essential to view this through an intersectional lens to fully understand the factors involved in how, when, and why a person camouflages. Alex described how the extent of their camouflaging varied depending on the country they were in. Furthermore, how they conceptualised camouflaging and its values and meaning were impacted by the cultural context they grew up in. Sexuality, ethnicity, disability status and identity will impact how others expect someone to behave, and therefore what form of camouflage is required. Intersectionality is particularly important when exploring the lives of autistic and disabled people because such individuals are often reduced to their diagnosis, and other aspects of their identity are ignored (Cascio et al., 2020). Disabled people are frequently "degendered and de-sexualised in media, popular imagination, and research" (Egner, 2019:125). Several of the women spoke of camouflaging being protection from infantilisation they received after disclosing their autism. Research into the experiences of racial and ethnic minority autistic families found that barriers to services were influenced by a combination of social, political and cultural factors, and therefore service access needed to be seen within an intersectional frame (Singh and Bunyak, 2019). It seems only logical that camouflaging too should be seen within an intersectional model.

One of the participants described the "layers and layers of acceptable cloaking" (Jo para, 38), including performing "womanhood", "motherhood", and neurotypicality. The composition of the layers will be unique depending on the person's background and will also change over time. Several participants described how social expectations (and with this, the pressure to camouflage) increase with age; included, as noted by one person, the social norms and pressure that come with motherhood. Again, how age and life stages im-

pact the pressure to and experience of camouflaging will also vary depending on the other aspects of an individual's identity.

The different aspects of someone's identity, including other physical, mental and neurodevelopmental conditions, will affect if and how they camouflage. Are they able to hide stimming behaviours? Does physical illness affect how much energy they have to camouflage? As Shinn (a blogger with Asperger's syndrome) argues, taking an intersectional perspective is essential as "autism is never the only facet of a person" (Shinn, 2016). As Hillier notes, these multiple identities interlace to create a unique experience:

"Those who hold multiple categories of identity experience a cumulative discriminatory impact which differs qualitatively from the prejudice experienced towards each identity" (Hillier et al. 2020:101).

The unique experience created by multiple identities will impact a person's camouflaging profile. This will be the case whether the person holds multiple minority identities or not. However, the impact on wellbeing and the role camouflaging may play in mediating this may be most significant with autistic people who have multiple minority identities.

#### 5.3.10. Diagnosis and camouflaging

Many of the participants' pre-diagnosis stories included feelings of deficit and defectiveness. This was also seen in research by Leedham et al. (2020), in which late-diagnosed women described being intrinsically flawed. Without the context and language of diagnosis, participants in this study attributed the difference they observed between themselves and others as a personal failure. The women described how this feeling of defectiveness motivated them to camouflage (although without such a label) as children and adolescents. Pearson and Rose (2021) note the importance of considering the circumstances and reasons individuals begin camouflaging and how this connects to stigma and wellbeing.

Many of the participants within this study also explained that this perceived difference increased with age, subsequently intensifying the pressure to camouflage and the internal experience of defectiveness.

This study provides further information on the connections between camouflaging, sense of self and diagnosis. In line with previous research and anecdotal data (Hughes, 2014:7; Griffith et al., 2012), several participants described feeling like a fraud or experiencing a lack of self before their autism diagnosis. They connected this inner experience to the social adaptations they made in order to assimilate with others. Lawson echoes this with his own experience:

"ultimately masking for me, is liberating and debilitating in equal measure...it provides me with opportunities to be what I need to be for the people I love. But living a masked existence has robbed me of me." Lawson (2020:520)

The research suggests late-diagnosed people continue to camouflage more in adulthood than those who are diagnosed early (McQuaid et al., 2021; Perry et al., 2021); however, the full impact of childhood camouflaging on the adult experience is unclear. What is evident from most of the participants within this study is that the experience of camouflaging as a child made the diagnostic process more revelatory; both in terms of understanding their autistic identity and bringing to light their camouflaging repertoire. Lawson's (2020) study also notes that autistic people may not be fully aware of their camouflaging behaviour until their diagnosis. The participants' descriptions of diagnosis highlights the profound impact of this revelation. They have to readjust their self-identity both in terms of their diagnosis and their previously unlabelled camouflaging repertoire. This may lead to increased vulnerability and psychological distress following a diagnosis for those who camouflage. Some participants within this study describe a period of questioning their

sense of identity in light of the revelation of their diagnosis. With individuals asking questions such as "what is me, what is my mask, what is my autism"? The participants' accounts support the commentary by Pearson and Rose (2021) that late diagnosis can trigger difficult questions around disentangling one's sense of self from the experience of camouflaging. This is perhaps particularly key if the individual had little awareness of their camouflaging before their diagnosis, and it is only revealed through conversation initially with the assessing clinician and then when reflecting on their own and with others.

Consequently, this period post-diagnosis becomes a crucial time of re-storying past narratives of self. Research has evidenced the importance of post-diagnostic support due to the impact diagnosis has on a person's identity and wellbeing (Scattoni et al., 2021; Crane et al., 2018). However, the stories of some participants in this study indicate that further consideration concerning the role camouflaging may play in how individuals understand their diagnosis and developing positive self-esteem would be helpful (Leedham et al., 2021).

Several of the participants noted the importance of obtaining a name for their camouflaging following their diagnosis. This allowed them to create a new narrative that no longer viewed camouflaging as a deceitful way to hide deficiencies. As Bruner suggests, clinical theory can provide a framework for individuals to examine and recreate their self-narratives (Bruner, 1997). The women's stories demonstrate the variation in this process of restorying. In line with previous studies, the majority of the participants describe their diagnosis as a sense of validation and self-acceptance (Leedham et al., 2021). Further to previous research, some of the women specifically described camouflaging as part of their autistic identity and something they had pride in. However, for others, the diagnosis re-

sulted in their camouflaging behaviour becoming a pathologised aspect of their autistic profile. This highlights the importance of the academic and clinical narratives concerning camouflaging behaviour, as these will influence how individuals incorporate their camouflaging repertoires into their understanding of themselves and their autism (Lawson, 2020).

The participants described camouflaging in pragmatic terms, both before and after their diagnosis. This included camouflaging to develop relationships, avoid bullying and harassment, and aiding the achievement of life goals. Previous studies have documented camouflaging being used as a practical tool in navigating social situations (Hull et al., 2017; Cook et al., 2021). The women's stories reveal how the diagnosis legitimised their camouflaging repertoires. Consequently, the 'pragmatic narrative' of camouflaging continues post-diagnosis, but no longer as a practical response to individual failure but a tool to cope with being from a minority group. Some participants also saw the inability to stop camouflaging in pragmatic terms. Irrespective of an internal desire to camouflage less or being in autistic friendly environments, the automatic nature of some aspects of their camouflaging repertoire meant that change was limited. The diagnosis and explanation of camouflaging helped autistic individuals to hold the conflicting experiences of wanting to camouflage less and not being able to without shame. They can legitimise and take ownership over both their autistic identity and camouflaging.

### 5.3.11. Re-storying past camouflaging

The study also highlights the impact of diagnosis on how the participants reconsider their past camouflaging behaviour. Many of the participants described past experiences of camouflaging with a sense of anger or grief at the lack of support they received, the ex-

haustion of camouflaging and the stigma they experienced. Leedham et al. (2021) also identified the grief, anger and re-adjustment that older women experienced after getting their autism diagnosis as adults. This included a process of "reliving life through a new lens" (Leedham et al. 2021:139), gaining a new perspective on past experiences in light of their diagnosis. The participants' stories in this study described this same experience of re-examining and re-storying memories in light of their diagnosis; however, extending the work of Leedham et al. (2021), the participants specifically noted their sadness and anger at the fact they had to camouflage and the negative consequences this resulted in. This process of re-examination and re-storying was fluid, beginning at the assessment but continuing for many years after. The interview itself formed part of this re-storying process, with some participants discussing their new reflections on their past camouflaging. The idea that the autism diagnosis initiates a "refashioning" of the self aligns with Bruner's theory of the narrative self (Bruner 1997:157). He argues that challenging situations (in his term "trouble") are the engine for narrative and extending our concepts of self:

"It is in facing troubles, real or imagined, that refashion a Self that extends beyond the here and now of immediate encounters, a Self better able to encompass both the culture that shapes those encounters and our memories of how we have coped with them in the past." (Bruner, 1997:159)

The women's stories of coping before diagnosis and how the diagnosis led to a reconsideration of themselves and their history are examples of facing these troubles and restorying oneself. However, Bruner also notes that this is a complex process and requires skill (1997). This is exemplified in the confusion some of the women described in understanding themselves, their camouflaging and diagnosis. Providing a safe environment in which individuals can examine and re-storying their experience of and attitude to camouflaging is essential and may mitigate some of the adverse effects of camouflaging.

#### 5.3.12. Future camouflaging; to mask or not to mask?

The participants' varied descriptions of camouflaging in the future demonstrated the competing tensions they are influenced by. All the participants described masking less or wanting to mask less in the future, but social or relational factors may restrict this. The process of diagnosis and subsequent confirmation of an autistic identity led to questions concerning future masking. Several participants directly referred to the "take off the mask" social media campaign and a collective desire for autistic people to feel able to camouflage less. However, these participants explained that camouflaging less was not always possible or desired due to the continuing discrimination and stigma (Botha, Dibbs and Frost, 2020; Little 2002; Baldwin et al. 2014). Consequently, exploration of future camouflaging is best viewed within a relational and social-cultural context, where the role of society in facilitating greater adaption and acceptance is foregrounded, alongside an individual's personal choice regarding the nature of their relationships and autistic identity.

Cage and Troxell-Whitman's (2020) study showed that autistic people with a strong autistic identity, who had disclosed their diagnosis, were less likely to camouflage. Some of the participants' stories supported this finding, with several women describing how they camouflaged less following disclosing their autistic identity at work or in personal relationships. However, many of the participants emphasised that disclosure did not mean that they no longer had to camouflage. Whether in work, social or family settings, the expectation to behave and communicate in a non-autistic way often remained even when their autistic identity was known and accepted. Someone may feel safe enough to disclose their identity, which may be supported or acknowledged to a certain extent, but

their autistic traits are still not accepted, meaning camouflaging continues. In fact, Cage and Troxell-Whitman's (2020) work also identified a competing positive direct relationship (unlinked to disclosure) between a higher sense of autistic identity and higher use of camouflaging and acknowledged that there are other factors, potentially stigma and discrimination, that may be contributing to this relationship.

It is also important to note that several of the women wanted to continue camouflaging, as non-autistic interaction was considered superior. In particular, Yasmin wanted to camouflage, but the difficulties maintaining this performance meant she withdrew from social interaction. As the participants' show, the question of future camouflaging depends on an individual's beliefs about social behaviour and norms, personal abilities, and the response of others.

## 5.3.13. Adaptation, acceptance and advocacy

The participants' narratives around future camouflaging also confirm the importance of accepting and adapted environments. Previous research has found that autistic individuals feel less need to camouflage when in safe, accepting spaces (Cage & Troxell-Whitman, 2020; Perry et al., 2021). The women from this study noted several factors that help to facilitate this sense of acceptance; a positive and respectful response to disclosure, adapting the environment, welcoming and accommodating autistic behaviours (e.g. stimming), and a willingness to change non-autistic expectations around social etiquette. They also referenced how valuable it can be to develop relationships with other autistic people. In particular, in line with previous research (Leedham et al. 2021; Bargiela et al. 2016), some participants mentioned the benefit and acceptance they gained from attending autistic women groups. However, it should be noted that some individuals still engaged in some

camouflaging behaviour in these "autistic friendly" spaces to facilitate communication and relationship building.

Furthermore, due to the COVID pandemic, several participants mentioned the positive impact of more flexible work and social arrangements. These changes (often working from home) meant they had been able to camouflage less or more easily take breaks when camouflaging, which reduced stress and exhaustion. In particular, regarding work settings, the pandemic forced helpful adaptions that were previously practically possible but not allowed by managers. It is crucial to consider the environmental and community factors influencing functioning and wellbeing in autistic individuals, alongside any individual difficulties (Tobin et al., 2014). The participants stories highlight that greater understanding and adaption from a community and societal level will influence the pressure to camouflaging in the future. These findings support other research that found the pandemic facilitated adaptions to services and workplaces that were beneficial for autistic people (Cassidy et al., 2020). However, other research noted that some autistic women were more at risk of psychological distress than other autistic people (Bal et al., 2020). It would be useful to explore the role camouflaging may play in determining whether the changes linked to the pandemic were experience positively by autistic women or not.

The topic of advocacy and assertiveness was discussed by multiple participants when describing their future camouflaging. The women discussed being more assertive about their own needs and advocating for the rights of other autistic people. For example, to reduce the pressure to camouflage and the stigma they face when they do not adapt their behaviour. In various ways, for all the women, diagnosis was a catalyst to renegotiate relationships and boundaries at the individual and social level. At the individual level, this in-

volved asking for adaptations from others, ending unhealthy relationships, and seeking relationships where they can express themselves more freely and camouflage less. This process of renegotiating relationships post-diagnosis was only briefly noted in previous research (Leedham et al., 2020) and highlights an area in which autistic people may benefit from support post-assessment. On the social level, this included advocating for the rights of autistic people, with some participants describing future hopes to support others in expressing and accepting themselves.

In line with Perry et al.'s (2021) work on stigma, participants camouflaged whilst advocating for autism acceptance and adaptations. Perry et al. (2021) suggest that one reason for this duality could be the practical factor of camouflaging in specific settings where autistic behaviours are still considered unacceptable whilst advocating for change and feeling a general sense of pride in their autism identity. The stories of several participants support this suggestion; however, as previously mentioned, some participants also described accepting certain non-autistic behavioural expectations as part of living within a mainly non-autistic society. Perhaps what is most crucial is each person's relationship to their camouflaging and whether it negatively affects their wellbeing. Choosing to camouflage in specific settings may not negatively impact mental wellbeing if this is experienced as an act of agency, whilst feeling accepted and supported as an autistic person without pressure to camouflage in other relationships and situations. However, this may not be the experience of other autistic people, for whom camouflaging in any situation leads to feelings of distress. The differing stories of the participants within this study exemplify the diversity of the camouflaging experience.

#### 5.3.14. Dynamic nature of camouflaging

This study identifies how individual differences, social expectations, and relational networks affected the participants camouflaging pre-diagnosis. Following their assessment, these individual and sociocultural factors continued to impact their decisions and experience of camouflaging; however, there was the opportunity for re-storying and renegotiating their interactions. The diagnosis also gave a new label of "camouflaging", complete with its associated social values, which they then had to assimilate into their "refashioned" self (Bruner, 1997:157). The women's camouflaging narratives were fluid; they changed over time, between situations, and continued to develop. The participants' relationship to their camouflaging was also one of tension, for example, both accepting and rejecting their behaviour and society's expectations. The dynamic nature of how the women thought about and engaged with camouflaging highlights the importance of considering social and academic narratives on camouflaging and the support individuals receive.

Recent research reveals differences in autistic adults current camouflaging is based on whether they were diagnosed as children or adults (McQuaid et al., 2020). Exploration of a person's camouflaging story (when they started, what was their home environment), from an intersectional and trans-diagnostic perspective, can provide insight into current experiences of camouflaging. Furthermore, the findings from this study indicate that taking this broader perspective is essential in determining the impact of current camouflaging, particularly crucial due to the correlations between camouflaging and poor mental health, including suicidality (Cassidy et al., 2014).

#### 5.3.15. Contextualising camouflaging

Much of the initial research into camouflaging focused solely on the individual's use of compensatory strategies with no consideration of the wider context (Lai et al., 2016).

More recently, researchers have argued that camouflaging must be understood within the social context and as a response to stigma (Pearson and Rose, 2021; Perry et al., 2021).

The findings from this study provide qualitative data to support the importance of viewing camouflaging within a sociocultural context, rather than a consequence of sex related phenotype. In his commentary on camouflaging Mandy states:

"Too often, the problems of autistic people have been assumed to arise simply from their own individual deficits." (2019:1880)

Unlike previous research, this study demonstrates the importance of considering autistic people's camouflaging as both dynamic (changing over time) and intersectional. Understanding each person's camouflaging experience requires examination of the different aspects of their identity and their relational and social environment. As evidenced by the women in this study, consideration of these intersecting factors provides insight into the type of camouflaging repertoire a person may display, the impact of their camouflaging and its maintenance. This includes examination of how other co-morbid neurodevelopmental and other medical diagnoses may influence how individuals camouflage.

Camouflaging has been viewed as an aspect of the female autistic phenotype; specifically that in women the expression of autism is qualitatively different including a higher likelihood of camouflaging (Hull et al., 2020a; Gould, 2017). The danger with this theory is that it perpetuates a gender binary approach to autism that fails to acknowledge the diversity of autistic experience. Several researchers have suggested that the female autistic phenotype model negates gender diversity within the autistic population, and heterogeneity in the expression and experience of autism (Murphy et al., 2020). The women's descriptions of disconnection from binary notions of gender support the argument that a more nu-

anced understanding of autism and camouflaging is required. Furthermore, the data high-lights the crucial impact of gendered stereotypes on the participants' camouflaging behaviour, providing evidence for the argument (proposed by Pearson and Rose 2021) that gender differences in camouflaging are linked to social context rather than differing diagnostic features. As previous research has shown men and non-binary autistic people camouflage (Hull et al., 2020a). The descriptions of gender and gender roles in the data reveal how integral social expectations and norms are in how people camouflage. In line with the recent research (Pearson and Rose, 2021; Botha, Dibbs and Frost, 2020), the findings from this study support the idea that it is most helpful to view camouflaging as a reaction to one's social and cultural environment, rather than individual 'disorder'. There is similarity between this individual-societal dynamic and the experience of other minority groups although, the specific nature of camouflaging and consequences are distinct for autistic people.

# 5.4. Multidimensional model of camouflaging

If we are to understand the impact of camouflaging, we need first to understand the context in which it has developed and how the individual views it. The women's stories in this study reveal that camouflaging is more than just hiding their autism, more than a mask. It is an act of protection or connection for some and often may not be about concealing their diagnosis at all. These varied and sometimes competing conceptualisations of camouflaging can only be understood through examining a person's physical, neurological, relational and social context. Furthermore, to better understand the negative consequence of camouflaging, it must be examined contextually, as demonstrated by the challenges of camouflaging within intimate and family relationships described by women in the study.

Figure 11 illustrates a graphical representation of a multidimensional approach to camouflaging based upon the findings from this research. The individualised camouflaging repertoire will be influenced by personal factors, such as their neurodevelopmental profile and physical health, including diagnosis of illness or disability as mentioned by some participants. For example, when and how they camouflage will be affected by their physical ability to hold eye contact or memorise scripts. As previously mentioned, other neurodevelopmental conditions such as ADHD will also impact the way individuals camouflage and the effort it may take (e.g. difficulty in hiding stimming or impulsive movement). How personal factors such as differences in personality, or IQ impact an individuals camouflaging repertoire, and whether it is experienced negatively or not, requires further research. The relational context refers to the influence of intimate and other relationships on the autistic person's camouflaging. For example (as mentioned by several participants) how family expectations and capabilities can result in lifelong camouflaging, including postdiagnosis. As previously noted, the sociocultural context plays a crucial role in the development and nature of camouflaging, for example gender stereotypes and stigma towards autism will influence how someone camouflages and their experience and attitude towards it (e.g. an act of protection). Finally, as demonstrated in the participants' shifting camouflaging narratives, particularly post-diagnosis, temporality affects an individual's camouflaging repertoire, and to fully understand the role and impact camouflaging has, it needs to be examined within the context of their life history. Furthermore, these dimensions will impact each other, for example the sociocultural context will influence the relational context, and all will be affected by temporality.

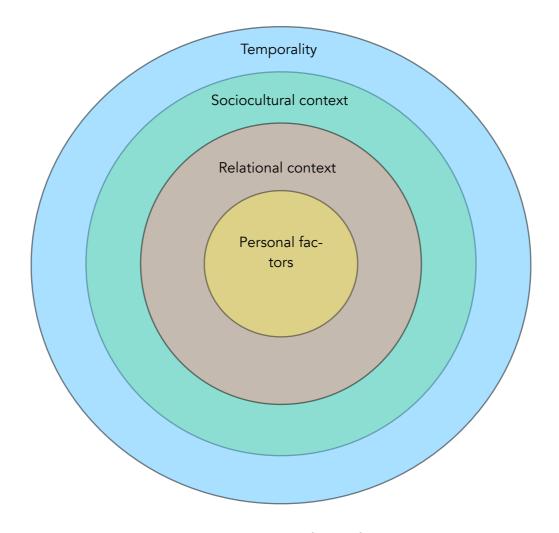


Figure 11: Multidimensional model of camouflaging

### 5.4.1 Further discussion of the temporality of camouflaging

The findings specifically highlight the impact of temporality on the participants' experience of camouflaging. This is particularly elucidated through the restorying narrative lens. Participants' describe the way their understand of their camouflaging changes following their diagnosis, as they are given the information and language to understand their experience. Crucially, for many this leads to a revision of their past self. Previously, their perceived difference from others was experienced as a deficit, and they attempted to conceal this through masking behaviours. Post diagnosis this 'defective' self concept can be seen as natural diversity, and camouflaging becomes a protective reaction to discrimination from a neuro-majority, rather than an attempt to hide personal failing. As noted pre-

viously, the point of diagnosis provides a new perspective on the past. The participants' stories reveal that the way each person goes on to restory their past is unique, as is the impact this has both on their understanding of their present and future self. For some, there is a radical revisioning of the past from deficit to difference, along with a present experience of self acceptance. Whilst, for others there is also grief for the suffering of their younger self, and for others a medicalisation and pathologisation of both past and present experience that is ambiguous in nature.

The findings also highlight that past and present experiences of camouflaging impact the participants' relationships to future camouflaging. As previously noted, for some, the process of diagnosis led to greater self-acceptance of their autistic identity which facilitated a desire to reduce their camouflaging and advocate for adaptations from others. However, other participants viewed their current camouflaging as a necessarily tool to managed perceived deficits of their autistic interaction, or an inevitable consequence of their neuro-minority status, meaning that further camouflaging was an accepted part of their future self. These examples demonstrate the effect current beliefs about their autistic identity and camouflaging influence their future and past narratives. Furthermore, that the process of, and response to, diagnosis is a significant factor in this dynamic. Figure 10. Illustrates that this is a multi-directional relationship, which was identified through the continually evolving nature of the participants' narratives around their camouflaging. Participants described how they were still developing their understanding of their past and present camouflaging and what they wanted from the future. The interviews formed part of this evolving reflective process. Recent research (Bradley et al., 2021) has noted that diagnosis can lead to greater self-acceptance of autistic traits and therefore a desire to camouflage less. However, this study provides greater insight, revealing the multiple ways

diagnosis can impact someones camouflaging and how they view it in their past, present and future.

The impact of temporality on an individual's experience of camouflaging has significant considerations for psychotherapists and other health professionals support autistic people. Firstly, it is important to acknowledge that how much and in what way a person camouflages will likely vary over time. Secondly, that the process of diagnosis has a significant impact, including revealing the phenomena of camouflaging for the first time. Previous research has evidenced that diagnosis can be emotionally unsettling, leading to feeling lost and questioning one self-identity (Crane, et al., 2018). This current study highlights that for individuals who camouflage this post-diagnostic period of reflection is further complicated by assimilation and re-storying of their camouflaging experience.

## 5.5. An existential exploration of the findings

The experience of camouflaging encompasses core existential themes, such as authenticity, self and other, freedom and responsibility. Within the interviews, some participants described the fundamental questions about their existence that were prompted by their camouflaging. For example, Jo (para 48) stated:

"so it is hard to know how to be authentic to yourself cause you don't know, that person has been so obscured by the daily effort of this for so long that, I mean that person doesn't exist do they?".

For existentialists, the self is in a constant state of becoming, and each person has a responsibility to decide who they are and will be (van Deurzen and Kenward, 2013). This uncertainty causes anxiety, which many people avoid through denial, or hiding in fixed circumstances or roles (Kierkegaard, 2015). The experience of being autistic and camouflaging can be seen as an ontic example of grappling with these fundamental human ex-

periences. For example, when consciously camouflaging, the women intentionally question "how to be" rather than slipping into social norms without awareness. Viewed existentially, the distress and exhaustion the participants experienced could be, in part, associated with the anxiety caused by facing one's freedom. In particular, the period post-diagnosis where participants described a new understanding of their camouflaging means having to confront when and how they have been assimilating to social norms. Existential thinkers (Kierkegaard, 2015) argue that such an open examination of existential choice and freedom is anxiety-provoking, providing another explanation as to why the post-diagnostic period can be stressful.

### 5.5.1. Bad Faith and Authenticity

Camouflaging could be seen as an act of bad faith, enacting the roles one believes others expect of them. Sartre (2003) argues that bad faith of this kind gives the Other dominance, becoming a being-for-others. However, arguably this imagines that the self and Other are equally powerful. The women's stories highlight the way social and cultural structures and expectations disempower and discriminate against them. Consequently, camouflaging is often a necessary act of protection. Heidegger's description of inauthenticity as an inevitable and practical part of living (1962) seems to capture this aspect of the women's experience. De Beauvoir (2010) also argues that a person's freedom is limited by their social and physical environment. The participants' descriptions of navigating social, family and work situations, with varying levels of camouflaging, encapsulates this tension of embracing one's freedom within the limitations of the environment. In this respect camouflaging is a pragmatic response to the limitations of their existence. Crucially, Heidegger puts no moral judgement on individuals for being in an inauthentic state (van Deurzen, 2010), and camouflaging should equally be seen without such criticism. This is

particularly pertinent as several of the women discussed their concern about their camouflaging being seen as deceptive.

#### 5.5.2. Self and Other

The dilemmas participants described when initiating and developing relationships echoed the tensions discussed by Sartre (2003) between self and Other. The duality of camouflaging both enabling and inhibiting relating can be viewed as an example of the unending oscillation between object and subject that Sartre (2003) describes as essential in all relationships. Either they camouflage and fix themselves in the shape of the social norms acceptable to the other person, or they assert their subjectivity and risk ending the relationship (Sartre, 2003). Notably, none of the participants solved this dilemma; instead, they described navigating relational dynamics differently depending on the circumstances. The participants also repeatedly described being caught in the Look of the Other, being labelled, determined by others, generally in harmful and inaccurate ways; an ontic example of the ontological given of relating. The participants' experiences of focusing on the needs of others, or being passive and invisible, can also be viewed as an example of becoming an in-itself, negating choice and possibility in order to connect with another person (Sartre, 2003).

Some women spoke about the benefit of developing relationships where they can be more authentic, although when this is possible depends on the attitudes and actions of those they are interacting with. Sartre's concept of we-relation highlights the importance of mutuality in moving out of a conflictual object-subject mode (Rae, 2009). To relate to the other as subject-subject there must be a "conversion" where the individual understands both their freedom and how their subjectivity is dependant on the subjectivity of

others (Rae, 2009). Thus, the subjectivity of both can be held at the same time. In a werelation, each party is working to affirm the other's freedom, creating a possibility that would not be achievable on ones own (Sartre, 1992). This theory of relatedness supports the participants' calls for acceptance from others in order to camouflage less (become less objectified). Martinot (2005) argues that this we-relation is dependent on a shared language that can overcome the subject/object relationship. Sartre notes:

"language reveals to me the freedom (the transcendence) of the one who listens to me in silence." (2003:396).

This is interesting to note considering the struggles autistic people can experience with communication, particularly when interacting with non-autistic people who may have a very different communication style. The interviews themselves could be seen as an opportunity to facilitate this change in relating (from the subject/object to a we-relation) by considering how to facilitate effective communication. Within a we-relation individuals can more freely enact their subjectivity; for the autistic person, this may reduce the pressure to camouflage.

Viewing camouflaging within this existential lens highlights the tension and anxiety individuals may experience both on a psychological, but also existential level. Camouflaging involves issues of identity, self-other relations, and freedom. However, an individual may vary in their awareness of these aspects and their ability to communicate them to another. Arguably autistic people exploring questions concerning their camouflaging are confronting the reality of how all people hide within social norms and the anxiety associated with this. Appreciating the existential content may help clinicians to better support autistic people who camouflage. Furthermore, the existential inter-relational perspective highlights the centrality of the Other and society within the phenomena of camouflaging,

supporting the argument (Pearson and Rose, 2021) that camouflaging needs to be seen within a social-cultural lens rather than simply a feature of autistic behaviour.

# 5.6. Implications for clinical practice

The study could enhance the clinical support autistic people receive in several ways. Firstly, it reinforces the importance of post-diagnostic support to facilitate an individual's understanding of their diagnosis and camouflaging repertoire. As highlighted within the study camouflaging can inhibit the development of a positive sense of self, and having the chance to explore the diagnosis (including teasing out camouflaging behaviours) with an experienced clinician, may be extremely useful. Post-diagnostic support is often not provided by healthcare services (Scattoni et al., 2021), and yet, as demonstrated within this study, many individuals take several years post-assessment to understand and assimilate their diagnosis; including debates around whether or not to "take off the mask" (Cassidy, 2018). Support from clinicians who understand camouflaging can assist an individual in uncovering what their autism means to them and how their camouflaging repertoire (which they may, or may not, have been previously aware of) is part of this picture. In addition, the results from this study note how a diagnosis can reveal camouflaging and lead to reconsideration of past experiences, including feelings of grief and anger. A clinician being aware of how an individual's understanding of their autism and camouflaging repertoire may impact not only their present and future but their relationship with the past would benefit any therapeutic intervention and post-diagnostic support.

Clinicians could also play a crucial role in helping to foster an individual's sense of agency over their camouflaging. The findings highlight the complexity of an autistic person's relationship with their camouflaging, particularly whether it is seen as a positive tool, as op-

pressive, or both, and with varying levels of awareness. Helping autistic individuals explore whether they want to camouflage or not, and clarify limitations (whether psychological or social) in their ability to control their behaviour, may help develop a greater sense of understanding and agency. Furthermore, providing support and scripts of how not to camouflage when desired could be helpful. Such interventions may help to reduce negative consequences when these individuals do choose to camouflage.

The participants' stories emphasise the presence of camouflaging within intimate and family relationships. Many autistic individuals seek psychological support due to relationship issues (Goodall, 2016), and for clinicians to consider the presence and impact of camouflaging within these relationships could be beneficial. Furthermore, supporting autistic children and adults to form safe and healthy relationships is an important topic of discussion within education and counselling settings. This study highlights how crucial it is to consider how camouflaging may inhibit healthy relationship development. As we already know, autistic individuals experience more abuse and bullying than the general population (Little 2002; Baldwin et al. 2014); further research into how camouflaging may exacerbate this issue, and clinicians being aware of this possibility and addressing it with clients seems particularly important.

The findings highlight how camouflaging and gender identity and expression may interlink. Studies indicate a higher prevalence of non-binary and trans identities within the autistic population (Murphy et al. 2020; Walsh et al., 2018). Therefore, links between camouflaging and heteronormative gender stereotypes are particularly pertinent. It is important for those clinicians supporting autistic non-binary and trans individuals (or those exploring identifying in this way) to consider how camouflaging their autism may overlap

with gender performance. Furthermore, the participants' descriptions of feeling outside the stereotypical presentation of womanhood indicate the benefit of having spaces where autistic people can express experiences of gender that may differ from a heteronormative non-autistic stereotype.

Previous research has evidenced that clinicians must know how camouflaging may impact presentation in assessments (Muggleton et al., 2019). This study notes the importance of considering how other potential diagnoses (e.g. ADHD) or identities (gender/ethnicity) may affect camouflaging behaviour and thus affect an autism assessment. Viewing an individuals behaviour within this multifaceted way may facilitate more effective autism assessments. When considering other diagnoses such as mental or physical health conditions, consideration of how a person's unique camouflaging repertoire may affect the presentation of symptoms would also be helpful.

The study reminds clinicians to be mindful of the language they use when discussing camouflaging. The women within this study used varying terminology when describing their camouflaging, and these different terms reflected differing experiences of and relationships to their camouflaging behaviour. As demonstrated by Lawson (2020) and women in this study, the terminology matters. Clinicians need to notice whether clients feel they are camouflaging as a protective response to social stigma, a tool for aiding relationship building, or an automatic act outside of their control. Acknowledging this and similarly noting and matching the terminology they use will be important in enabling effective interventions without re-shaming the client, which can be a particular pitfall when discussing invisible or hidden identities (Perry et al., 2021; Hull et al. 2017).

It is noteworthy that the study is relevant not only to psychotherapists and psychologists, but also to all healthcare professionals who encounter autistic people. Research has highlighted the lack of adequate training for doctors and other healthcare professionals regarding autistic individuals (Doherty, et al., 2021). Understanding how camouflaging can impact an individual's presentation, and in particular as noted in this study in a intersectional way (in combination with gender and other identity statuses), can facilitate healthcare professionals providing more adequate treatment. For example, general practitioners trying to assess whether a patient requires access to mental health services would greatly benefit from understanding autistic camouflaging. More specifically, this study highlights how camouflaging may increase the risk of being a victim of abusive relationships, a fact useful for all healthcare staff when assess safeguarding needs.

### 5.7. Recommendations for future research

The participants' descriptions of camouflaging highlight the influence other diagnoses and social and cultural factors have on individual repertoires. This supports a small number of previous studies that have pointed to a trans-diagnostic (Livingston and Happe, 2017) and sociocultural model of camouflaging (Pearson and Rose, 2021). Further research exploring how co-morbidity (e.g. ADHD and autism, or chronic physical health conditions and autism) may impact camouflaging repertoires and the individual experience would be fruitful. Not only could this better inform autism assessments, but it may also help therapeutic support. For example, we know that camouflaging can be extremely tiring; therefore, specific awareness of how it affects autistic individuals with chronic fatique syndromes would be useful.

Various studies have explored the impact of gender on camouflaging (Hull et al., 2020a; Wood-Downie et al. 2021; Schuck et al., 2019). However, what is apparent from this research is that an intersectional approach would be more accurate; examining how gender, ethnicity, class (and other identities) interlink to influence how, when and why autistic people camouflage. Extending the literature to examine these factors, particularly issues of race and ethnicity, an area of paucity in autistic research (Matthews, 2019), would be invaluable in understanding the experience of autistic people.

This study supports the previous research that frames camouflaging within a social minority model and within the context of stigma and discrimination. Further research is needed from an intersectional approach that considers how gender, race, poverty and other identities may affect the experience of discrimination and the expression and consequences of camouflaging. In terms of gender, although research is beginning to explore gender diversity within the autistic population, how camouflaging may impact gender expression has not yet been considered and is an important area of exploration considering the higher prevalence of gender diversity (Walsh et al., 2018).

Currently, the issue of awareness and camouflaging has yet to be fully explored. Although it is accepted that camouflaging can be both conscious and unconscious (Lai et al. 2017), why and how this occurs has not been comprehensively considered. This study provides further evidence that camouflaging may initially be done with awareness and become more automatic over time; however, unlike previous studies (Livingston & Happe, 2017), the participants' stories suggest that this does not necessarily reduce the effort required. The differing accounts of the participants within this study also suggest that there may be

significant variation in how much of each person's camouflaging repertoire is outside of awareness. A large scale study exploring levels of awareness could elucidate our understanding of camouflaging. Furthermore, it seems particularly important to explore how awareness and agency during camouflaging may impact an individual's mental health.

Many studies have identified links between camouflaging and mental health difficulties; however, there is a lack of clarity around how these connections occur. This research suggests that examining the nuance of the camouflaging experience (i.e. from a trans-diagnostic, sociocultural, relational level) may help understand how and why it is associated with poorer mental health outcomes in some individuals. For example, camouflaging may inhibit achieving relational intimacy, which increases feelings of depression, or increased pressure to camouflage at home due to religious background may impact anxiety. This is an important area of research as autistic people experience higher levels of mental health diagnoses than the non-autistic population (Lai et al., 2019). In particular, the effect of camouflaging within intimate and family relationships both for children and adults merits further investigation. Autistic literature often refers to autistic people keeping up a non-autistic facade outside the home and expressing themselves (including emotionally) at home. However, this study has revealed that this may not be the case for many individuals, and there may be significant implications for mental wellbeing.

### 5.8. Conclusion

In recent years the topic of autistic camouflaging has drawn more attention in the academic and public domain. There has been multiple news articles written by autistic people describing their personal, and often challenging experience of camouflaging (Russo, 2018; Nirode, 2021). This reflects the research literature which is has revealed increasing

levels of complexity; with debates over how best to define and operationalise camouflaging, the connection to gender and mental health outcomes (Fombonne, 2020). The aim of this research was to explore the lived experience of autistic women, gathering rich data that can better inform how we conceptualise camouflaging. The study reveals the multiple factors that influenced the participants' camouflaging and their relationship to it, providing qualitative data to support the commentary of previous academics that camouflaging should be considered through a multidimensional lens (Pearson and Rose, 2021). Furthermore, the research suggests a model that reflects the dynamic, intersectional and interactional nature of camouflaging and how this influences individual's experience of camouflaging. Examining personal factors, within a relational, social, and temporal context can also help to explain the nuanced impact of camouflaging. For example, much of the previous literature has noted the use of camouflaging to initiate friendships, but the women's stories in this study reveal how camouflaging can also lead to difficulties within familial, romantic and long-term relationships.

Previously, research has often consider camouflaging as an individual hiding deficits, however the study highlights this is an inadequate representation. Firstly, as camouflaging may not involve any concealing of traits or identity, rather strategies for connection or protection, and individuals may hold multiple and conflicting narratives concerning the intent and meaning of their camouflaging. Secondly, camouflaging is inherently an interpersonal act and therefore should be examined within the relational, social context. The data from this research also suggests that this multifactorial model can elucidates gender differences and the role of gendered stereotypes. The participants' stories revealed how camouflaging was woven into their past, present and continued to evolve influenced by current events such as COVID and the interviews themselves. Viewing camouflaging with-

in a multidimensional lens can help to understand the experiences of autistic people and better equip professionals supporting them.

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# MIDDLESEX UNIVERSITY DEPARTMENT OF PSYCHOLOGY ETHICS COMMITTEE

# **Application for Ethical Approval and Risk Assessment**

No study may proceed until approval has been granted by an authorised person. For collaborative research with another institution, ethical approval must be obtained from all institutions involved. If you are involved in a project that has already received ethical approval from another committee or that will be seeking approval from another ethics committee please complete form 'Application for Approval of Proposals Previously Approved by another Ethics Committee'

**UG and MSc STUDENTS:** Please email the completed form to your supervisor from your <u>University</u> email account (...@live.mdx.ac.uk). Your supervisor will then send your application to the Ethics Committee (<u>Psy.Ethics@mdx.ac.uk</u>). You should NOT email the ethics committee directly.

**PhD Students and STAFF:** Please email the completed form to <a href="mailto:Psy.Ethics@mdx.ac.uk">Psy.Ethics@mdx.ac.uk</a> from your <a href="mailto:University">University</a> email account (...@mdx.ac.uk)

This form consists of 8 sections:

- 1) Summary of Application and Declaration
- 2) Ethical questions
- 3) Research proposal
- 4) Information sheet
- 5) Informed consent
- 6) Debriefing
- 7) Risk assessment (required if research is to be conducted away from Middlesex University property, otherwise leave this blank. Institutions/locations listed for data collection must match original letters of acceptance)
- 8) Reviewer's decision and feedback

Once your file including proposal, information sheet, consent form, debriefing and (if necessary) materials and Risk Assessment form is ready, please check the size. For files exceeding 3MB, please email your application to your supervisor using WeTransfer: <a href="https://www.wetransfer.com/">https://www.wetransfer.com/</a> this will place your application in cloud storage rather than sending it directly to a specific email account. If you/ your supervisor have confidentiality concerns, please submit a paper copy of your application to the Psychology Office instead of proceeding with the electronic submission.

# Application No.: Click here to enter text. Decision: Click here to enter conter text. Click here to enter a date.

	☐ Yes	Signed by:	☐ Student ☐ Supervisor
	□ No	-	☐ Programme Leader
Date:	Click here to enter a dat	te.	

# LETTER/S OF ACCEPTANCE/PERMISSION MATCHING FRA1 (RISK ASSESSMENT) RECEIVED (SPECIFY):

	Date	From	Checked by
All	Click here to enter a date.	Click here to enter text.	Supervisor
			Ethics Admin
Part	Click here to enter a date.	Click here to enter text.	☐ Supervisor
			Ethics Admin
Part	Click here to enter a date.	Click here to enter text.	☐ Supervisor
			Ethics Admin

# **DBS Certificate(s) Required?** *(complete relevant boxes)*:

DBS certificate required?	Click here to choose an item.	Seen By:	Choose an item.
DBS Certificate Number:		Date DBS Issued:	Click here to enter a date.

# 1. Summary of application (researcher to complete)

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LITIE OT Proposal:			e exploration of D) conceptualise		_		ith Autism Spectrum Disaging."
Name of Principal Investigator/Supervisor  Prof Digby			<i>r</i> Tantam				
Name of Student Re- searcher(s) and student number(s)			nan M00558034	1			
Please click	one of the fol	lowing:					
UG Stud	dent		PHD/MPHIL:	PHD/MPHIL Student			MSc Student
C Staff							
Proposed start date Jan 2		Jan 2019			Proposed end	d	
Details of any co-investigators (if applicable)							
1. Name: text.	Click here	to enter	Organisation: enter text.	Click	here to	Email text.	: Click here to enter
2. Name: text.	Click here	to enter	Organisation: enter text.	Click	here to	Email text.	: Click here to enter
3. Name: Click here to enter text.		Organisation:	Click	here to	Email text.	: Click here to enter	

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	☐ Social/Psychosocial ☐ Occupational ☐ Forensic ☐ Developmental
	☐ Sport & Exercise ☐ Cognition & Emotion ☐ Psychoanalysis ☐ Clinical
	☐ Psychophysiological ☐ Health
T /D	
•	search Area (tick as many as apply)
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•	logy (tick as many as apply)
•	logy (tick as many as apply)  □ Qualitative □ Experimental □ Field Experiments
•	logy (tick as many as apply)  □ Qualitative □ Experimental □ Field Experiments □ Questionnaire

1.	Are there any sensitive elements to this study (delete as appropriate)? If you are unclear about what this means in relation to your research please discuss with your Supervisor first	Yes
1. 2	If the study involves any of the first three groups above, the researcher may need a DBS certificate (Criminal Records Check). PG students are expected to have DBS clearance. Does the current project require DBS clearance? Discuss this matter with your supervisor if you unsure	No
1.	Does the study involve ANY of the following? Clinical populations; Children (under 16 years); Vulnerable adults such as individuals with mental or physical health problems, prisoners, vulnerable elderly, young offenders; Political, ethnic or religious groups/minorities; Sexually explicit material / issues relating to sexuality; Mood induction; Deception	Yes adults with a diagnosis of Autism Spec- trum Disorder

	Is this a resubmission / amended application?	No
1. 4	If so, you must attach the original application with the review decision and comments (you do not need to re-attach materials etc if the resubmission does not concern alterations to these). Please note that in the case of complex and voluminous applications, it is the responsibility of the	
	applicant to identify the amended parts of the resubmission.	

# By submitting this form you confirm that:

- you are aware that any modifications to the design or method of the proposal will require resubmission;
- students will keep all materials, documents and data relating to this proposal until completion of your studies at Middlesex, in compliance with confidentiality guidelines (i.e., only you and your supervisor will be able to access the data);
- staff will keep all materials, documents and data relating to this proposal until the appropriate time after completion of the project, in compliance with confidentiality guidelines (i.e., only you and other members of your team will be able to access the data);
- students will provide all original paper and electronic data to the supervisor named on this form on completion of the research / dissertation submission;
- you have read and understood the British Psychological Society's *Code of Ethics and Conduct,* and *Code of Human Research Ethics*.

# 2 Ethical questions - all questions must be answered

	r questions an questions must be unswered	
2.1	Will you inform participants of their right to withdraw from the research at penalty?	Yes
2.2	Will you provide a full debriefing at the end of the data collection phase?	Yes
2.3	Will you be available to discuss the study with participants, if necessary, to ive effects or misconceptions?	Yes
2.4	Under the Data Protection Act, participant information is confidential agreed in advance. Will participant anonymity be guaranteed?	Yes
2.5	Is this research or part of it going to be conducted in a language other than Note, full translations of all non-English materials must be provided and at ument	
2.6	Is this research to be conducted only at Middlesex University?  If not, a completed Risk Assessment form - see Section 8 – must be complet from any hosting or collaborative institution must be obtained by letter or ded to this document, before data collection can commence. If you are co survey or interviews via skype or telephone whilst you are at Middlesex Un need to fill in the risk assessment form.	

=	e answered 'No' to questions 1, 2, 3, 4, and 6 above, please justify/discuss this below, outlining the meahave taken to ensure participants are being dealt with in an ethical way.
	Participants may potentially come from Sussex, Surrey, or London and therefore travellir University could be stressful. In order to minimise any difficulties with travel several local have been identified which can provide a safe, convenient location for interviews. This in and Family Centre, Carer Support Centre, and education centre. Possible venues will be participants prior to the interview. Being aware of difficulties with travel is particularly impals with ASD may struggle to travel due to sensory or cognitive differences. Participants pensated for travel expenses up to £25.

Are there any ethical issues that concern you about this particular piece of research, not covered elsewhere on this form? If so please outline them below

The research covers potentially sensitive topics, such as diagnosis, health, identity and could lead to emotional distress. Bearing in mind this ethical concern, the research questrusive or specific. The semi-structured nature of the interview means that participants what they want to discuss. Participants will be reminded that they are not obliged to an with which they feel uncomfortable, they can take a break if they require during the interval can end the interview at any time. If the participant becomes distressed during the intervected to services that can support them (e.g. local autism services, local mental health gency and crisis services). Participants will be made aware that the researcher may have seek help if the interview reveals significant concerns. This will be communicated both information sheet.

Another ethical concern is that the participants may feel obliged to participate in order to treatment. It will be made clear to the participants, both verbally and as part of the information their access to support or treatment will not be affected in any way irrespective of who withdraw, or do not engage with the study. Participants in the study will have written and about the study, consent and confidentiality. There will be transparency about the nation scope, and those involved so the participants can make an informed decision. Voluntary tain through participants signing a written consent form. All participants will be able to decite they want to take part in the study, they will be given time to consider their decide and can withdraw at anytime.

It is also possible that a participant may experience some distress if they wish to take p are not eligible; e.g. not having an official diagnosis or not attending mainstream sch sensitively to such individuals is important. If this was to occur, individuals would be thank and it would be highlighted that this study has a limited focus, however they can regist volunteer with the Autism Research Centre who can contact them about research projects eligible for.

An aspect of ASD is communication differences and difficulties, being aware of these sponding sufficiently to them is key. Participants will be asked prior to the interview if the ences or require any particular adaptions; where possible these will be accommodated possible this will be explained carefully to the participant. The information on consent verbally and in written form, and this form can be adapted (e.g. coloured paper) if require aware that some individuals with ASD may take longer to process information and there will be mindful of the pace of speech (the researcher has over 10 years experience of w als with ASD). Furthermore, time will be given to allow the potential participants to cor wish to take part in the study. When the potential participants first make contact the nat be discussed, if the individual is interested in taking part they will be sent the information form to allow them time to review the documentation. Another time to discuss whether the part in the study will be arranged, and it will be highlighted that they can contact the res date. During the second contact any questions the participant has will be discussed, and take part the interview itself will be organised. At this point the details of what will happen be discussed, along with the fact that the information sheet and consent form will review cipant is happy to agree) signed before the interview begins. It will be made explicit both ing that the participants can withdraw at anytime.

For some individuals with ASD going to new venues can be stressful and having detaile is extremely helpful. Therefore, participants will be sent written details of what will happe along with detailed information on how to get to the venue and photos of the venue. At the participants will also be reminded that during the interview they can take a break or stop the time. There will be also be cards with "stop" and "take a break" written on them in the inthe participant can use if they choose. Visual communication systems, such as cards, help some ASD individuals communicating. They will be asked if they have any particular could be accommodated, for example the lights being dimmed. Again it may not be poss aptions, but where possible this will be attempted and if not this will be sensitively excipant. Participants will also be told that if they wish to bring sensory or other objects with full to use during the interview to make them feel more comfortable (e.g. sensory putty) the doso, and if they need to move, stand, look in a particular way to make them more comfortable or the particulated verbally and within the information sheet.

It is also very important that participants are given the opportunity for a full debrief. After been completed the participants will be thanked for giving up their time. The next steps be explained (the data will be anonymised and written up for analysis, prior to the thesis They will be asked if they have any questions. The researcher will also check how the propaying particular attention if the interview evoked heightened or difficult emotions. The given information on services they can access if they want information on ASD, and shealth difficulties. This will also be highlighted in a written Debrief Information Sheet (which apted if required). The participants will be reminded that they can contact the research they have further questions and how to do so.

# 3 Research proposal

Title: A narrative exploration of how women diagnosed with Autism Spectrum Disorder conceptualise and experience "camouflaging."

The aims of the project:

- To gather data on how women use and conceptualise camouflaging behaviour to hide or minimise autistic traits within social situations.
- To add to the minimal but growing body of research around the experience of being a woman with ASD. Currently, there has been less research into adult women with ASD (Bargiela et al., 2016).
- To look at the experience and impact of camouflaging may change over time, an area still to be focused on (Lai et al., 2016).

#### Literature review and rationale

In recent years there has been a growing body of research exploring how individuals with ASD camouflage their autistic traits within social situations (Hull et al, 2017). Ryan and Raisanen (2008) argue that although monitoring and adapting behaviour to manage social situations is familiar to those without ASD, for people with ASD who struggle to identify and internalise social norms, the intensity is greater. Furthermore, for those with ASD, the focus of camouflaging is upon minimising or masking ASD-related characteristics (Hull et al, 2017). Existing research has suggested that camouflaging includes masking or concealing behaviour that might be viewed as abnormal, and engaging in compensatory behaviours or techniques to identify and comply with social rules (Lai et al. 2016; Hull et al, 2017). More specifically this can involve, imitating the facial expressions and behaviour of peers or from the media, and learning set phrases, anecdotes or jokes (Lai and Baron Cohen, 2015; Hiller et al., 2016; Lai et al.2016).

The behaviour of camouflaging has been particularly linked to women with ASD, including being seen as part of the female autistic phenotype (Hull et al, 2017; Kirkovski et al. 2013; Baldwin and Costly, 2016). From clinical observations nearly 20 years ago, Attwood (2006) suggested that the female profile was subtly different, including fewer aggressive behaviours, greater motivation and ability in learning social skills, including skills in imitation, and more socially appropriate specialist interests. Recent research supported the theory that females:

"...exhibit better expressive behaviours, reciprocal conversation, sharing interests, integrating verbal/non-verbal behaviour, imagination, adjusting behaviour by situations." (Lai et al., 2015:14)

Such differences in the female ASD profile mean that individuals can camouflage their difficulties well enough for an observer to remain unaware of potential underlying deficits, leading to issues of mis- and under diagnosis (Kirkovski et al., 2013, Head et al., 2014, Hiller et al., 2014). Research has also suggested that cultural expectations concerning gender-appropriate behaviour place greater pressure on women to camouflage (Lai et al., 2016; Kreiser and White, 2014; Holtmann et al., 2007).

A distinguishing feature of camouflaging by ASD individuals appears to be the negative impact it has on mental wellbeing (Hull et al., 2017). Research has linked the experience of camouflaging to stress, depression, anxiety, alienation and loss of self (Lai et al., 2016; Hendrickx, 2015, Davidson and Henderson, 2010, Hughes et al., 2014). There remains a need for further study into ASD and camouflaging, in particular qualitative research looking at the experiences of adults, and how this may change over time (Lai et al., 2016). Furthermore, questions still remain around the influence of gender on camouflaging. Hull et al. (2017) identified that most participant's reported camouflaging, irrespective of their gender identity.

The research so far highlights the many ways camouflaging behaviours impacts individuals (e.g. accurate diagnosis, access to services, and mental wellbeing). This study aims to develop understanding of the phenomena by conducting an in-depth study of the experience of adult women, who have been particularly associated with this experience. The research will consider "how women women diagnosed with Autism Spectrum Disorder conceptualise and experience "camouflaging." Not only will this provide an opportunity for the voices of women with ASD to be heard, but can help enable clinicians to better support those individuals they work with.

#### Method

The chosen method is a narrative enquiry. The study will adopt an experience-centred and socially-oriented narrative approach, examining each personal experience of social interaction and camouflaging, but also one expressed within a particular temporal and sociocultural context (Squire, 2016:65). Narrative enquiry has often been used to explore issues of identity and minority social groups (Frost, 2009; Davidson & Henderson 2010), as it considers how individuals make sense of their lives within a broader social context (Kanfiszer et al., 2017), such as cultural norms around gender, disability, and power (Squire et al., 2014).

# Design

Semi-structured face to face interviews will be conducted to obtain qualitative data on the participants experience. A list of the interview questions can be found below. Demographic data (namely age, gender, ethnicity, age of diagnosis, type of diagnosis, employment, living situation and relationship status) will also be collected.

### **Participants**

The study will aim to recruit 8-10 women (over 18 years old) with a diagnosis of Autism Spectrum Disorder. The diagnosis will need to have been given by a suitably trained psychiatrist, clinical or educational psychologist, and to have been diagnosed for at least a year. Participants will be asked to provide written evidence to support this. In order to ascertain that participants are aware of, and able to articulate, their camouflaging behaviour a short questionnaire will be administered (see below). Currently the phenomenon of camouflaging has been specifically identified (Attwood, 2006) in individuals without a language delay or learning disability. Consequently, I will limit the study to adults who have attended mainstream schooling. Participants will need to be fluent in English.

#### **Procedures**

Adverts to be placed in NHS adult autism assessment services, London, West Sussex, Hampshire, Surrey, as well as autism charities and community settings (e.g. Children and Family services). Within the advert potential participants will be asked to contact the researcher via telephone or email. Potential participants will be contacted via telephone or email to explain the study, confirm eligibility, and discuss if they wish to take part and issues of consent. This will include answering a short questionnaire (see below) clarifying that they have or do use camouflaging behaviours. If the participant is eligible and wishes to take part they will be sent written information on the study and the consent form. Another time to discuss the study will be arranged, in order to allow the participant time to review the documentation. At this second contact if the participant is happy the interview will be arranged and the details of what will happen will be discussed (including that the consent form will be reviewed and signed prior to the interview starting). The participant will be regularly reminded that they can contact the researcher with questions at anytime and can withdraw at anytime. The interview will take place within a neutral setting, for example charity offices, community centres. Prior to the interview beginning information on the study will be reiterated, along with consent and the participants ability to withdraw at anytime. If the participant is happy to continue demographic information will be collected via a written questionnaire, and then the interview will begin. The interview will be recorded on a digital dictaphone. Information about how this data will be anonymised, used and stored is outlined in the information sheet. At the end of the interview the researcher will give the participant the opportunity to debrief and ask any questions.

# **Analysis**

As with previous narrative studies of autistic individuals, (Kanfiszer et al., 2017; Webster and Garvis, 2017) a multi-stage narrative analysis process will be used. As noted by Polkinghorne, (Kim, 2016) the framework of both analysis of narratives, and narrative analysis will be used. This entails finding the themes within the data and relationships between these and employing the data temporally and contextually into a cohesive whole. More specifically, the analysis will begin by looking for themes within and across individual stories, moving between the two in a hermeneutic circle (Squire, 2016). Subsequently, Connelly and Clandinin's (1990) use of the analytical tools of broadening, burrowing and storying will be employed, as used within Wester and Garvis' (2017) study into critical life-moments for autistic women. The tool of broadening will explore the experience of participants within their socio-cultural context, for example, the impact of stereotypes concerning gender, disability and health in their lives. Also "broadening" can capture values and char-

acteristics that occur across participants. It is hoped such an analytic approach will enable exploration of how adults with ASD define and present themselves within these over-arching discourses, and the use (or not) of camouflaging techniques will be examined. The process of "burrowing" focuses on capturing personal experiences and understandings of camouflaging. "Burrowing" allows a deeper examination of the unique dilemmas and emotions each participant discloses. Finally, the tool of storying will aim to reflect the lived experience of camouflaging over time, as well as framing it as part of the participant' large life narrative.

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# 7 INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

This proforma is applicable to, and must be completed in advance for, the following field/location work situations:

- 1. All field/location work undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).
- 2. All field/location work undertaken by postgraduate students. Supervisors to complete with student(s).
- 3. Field/location work undertaken by research students. Student to complete with supervisor.
- 4. Field/location work/visits by research staff. Researcher to complete with Research Centre Head.
- 5. Essential information for students travelling abroad can be found on www.fco.gov.uk

# FIELD/LOCATION WORK DETAILS

Name:	Ruth Millman	Student No Research Centre:(staff o	
Supervisor:	Digby Tantam	Degree course	Counselling Psychology

NEXT OF KIN Telephone numbers and name of next of kin who may be contacted the event of an accident	<b>Phone</b> : 01732 352757
Physical or psychological limita to carrying out the proposed ficure location work	
Any health problems (full detail Which may be relevant to proposities field/location work activity in case mergencies.	

Locality (Country and Region)	London and South East (Surrey, Kent, West Sussex)
Travel Arrangements  NB: Comprehensive travel and hinsurance must always be obtained for independent overseas field/tion work.	
Dates of Travel and Field/locati work	Click here to enter text.

# PLEASE READ THE FOLLOWING INFORMATION VERY CAREFULLY Hazard Identification and Risk Assessment

List the localities to be visited or specify routes to be followed (Col. 1). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (Col. 2).

# **Examples of Potential Hazards:**

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), p tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, eth economic differences/problems. Known or suspected criminal offenders.

Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of hig III health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma eral fitness, disabilities, persons suited to task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training injury.

Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, bu Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

1. LOCALITY/ROUTE (specify here the exact name and address of each locality/organiza tion)	
,	
The Needles Children and Family	Slips, trips, falls: All venues adhere to general risk assessed a
Centre, Three Acres, Horsham, W	health and safety standards. Other staff will be in the buildir
Sussex, RH12 1RS	whilst the interviews take place in case of assistance being required in an emergency
19 Liverpool Gardens, Worthing,	
West Sussex, BN11 1RY	Dealing with unexpected visitors to the building. As the venuare used by multiple groups there is the possibility that unex
NSPC, The Existential Academy, 6:	ted visitors may arrive during the interview process. All venu
63 Fortune Green Road,	have a restricted manned/waiting room, so visitors and men
London NW6 1DR	bers of the public will not have access to the building and int view rooms, there will be other staff in the building whilst the
Birch House, National Autistic So-	interviews take place in case of assistance being required in
ciety, 6 Godalming Business Centr Godalming, Surrey GU7 1XW	emergency

The University Field/location work code of Practice booklet provides practical advice that should be followed in planning and conducting field/location work.

# **Risk Minimisation/Control Measures**

#### PLEASE READ VERY CAREFULLY

For each hazard identified (Col 2), list the precautions/control measures in place or that will be taken (Col 3) to "reduce the risk to acceptable levels", and the safety equipment (Col 5) that will be employed.

Assuming the safety precautions/control methods that will be adopted (Col. 3), categorise the field/location work risk for each location/route as negligible, low, moderate or high (Col. 4).

Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

# **Examples of control measures/precautions:**

Providing adequate training, information & instructions on field/location work tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with col-

leagues (pairs). Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility. Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of field/location work area.

**Examples of Safety Equipment**: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

3. PRECAUTIONS/CONTROL MEASURES	4. RISK ASSESS- MENT (low, moderate, high)	5. SAFETY/EQUIP- MENT
All venues adhere to general health and safety and fire standards	Low risk	Personal alarm, along with standard fire safety equipment
The interviewer has experience of working clinically and managing distressed individuals.		and first aid kit in all locations.
The interviewer will not be lone working; there will be o staff in the building whilst the interviews take place in ca of assistance being required in an emergency		
All venues have a restricted waiting room, so visitors and members of the public will not have access to the building and interview rooms		

#### PLEASE READ THE FOLLOWING INFORMATION AND SIGN AS APPROPRIATE

**DECLARATION:** The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the field/location work period and additional precautions taken or field/location work discontinued if the risk is seen to be unacceptable.

Signature of Field/location w (Student/Staff)		Date:	
Signature of Student Supervi	Click here to enter text.	Date:	Click here to enter a dat

APPROVAL: (ONE ONLY)	Click here to enter text.	Date:	Click here to enter a dat
Signature of Director of Programmes (und graduate students only)			
Signature of Research Degree ordinator or Director of Programmes (Posgraduate)		Date:	Click here to enter a dat
Signature of Research Centre (for staff field/location worke		Date:	Click here to enter a dat

# **FIELD/LOCATION WORK CHECK LIST**

1.	Ensure that all members of the field party possess the following attributes (where relevant) at a level
	appropriate to the proposed activity and likely field conditions:

☐ Safety Knowledge & Training?	☐ Awareness of cultural, social & political differences?	
☐ Personal clothing & safety equipment?	☐ Suitability of field/location workers to proposed tasks?	
☐ Physical & psychological fitness & disease immunity, protection & awareness?		

2. Have all the necessary arrangements been made and information/instruction gained, and have the relevant authorities been consulted or informed with regard to

☐ Visa, permits?	☐ Weather conditions, tide times and ranges?
Legal access to sites and/or persons?	☐ Suitability of field/location workers to proposed tasks?

☐ Vaccinations and other health precautions?	☐ Safety equipment and protective clothing?	
☐ Financial and insurance implications?	☐ Travel and accommodation arrangements?	
☐ Health insurance arrangements?	☐ Arrival times after journeys?	
☐ Civil unrest and terrorism?	☐ Emergency procedures?	
☐ Crime risk?	☐ Transport use?	
☐ Political or military sensitivity of the proposed topic, its method or location?		

# Important information for retaining evidence of completed risk assessments:

Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the field/location worker participating on the field course/work. In addition the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.

RP/cc Sept 2010

# Appendix ii: confirmation of ethical approval



NEW SCHOOL OF PSYCHOTHERAPY AND COUNSELLING

NSPC Limited Existential Academy 61–63 Fortune Green Road London NW6 1DR

Ruth Millman 48 Yardley Park road Kent TN9 1NF

16th June 2020

Dear Ruth

Re: Ethics Approval

The panel have reviewed your ethics amendments and your application has been approved by Chair's action and ratified by the ethics board.

Yours sincerely

Prof Digby Tantam Chair Ethics Committee NSPC

# Appendix iii: Participant information sheet



The Department of Health and Social Sciences Middlesex University Hendon London NW4 4BT



#### PARTICIPANT INFORMATION SHEET

Researcher's name: Ruth Millman

Institute information: Middlesex University; New School of Psychotherapy and Counselling

# Study Title: How do autistic women experience and conceptualise camouflaging.

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You may want to talk to others about the study to help you to decide whether you would like to take part.

A researcher will go through the information on this sheet with you and answer any questions that you have. This should take about 10-15 minutes. Please ask the researcher if there is anything that is not clear or if you would like more information.

# What is the aim of the study?

The aim of this study is to find out how women with a diagnosis of Autism Spectrum Disorder (ASD) camouflage in social situations.

Within this study the term camouflaging means trying to hide your ASD from others, for example by using coping skills or strategies during social situations. Research has shown that autistic people use strategies to hide behaviours linked to their autism, and that camouflaging may be a reason why people's ASD is missed. This study aims to find out more about people's experience of camouflaging to help clinicians understand and support autistic women better.

In this study we will be interviewing women with a diagnosis of ASD to find out about their experience of camouflaging. This will involve a face to face interview with a researcher where you are asked questions and can talk about your experience.

# Who are we looking for?

We are looking for women who

- Are between 25-40 years old
- Have been diagnosed by a qualified professional as having an Autism Spectrum Disorder (ASD).
- Currently use camouflaging behaviour in social situations.
- · Have gone through mainstream schooling
- Speak fluent English

#### What will happen to me if I take part?

The researcher will arrange a time and place to meet to have an interview. If you want to, you can ask someone to come with you, although they won't be able to come into the interview room with you. There will be one researcher asking you questions about your experiences of camouflaging. This will take approximately 1-1.5 hours. You will be asked fill in a questionnaire asking for demographic information (e.g. age and ethnicity). You are able to ask for a break at anytime and can end the interview at any time. The interview will be audio recorded. Once you have re-read the information and understand the research, you will be asked to confirm your consent to proceed. There will be cards you can use to show you need a break, or to stop the interview if speaking becomes difficult. You can bring sensory equipment with you to use during the interview if that helps you. If we can alter the environment (e.g. dim lights) to make it more comfortable for you please say. At the end of the interview you will have the chance to ask any questions and talk to the researcher about how the interview was for you.

### What might be the benefits of the study

Taking part in this study will give you the chance to talk about your experiences of having ASD and dealing with social interactions. Some people find it useful to talk about their experiences in this way. Also sharing your experiences will help us to better understand what camouflaging is and how it affects autistic women, and how to support them.

#### What might be the disadvantages of taking part in the study?

There are no physical risks, but some people may find the process of talking about their experiences tiring or stressful. If you do become upset during the interview for any reason, you can ask to stop without having to explain why. If there are certain questions you do not want to answer that is okay. At the end of the interview the researcher will check how you are feeling and can give you information about services that could offer you further support should you wish. If the researcher is concerned about your wellbeing, with your permission, they may contact relevant services to assist you.

#### Do you have to take part?

No - Taking part in this study is entirely voluntary. Whether or not you take part will not affect any treatment or help that you are getting at the moment or in the future. If you do decide to take part you may withdraw at any time without giving a reason. You can withdraw from the study after you have completed your interview, however once the interview information has been processed and analysed you are no longer able to withdraw your contribution. At this point, your personal identifying data will have been destroyed and only the analysed anonymized research data remaining.

#### What will happen with the information that you give and will it be treated confidentially?

Your personal information will be kept confidentiality, this means it will not be passed on to anyone else. Only the researcher and their supervisors will know who you are. Your contact details will be kept separately from the other data in a secure location, and destroyed after the analysis has been completed. The interviews will be written up anonymously, this means that all identifiable information (e.g. your name and anything else that might identify who you are) will be removed or changed. The demographic data will also be anonymised. The digital recording of the interview will be kept on an encrypted USB stick. The anonymised research data will be stored in a secure repository at NSPC for 10 years.

This information will be looked at as a whole, to find out what it tells us about the experience of camouflaging for autistic women. We would want to directly quote some of what you say, but without identifying who you are. You will be asked on the day of the interview whether you are happy for us to quote you, if you are

not we will not use your exact words. This study is part of the researcher's doctorate course in Counselling Psychology and will be written up as a doctoral thesis, and may be published in relevant journals or conferences.

# When will confidentiality be broken?

If you are at serious risk of harming yourself or others; or there are concerns for the neglect or abuse of children, then we will have to share this with agencies. If this was to happen we would aim to talk to you about it first.

# Who is organising and funding the research?

This research is part of the researcher's doctoral Counselling Psychology course overseen by The New School of Counselling and Psychotherapy and Middlesex University. The research is not organised or sponsored by any external body.

# Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The New School of Counselling and Psychotherapy's Ethics Committee have reviewed this proposal.

Thank you for taking the time to read this information. If you have any questions you can contact the research on:

Researcher details: Ruth Millman
Email contact: r.millman@alongsideautism.co.uk
Address: NSPC, 61-63 Fortune Green Road, London NW6 1DR

Supervisor details: Digby Tantam
Email contact: digby@nspc.com
Tel: 0207 435 8067 or 0203 515 0223

Address: NSPC, 61-63 Fortune Green Road, London NW6 1DR

# Appendix iv: Participant consent form



The Department of Health and Social Sciences
Middlesex University
Hendon
London NW4 4BT



# Study Title: How do autistic women experience and conceptualise camouflaging.

Researcher: Ruth Millman Supervisor: Prof Digby Tantam

Please initial the boxes to indicate you agree to the statements and sign

- 1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 3. I further understand that the data I provide may be used for analysis and subsequent publication (postgraduate dissertation, journal articles and conference papers)
- 4. I consent to the interview being audio recorded

6. I agree to take part in the above study.

5. I consent to my comments within the interview being anonymously quoted as part of the above study.

Print name Sign Name	· <del></del>
-	
date:	

**To the participant:** Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Science and Technology Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: \_\_\_\_\_\_\_

# Appendix v: Initial questionnaire



The Department of Health and Social Sciences Middlesex University Hendon London NW4 4BT



# Questions about your camouflaging behaviour

A reminder: in this survey we use the term 'camouflaging' to refer to "consciously or unconsciously, trying to hide your autism (ASD) from others, for example by using coping skills or strategies during social situations."

1) Do you currently 'camouflage' your autism (ASD) in some/all social situa-
tions? (please indicate by deleting / circling / emboldening the relevant an-
swer)

Yes / No

2) In what situations do you camouflage (for example, when meeting new people, in large groups, job interviews etc.)?

3) How frequently do you camouflage in social situations?

# Appendix vi: Interview questions

# **Interview Questions**

1. What do you understand by the term camouflaging?

Further prompts: What does the term mean to you? Do you ever use it / say it? Do you use other terms?

2. Can you tell me about your experience of camouflaging your Autism Spectrum Disorder?

Further prompts / questions: In what situations do or have you camouflaged? What do you consider to be camouflaging? What things do you do or stop yourself from doing?

3. What you do think / feel about the fact you camouflage?

Further prompts / questions: What's positive about it? / What's negative about it? / Has it changed how you think about yourself?

4. Can you tell me about when you first started to become aware you were camouflaging?

Further prompts / questions: Is it something you are always aware of? Did you specifically learn how to do it, if so can you tell me about this?

5. Has your camouflaging changed over time? If it can you describe how?

Further prompts / questions: Has the way you think about it changed? Has what you do to camouflage changed? Has when or how often you do it changed?

6. Are you able to tell me why you camouflage in social situations (it may be different reasons for different situations)?

Further prompts / questions: Do you feel a pressure to camouflage? Are there particular things you try to achieve by camouflaging?

7. How do you think camouflaging has impacted / affected you?

Further prompts / questions: Has it had a physical / emotional impact? Has it been stressful? How does it make you feel afterwards?

8. How do you feel about camouflaging in the future?

Further prompts / questions: Would you like to change the way you camouflage in the future? Would you like others to respond to your camouflaging differently?

9. Do you think camouflaging has affected your relationships?

Further prompts / questions: How have people reacted to your camouflaging?

10) Do you think "camouflaging is the right word to describe what you may do in social situations? If not, what do you think is a better term to call it? Why?"

# Appendix vii: Full transcript

Speaker	Transcript
Ruth 1	The first question was just what you understand by the term camouflaging?
Alex 1	Sorry can we just like move those cause I can see them out of the corner of my eye and they are like freaking me outoh perfect! Behind your legs, oh will you still be able to hear me [oh that will be absolutely fine] thank you! Sorry what was the question?
R2	So it was what you understand to by the term camouflaging?
A2	Just things I have to do to pass, so people don't think I am weird, yeah that's pretty basically it
R3	And when you say things that you want to do to pass?
A3	Not want!
R4	Or things that you have to do to pass?
A4	Yeah umm(sighs)pausethe things like I am staring at the bridge of your nose instead of your eyes, or errrr, shoving my hands in my pockets so that people can't see what I am (you can see it obviously) what I am doing with my hands [she is fiddling with a fidget toy] or sitting on my hands, errnot moving around so much, like one of the good things with my new job is, you know I have this stand/sit desk now so that I can move around [okay] where as before I was just sit still sit still sit still, all that sort of fidgety energy having to keep it inside, trying to remember social scripts for things, which is exhausting, erm, pretending to be interested in people (laughing) [yeah] I am interested in people (laughing) but sometimes there are questions that you have to ask people you have just met or don't really know and don't give a shit about and its its usually worth it in the end because I get to connect with that person more and then we can have more meaningful conversations, but its like if I don't know you and I don't care about you I don't really want to listen to that, as I have to focus energy on the auditory processing which is like, I am always doing this mental calculcus of is this per-
R5	The energy that it takes and the are you able to say any more about what the efforts like what the impact is on you when you are doing this?
A5	That's too broad, can you be, sorry
R6	Umm, absolutely, I am wondering how that exhaustion manifests in you, so what you experience as exhaustion you know?

A6	I think during I am so kinda in, I hate to call it crisis mode cause I have done it all my life and I hate to think of it as crisis mode but I am always doing what, my brain is doing triage, so I am not maybe immediately aware, until it has happened and then I am
	like exhausted, and you know before I was diagnosed I would come home from work and I would completely shutdown and I would not even be able to talk to A when we first got married, and it was so weird and we hadn't lived together so it was, he was like what's going on with her, she didn't used to be like this, I had lived alone before, or just with my grandmother so no-one really twigged that I wasn't interacting with anyone, and basically I would have to go home and wouldn't talk to anyone and take a steaming hot shower and you know until my skin was red to you know reset my system and (ha ha [panting]) hid in world of warcraft for the rest of the evening and I just couldn't, couldn't take anything. And you know I wasn't aware that that wasn't a way to live, and you know I didn't have another option (laughs), but it is definitely a physical thing. Just my auditory processing will just go to shit and I will hear things like "hallfbi babldkblb" you know, and if there was a drug for that I would absolutely take it, ha(she sighs). I am just jealous of A and his ADHD and that he gets medication to
R7	And that's something you will notice in the moment, that sense of loosing it, and not being able to understand?
A7	yeah, and A will sort of know now, because he is able to know my tells, and you know that I am having a bit of a hard time, (sighs) and I do want to see people I do want to have friends but it is still that constant, you know I am going to have to recuperate afterwards, you know the introvert thing is totally true, [umm] and most of the people I am close to understand that or will give me space, yeah,
R8	When it comes to [sorry I need to blow my nose, I sorry] no its fine, blow as much as is required, [I think I had some pressure (laughs) it's the worst I am so sorry, anyway (laughs)] I am fully happy with all sorts of snot, it's not a problem [its disgusting, you know when you pinch your nose and then it sticks, it's disgusting, yeah (laughs) this morning I was like] ahhh its grim isn't it [yeah it horrible] do you have a sense of like when you started to camouflage[sighs] is there an awareness of a start date or is

A8	I mean I probably would have been doing it before this, but the one thing that always sticks out in my head because I got bullied so much in school, was like, I was in american public state schools, until like high school, cause the public school in our area the state school was really rubbish and so my parents switched me over to a private school that was more academically focused, so it was a fresh start, and I can remember thinking to myself okay I am not going to be weird anymore, mentally telling myself that, cause there were sort of things that, I can give you a few examples, things that I did that I kinda of in retrospect as I was older realised that kinda turned people off to me, umm, and I do remember that freshman year of high school when I really really worked on being normal and I got invited to a couple of house parties and things and the popular crowd did talk to me, but I I couldn't keep it up to that extent, I did find friends in high school, but they were more sort of like the geeky crowd but I think we had sort of awe kept ourselves to ourselves and no one sort of bothered us, and we were a wonderful cohort of students and I am still friends with them now like 20 years later, but even then I didn't have to mask as much with them as they were either computer geeks or you know artsy and we all had you know weird interests and I had, we liked played video games, and I had things to talk about and were as when I first started at school, I kinda of got, I just I just, I don't want to do this, that's not me, I don't want to do it, but, I think yeah, early teenage years, my middle school years were really
A9	I think even childhood, this is so weird but this is such a, I remember talking to the lady who diagnosed me about this, I remember one of the things I used to do as a kid was smell my feet a lot just cause it had a very vinegary smell (laughs) I don't do it any more (laughs) but like I love the vinegary food so I am like thinking that that is like why [yeah yeah] but and I would have people over my house and I would do it and I would be like "oh my god M what the fuck is wrong with you, why would you do that?" Err or I definitely had the sort ofwhats the word, you know when you are using the archaic stilted language, I would use really specific words for things, and I read a lot too and I am like really smart [yeah] and I remember one of the ring leaders of the people who bullied me was ironically my cousin and I remember saying that I had to go to school for orientation and its like "orientation what is that" [put on voice] but that's just like one example and I did have a big vocabulary and I remember dialing back how I talked and even now I write emails to my dad (who we are all pretty sure is on the spectrum as well) and A will be like "you take a completely different tone with him" and it's like reading things from the victorian era when we are talking, not talking verbally but like writing, its like very formal [yes] but its not that I am distancing from him, its that I want to be that precise, and my dad gets that, we have a very complic-
R10	You say you want to be that precise, is that, does that, feel like something you prefer

A10	Yes because then I fill like there is less margin for error, "margin for error" who says that? You know like, we just watched star-trek last night, but we used to watch star-trek as a kid and of course Data was my favourite, [amazing!] and now I know why!, and the whole thing about not using contractions even now when I am stressed out, I will drop them, sometimes its not so conscious anymore but, its when my brain shifts gears and I like do know a couple of other autistic folks and its like, oh god, and actually the person who suggested that I start this whole process in the first place, its like her, them sorry, and another person and A says that when he is listen to us talk to gather he says "you two talk in paragraphs and I have no idea how either of you are able to follow this conversation but some how you do, but its completely different to how you talk to any
KII	So from what you are describing there is a, there is a variance on how you present and talk depending on who you are with?
A11	Yeah absolutely[what determines how you behaviour, do you have a sense of that metric?] well I just assume that they are neurotypical until I am proven otherwise really, [umm] I just don't even know it is is conscious, I mean that I read other people's tells and I just do it like that still, that underlying programming, I hate to talk about myself like a computer but was else can you do!
R12	When you say underlying programming, do you mean that that is something that you have programmed into kind of read tells?
A12	Ah well no, I always joke about how I am running the wrong operating system, like I am actually lynex running windows, [yeah], like I have the stimulator and its okay, but its still really shit running certain things, but the underlying thing is like you know, lynex or whatever (laughs) and I don't have to you know, eh, its so tired the computer metaphor but its all I got cause I don't see myself as that, but when I don't have to devote energy to running the other not optimised operating system then I can actually you know spend it on things I want to do, on what I actually want to talk about, and its getting easier to show that side of myself with A over the years, you know he has commented on that, and I don't feel, like I can definitely let my guard down with him more than I used to and that's why he started to look at the whole adhd thing, because he is realising that he doesn't have to mask with me, cause we have some similar challenges like you now [yeah] ummyeah, err its probably, I think I have lost sight of the ques-
R13	Yeah that's fine, well I'll go back to the question before and then I will pick up on what you said its really interesting. So in terms of you said "I assume that everybody is neurotypical unless I have been proven otherwise, and you have mentioned that there're with you dad and with certain people that you are less erm likely to mask with.
A13	Well my dad is a complicated example because my dad wouldn't you know know or accept, and I think he has a lot of internalised self hatred about that and one of the things that will set him off and set off his anger is when he sees himself in me, particularly an autistic thing, so sometimes I have to be quite guarded with him, but in terms of like how we speak to one another, like as I said in writing or there are just something I know that he will understand like about shared interests, like I don't need to elaborate on it, like he will just get it, like I don't need to elaborate on it, like why certain things would make me anxious like, it is it is so hot and cold, but like why my mum was pushing me to do something he would understand why I wasn't able to do it, and my mum might have something herself (laughs) but that's another story

R14	I was wondering about how it was with other family members?					
A14	I think my mum might be a little bit adhd herself, she is a bit of a hoarder, very personable, very extraverted but struggles to finish things, does like to flick from task to task					
R15	Do you feel like you have to mask with her?					
A15	Yeah and its funny because we are very very close but she would get very frustrated as to why I couldn't understand certain things and she would always turn it back on me, when really if I was asked her questions it was more cause I was trying to understand and my dad, he didn't see us fight very often, as it would stress him out, but you now he, like autistic people, couldn't cope with the tension "it's too many feelings in the room!" And erm(pause) yeah I would be asking these questions and she would be like, "let it go, let it go let it go", and even now you will see it happen and now she understand why I am asking that and if he needs a break he will like go and cool off and its not that I am trying to be irritating its that I do not literally understand what I have done wrong here, and I probably will fuck up again but I want to try and understand, I want to try and eliminate that possibility, I care about not hurting you, I want to understand how to not hurt you again and it seems like neurotypical people, or people who are not autistic just don't get that [um um um], or that if they, I have heard other autistic people say this, that if they are, no if I am upset I don't want people to be like I am listening, I want you to tell me about something when you found something similar I want you to draw on your own experience I want to you talk about yourself and that is not I think what neurotypical people want and so I have to sit on my hands about sharing these, look I understand and they are like, "no you don't stop talking about your-					
R16	That transparency and that connection and that shared experience[yeah yes] so with your mum there is a sense of sometimes having to mask because there is a sense that she can't cope with					
A16	Er, like we have a lot of shared interests, like we were quite close, she's ill now so like, rubbish, but, erm, like yeah I don't think that she would be just frustrated by some of the more aspie aspects of me					
R17	Does your, how much or how you mask change over time do you think?					

A17 I definitely don't do, I don't think I do it as much as I used to (laughs) which is nice, I don't feel I have to do, it when, we were talking about clothes earlier on and I feel like I can wear clothes that I like, rather than clothes that present a certain image like professional clothing or good I remember thinking that everybody went into the bathroom to cry and everybody's clothes hurt that much and I was just shit at dealing with it. erm, its so like something as literal as what I wear and so just like whether I care about certain fashion trends or not, like I have always been hyper aware of that, whether I can follow that is another matter, people say that autistic people aren't fashionable, some of them are, some of them are very aware but just can't deal with it, I hated, urgh, I felt like I had no agency, to do what I wanted to do, its was just like very performative [and performative that was was included your image, what you wore] my gender [yup yup] I joked before but its like, that's why I decided like non-binary thing cause I feel like both of them are something I can play with, what people wear how people present to me are just like, its its not something I understand, its something quant to play with, I feel like I am wearing a costume, I want to dress fem today or I want to dress butch today its its something like I feel like is for other people, so yeah even gender is masking, for me, either one, people are like what pronouns are you and I am what you meant?  A18  So you mentioned that you felt like you had no agency, can you say a bit more about what you meant?  In terms of like clothes that is what I was referring to, its funny cause we were talking about starting up my own business, and (this is going somewhere) and thinking about my vision and values and things like that, and I wanna be able to give clothes or designs to other people that are a bit not typical or give them the freedom to be who they are cause that's like not something until relatively recently and I have disco		
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R20 And that was the process of diagnosis, was that mask, that outer skin layer coming off?	A19	for who I was and why I was the way I was and I am trying to, I always struggle for the words for it, but it was like having a literal mask, I can literally visualise it, having this literal flesh mask ripped off and having these horrible stitches in my skin and this really raw glistening skins underneath, but lest it was real (sorry I will probably get emotional talking about this but) ha, I had to harden that, but at least it will turn into something that was true and I just remember being so angry, that this thing had been put on me and I had no say in it (becoming emotional, tremor in her voice) because I was too little and then just like feeling really lost and adrift and who was I but at least it was true, [umm] and you know its been seven years now and I have been building that back up,
	R20	And that was the process of diagnosis, was that mask, that outer skin layer coming off?

A20	Yeah just sort of that process of letting myself be like that, that yes that is you, I remember before I got diagnosed and I was seeing lisa, and I was researching, seeing films and reading books, and I could not tolerate watching autistic people on TV because it was like seeing myself in the mirror but I hadn't consented to it, and there was this deep sense of shame and I felt really vulnerable and I had to leave the room, like you are not allowed to have, that how is another person allowed to have that thing that is really really me, [mmm] it made me feel really violated and that made me feel really awful, cause this was another person who was dealing with the same things I am but it did it made me feel really violated, watching other autistic people.						
R21	Because there was a sense of that's me and seeing?? [interupts]						
A21	and you're not allowed to have that, I think I still struggle with it a little bit, but not to sort of to the deep visceral sense						
R22	That, you described that kind of glistening, that skin, your skin and I wonder where you are with that now, what that skin looks like feels like at the moment?						
A22	You know I think it is going to be a life long process, you know and that's one of the things that I still feel angry about, you know that's what grief is you know you sometimes it hits you when you least expect, you know it doesn't knock you over like it used to, but I don't know if I am ever going to really get over it, that's its like my life has been wasted and I wondered how it would have been different [voice breaking, tearful] [if] if I'd known, you this didn't exist when I was you know, and even if it had I lived in the States so god knows what would have happened, here you still have naturalisation						
R23	Do you have a sense of						
A23	oh that's something I put on the form that I definitely have to mask more in the states [okayhow come?] I think Britain's more tolerant of introverted people and people who are a little bit weird, whereas even A will say, as soon as you arrive it is very full on and you have you have this whole sort of "hey"I am making an expression and pointing to my face in a smile [forced smile]this relentless optimism and this relentless can do, I mean there are good things about being, the American culture I don't want to say [um] we are deeply flawed but we have our good aspects but it's just I, I I tell L about this all the time but I have developed this sort of fantasy when I was 9 10 11 years old where I kinda got obsessed with Britain and being an anglophile and "i am going to move there" and you know I I actually did come here it is different from what you expect it is not as magical fantasy place but still felt like a better fit even after I was a student here for a year and got over the initial you know kinda honeymoon						
R24	What does it allow you to do here or what are you more comfortable to do here than in the states?						
A24	Its just feels like the more, well I grew up somewhere that was really conservative, maybe I would feel different if I grew up with my friends somewhere in Seattle you know its a big country, ummm, "god Trump!" (laughs) that's another conversation! (laughs) um yeahI don't know, just like the dark humour that you guys have and the ummmmm its weird people say autistic people can't be sarcastic and I am likehave you met me? (both laughs) and most people I know think that I am hilarious, when I left my most recent job and I had 4 or 5 people say that they were really going to miss my sense of humour, [aww, that's very cool]						

R25	What's you, cause that kinda feels like another component of this in a way, eh, people's assumptions around autism and then how you present yourself, you know, whether youI suppose how you respond to the assumptions people have, if you do			
A25	Okay, eh (blows nose) oh god the pressure difference (aww] for me apparently! I have the oh "you must be very high functioning!" Ummand I usually I have got more aggressive about it and I sort of stand back and I am like, well I will just wait until a fire alarm goes off, but it is still the stereotype of five year old boy banging his head against the wall and its like when I look like that I am in a horrible place and you are never going to see it, you know I know to hide that, thankfully I haven't had a proper meltdowni have had maybe one, no not even any since my son was born I don't think, probably cause I quit working full time, you know it it true you know only people that I deeply trust, so probably just my husband is ever going to see me like that, you know if someone is like that they are under a massive amount of stress they are not			
R26	What does that mean for you though, because if I am understanding you right that means that, that this is something that you are aware of cognisant of and you are cognisant of not showing			
A26	Actually as you just said that (let me just take a sip of tea) I remember like whenever my mum and I would get into an argument, and we would be in the car I would start punching the chair (she bangs the table) and I remember just wiggling and writhing around in the chair cause I was getting so frustrated and I remember talking to my therapist about it cause I started to go to therapy as a teenager and one thing my mum for her own reasons didn't deal well with was sort of physical expressions of anger or violence and I remember having this incredible desire to go and smash a glass or something in the back yard, and even when the therapist said like, give her the consequences of cleaning it up, but let her do that, but my mum wouldn't, but this like really, thank god I haven't felt this way in ages either, but this really physical anger, because and it its one of my trigger things now if I feel like I am being misunderstood or if I say something and its got twirled around the wrong way and not getting my intent and someone is not giving me a chance to make it right to say like what I actually mean, like I just get so frustrated if I am saying something and someone gets the opposite of what I am saying and I am like "what the fuck am I doing wrong?" You know I don't know if this is related to it or not but one thing with my World or Warcraft (funny voice) fanfiction, people who have read it people are like, this is really good dialogue I wish I could write these stretches of dialogue how do you do it, cause I am constantly writing these scripts in my head, [yeah] even now I was reading a Mr Men story to my son in bed and I don't know which one it was, but he was like, "you are really good at the voices" and I was like "becuase I can hear people doing this!" (voice louder, animated) because I am constantly having to do this all the time, and I don't know if I am			
R27	So that is doing scripts before			
A27	On the fly (R makes noise symbolising constant movement) yeah its sort ofalmost like drop downs, I think I talked about this when I got diagnosed its like this really really quick mental drop down, if this then that, you know and it can't be something that is prepared before, you know I will sometimes have situations when it is prepared before			
R28	Its this continual process of someone says something and then its "digger digger dig-			
	ļ II			

# Yeah its like a flow chart with the diamonds and stuff [yeah "and then this"] yeah like there are so many problem with Sheldon as an autistic person but I remember him getting caught in the infinite loop and I was like "Yes!" That is very relateable. [yeah] and usually people who know I am autistic are like, I am sorry this is where we need to step back and this is where Ive lost the plot and they understand why and they don't get insulted you know and I think I am much better at being straight up with people I get close to, I will be like these are the issues I have and if you don't think you can handle that that fine and I won't be offended but that's like where I am at and I need you to meet me with this and if I get the sense that that is not something they are willing to

do then I will just ease back or ghost them or whatever, (laughs) you know I am getting

#### R29 As opposed to whereas previously you would have maybe pretended?

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**R30** 

#### A29 Oh yeah!! (sorry more tea) god I have so many stories! One of the things that happened after I got diagnosed was that I did lose some friendships because I feel like I realised what real friendship was as opposed to toxic relationships and one of the things people can't believe to this day is that I cut lose of someone I had know since I was 14 and I diagnosed when I was like 31 and we had always kinda run a bit hot and cold and I remember always having an underlying fear that I would say something that would offend her and er set her off cause she would come back with like you know you have done "blah blah" and I would always feel like at a loss to what I had done and that happened probably half a dozen times and then it started happening when I was diagnosed and I wanted to process it with her and I wanted to talk about it and then she came back saying all my emails were too heavy and can't you talk about something else and I was like okay well what do you want to talk about and it was like I should know what she wants to talk about and I was like I need to take a step back and I need some space, I actually said that and she flipped her shit and she was like tweeting about me and she didn't refer to me personally but she was like she was talking about how she was so mad and "why am I worried about this so much, I have been wanting to cut loose this friendship for so many years" (high pitched voice mimicking ex-friend) and I am thinking "because I am the one who did it you bitch!" (laughs) er yeah there were a couple of other friends, but nothing as long lasting as her, I do occasionally wonder how she was doing cause she has some depression, anxiety, her dad was bi-polar (so none of this should probably me written down cause she hasn't disclosed to that, [its all totally confidential] I know, this sense of and kind of around the same time I had met someone, my friend S, she one of my best friends, she is like a sister to me and I feel like her and A are like templates of what healthy relationships should look like, in romantic and platonic, and I have just sort of framed everything on that and like well, you know if you don't treat me like those people treat me then you are not really worth it, maybe not to the intensity but in terms of respect and erm

## So it feels to me as we are talking now that erm, you know there is a connection between the relationships you have had and the masking, because where previously you may have been masking, but that meant putting a lot of effort in to meeting them, you know that meant that you were only getting err, type of relationship, do you see what I mean, [yeah yeah] I am trying to put it into words, but I am trying to get a sense

why I am you know isolated from the "Capital A" autistic community because you know we are black and white thinkers, sometimes, and sometimes people say things that I don't really agree with, and I am like "unpopular opinion here"  So there is this new awareness of the percentage, the ratio of how much am I masking / accommodating and how much are they masking / accommodating, and I am wondering errm, where you will now choose to mask and what, err, lets just start with the, the scenarios where you currently do mask?
masking / accommodating and how much are they masking / accommodating, and I am wondering errm, where you will now choose to mask and what, err, lets just start
with the, the scenarios where you currently do mask:
errm, I mean like a job interview, err, A says you know you never see anyone sort of put into a job interview as I do, and I am like well you don't understand because I have to rehearse everything in my head I have to write stuff down so I don't forget, and I have to put on this, (sighs) cause we don't live in a place where people don't care yet, you know once I am there and I have the job, especially where I am now they are fine with the things I need, even to the extent, so something like that, or even just random interactions with people, poor social situations, I was just at a conference yesterday and it was on decolonisation, so very inclusive and they actually apologised to me because it was a really enclosed space and lunch was really love and I was like, is there anywhere I can go to like decompress and I mentioned that I was like autistic, and they tried to fine somewhere and eventually I had to go to a stairwell and they were like really apologetic and were like it is the first time we have run this, and we should have done better by you, I am like not upset or anything but like you know maybe being somewhere where I don't feel like I can even ask for that, you know just err, yeah,
Do you think thathow do I phrase thisyou talked about the energy that it takes the exhaustion, do you think that masking has had any other effects on you? I know that is a broad questions [yes that is a broad question, can I also use the toilet while I have think (laughs)] absolutely! [thank you!] (laughs) take you time it is absolutely fine [no
(participant comes back into the room) I think I have answers but can you just remind me of the question?
Absolutely, so it is an open question so it maybe that it is just like no and that's fine, it is whether you see camouflage as effecting you in any other way you see that there has been an impact other than the physical exhaustion
A33 Are you autistic? (curious light tone)
R34 I am err neurodiverse, I am not autistic, I am dyslexic and I am hypermobile.

A34

Me too! Yay!!! I was going to say you were doing some weird stretches and I was like... yeah (laughs loudly) [yeah that's one of my fav ones that you were doing] I was thinking how do I break this into the conversation, and I was like, I wasn't sure but I was think "she's she's something, she's not one of...(laughs) anyway! So I think there are two strands to this and I am going to say them now because I want to talk about both of them, don't let me forget, one of them is the more general liking things and the other one is sort of my identity as a queer person, so we will talk about both of those. So I remember one of the things I first struggled with when I first was diagnosed which was am I allowed to like things, and what do I like, and you know that could be, god its such a ridiculous movie but have you seen Runaway Bride [yeah] do you remember the seen when she doesn't know what kind of eggs she likes [yep] like that's it, like I think I have been so, like everything is performative, unless I am doing one of my special interests, everything is performative and every decision from what you wear, to what you are eating, to what you are reading what like what you don't like, what music you are listening to, its all this construct, of how people see you and I felt like before if I liked x and y I had to like z, abc and if I wasn't getting it right and I think that it what it is like with "real fans/fandoms" cause there are a lot of autistic people in them, you know if there was something that seemed kinda unrelated to my interest and then I didn't feel like I was allowed to have that, err I don't think that comes up so much know but that is something I would talk through with A or L, you know or something be like, I have to kinda process my interest in something and kinds of justify it to myself that it is okay [yeah] and I sometime think if I had known I was autistic earlier I would have had this "oh fuck it this is who I am I don't need to do this justification, I wouldn't have wrestled with that so much, [eh eh] and I think this goes as profoundly as I have my art business going and I went to university to do design and illustration and quit and I think it is because I was so busy trying to be this constructed person I couldn't tap into sort of my true creative voice, whereas now I am absolutely able to do that, you know and its because I have got this, skin is the real skin, and its not guite so sensitive anymore, as it was before, you know if someone doesn't like who I am I can kinda take that, you know, not everybody likes everybody and that okay you know I don't have this expectation to defer and please everybody which I think is also a specifically women thing, but you know just to go back to the queer strand of things, two forks of that, one is god like, I grew up in a very catholic area, and the other is a married a man so I couldn't possibly, you know (laughs), but after I got diagnosed with autism, I was like actually yes I am bi-sexual and if you kiss a girl and if you sleep next to her for an entire night in college when you are both very drunk, and you enjoyed it that is kind of telling, if you remember the other girl you used to walk around with when you were like 16 years old and you were like "god she's smelt really good and you still think about her sometimes and who incredible her eyes were, your bisexual and its fine, you know and I don't regret marrying my husband and I don't regret not being with a woman, but even being able to say that to myself you know its just like this massive load of, I think I struggled with like feeling like I am not gay enough, you know feeling like I can't be part of the group that I would really like to be, erm and the gender thing, I remember pulling my hair back into how it is now and wanting to see what I was like with short hair and I did go through a little stage as a teenager, cause I was quite tall, and I was like 14, I grew tall before I had hips so for a while I had to buy my jeans from the boys side and I found that fantastic, I love that, erm sometimes I do dress quite fem and but it like when I have the mood, because I feel like it takes more effort and energy, and when I have had more of a butch day, I mean I have definitely passed as a guy, I mean I have, but its not cause, oohhh I am a man, its more cause I have pulled

R35	So has there been a gendered element to your masking then?			
yeah[having to do a performance] yeah Igoing back to friends, most of were guys, until kinda of I was an adult and until really recently I have met so unquote mum friends, but they are like geeky mum friends, until I started we craft I didn't have any close female friends you know, other than that one per cut loose, most of my friends were guys, cause it is just like, this is bullshit, a like it is really sexist to say and makes me a bad feminist and I don't think its fault that we are that way but neurotypical women are probably better at met those expectations, but because I have this extra vector of having to like I few whole male and female brain is like really bad terminology, because I don't a male brain, but it is different. They need to have other words for it.				
R36	Yeah yeah, you say that other neurotypical women erm kind of what they they are better at that stuff are you able to define, what that stuff is that neurotypical women have			
A36	Err I do not know, just like in mum groups I can tell immediately if I am not in, its just this whole talking about pointless shit or having a bit of a rant about your husband, which does not reflect my relationship with my husband at all my husband, I think, you need to dump your men to be honest they should like dreadful, I don't know its something like very difficult for me to talk about because I think all women have very legitimate gripes but I think in some ways it is just sort of patriarchy isn't it, it is like self imposed like we have been trained to continue it and its making me sound like an asshole, and I think that maybe because I am autistic maybe I can see through it, and I don't have time for it and I feel like in order to be included, in that space I need to agree with the bullshit and I don't have that and I don't want to minimise their struggles because they are real but it is just like being able to see something for what it is and I really have less and less tolerance for you know that nonsense the long it is since my diagnosis and the older I get, I am looking forward to being forty, I am like bring on crone years its going to be like great, it is going to be great, I am going to			
R37	Yeah and that's a process that the diagnosis has been part of [yeah yeah absolutely] and the the getting older, but also the diagnosis and not have to behave in the same way [yeah yeah] you mentioned about passing, at the beginning about masking to pass and I just wondered what it meant to you to say that in the context			

A37	It just means so that people don't think I am a bit weird, I mean likesigherri don't know it is kind of a safety thing and maybe cause I was bulled so much as a kid to my default response is still to behaviour neurotypical when I am out and about. Because you know I don't want to get shoved into my locker or beaten up in the school yard, or cornered in the bathroom or forced to, one of my favourite traumas to talk about that happen when I was an early teen was being forced to sit down and watch a scary movie that I didn't want to watch, like literally people holding me down to watch, so I don't, in addition to being scared because I present as a woman, I have that. And I don't think that is something I am ever going to fulling unlearn and or even if I should its not a safe place for autistic people, I can, this sis a safe space for me, (indicating the service), I remember when L did the assessment of me and she pointed out that I was biting my hand and knew what to get so me and that I was doing little doodles and the fact that it was so effortless, that she could see things for what they were, and I am going to get emotional now (starts getting tearing) that this is okay and it doesn't have to be like this anymore(pause) [it was a safe space for you to be and you didn't have to protect] yeah (less tearful) I feel like I went through a phrase and I thin it is probably normal for anyone who gets diagnosed later in life, that that was all I could think about and all I could rant about and it probably was annoying for a lot of my friends, but that's just the process, and I am still pretty involved in like advocacy stuff at work, but it not all that I am putting out on social media and whatever, but it is not something I am going to stop talking about because it is who I am, and I am in an oppressed group and if you want me to shut up so you don't have to deal with me fuck off (laughs) [yeah yeah] and I think that actually that been kind of, going back to my parents, and especially int he last year or s
R38 What impact does that have when they say that?	
Its hard, its always going to be hard, you know because I still feel like with to be this expectation of what they need me to be almost, and if my mum I don't know if I would be willing to keep that up to the extent that I am rig cause you know cause you know it is likely that my mum is going to go first its just me and my dad cause he'syou knowautistic, it will be a little east on one, because we don't have that third angle of my mum trying to preter are not as weird as we are, (laughs), yeah its hard and I still get sad about it itsbecause I feel you know, she loves this idea of a person that isn't real not the kind of parent I want to be to my son, we love them but it is really know.	
R39	Its such a difficult experience when you are aware of what they are wanting and it not actually who you are?
A39	yeah, it doesn't help that one of my dad's special interests is basically politics and he is basically very conservative, you know they don't know any of the gay stuff. They never will (blow nose), I joke that when they are dead I will go to pride

R40	So i am wondering when you look at the future how you are, whether you, your relationship with whether you mask or not, would you say yeah I will continue to do it, as it masking or do you have a sense of,				
I think like I have said before it is situational, I mean I think I have to when when I am out as a safety precaution and I think most women you know re whether they are neurotypical or autistic or what can understand that, I do world is an understanding enough place as yet, but I can let it down until I to know a person, like I said I think I am better at sensing if a person is for ter at knowing what my boundaries are, but I don't think I could let them of pletely unless I, this is where I get so lonely sometimes, my two other autis who I don't get to see very often, cause ones up in Leeds and the other or America and has two kids, ah god, me and the American friend, we have a American friend who lives up in Manchester, up there somewhere and she about 6 years ago and the two of them have been best friends since she wold and so she was staying with me and then we went up for the wedding, member that while the bride was doing her thing me and T we went to, the museum and we started texting photographs of stuff we saw and it was creating way, and it became this really incredibly intense experience for the hours, and we didn't say anything to each other and went off on our own sways and just texting each other these photographs, and god it was like b [wow!!] and there is one other person I know we don't talk so much anymon no no she, she has transitioned, there are some other things going on in he the reason I met her, I am going to have to say him cause I don't have the the moment, he used to post these photographs you know you joke about but I remember before I knew anything about them they were just an account my heart would start racing because I felt so vulnerable, you see it, you stand, you see this, there are other people, I am not alone, after I got diag like oh my god, but I don't know how to make that connection with people perately just want people who see that, and I post pictures on my instagra					
R41	That must be so powerful when you get that connection				
A41	Pause(tearful, crying) I get so lonely sometimes (crying) [that must be really tough] but at least I have started to put that stuff out there now, I wasn't even able to do that				
R42	So you are putting out there your images, what is it like to start to do that and start to put that stuff out?				
A42	Liberating, you know I am living the life I was supposed to live.				
R43	That sounds really important, that you were able to feel liberated				
A43	Pause				
R44	Shall we stop?				
A44	No no I am okay				
R45	You sure? You have shared so much it is amazing				
A45	(jokes) I am nothing if not articulate! (laughter between both)				

R46	I was wondering the term camouflaging is what is used in scientific research and I was wondering what you thought of that terms, whether it feels like it fits whether it				
	doesn't, cause masking is kinda of used, but camouflaging is particularly used, and I am like, is that even the right word even?				
A46	You know i have never really thought about it, they are fairly interchangeable, to me masking is like you are putting this physical thing up, whereas camouflaging is blending in, so like either really [okay okay]				
R47	So there is a sense of hide, and blend in and putting on,				
A47	Yeah i feel like both I feel like there are fairly interchangeable to be honest at least in this context				
R48	Yeah yeah, is erm, you mentioned and I am just touching in cause it is kinda of a side bar, but you spoke about the autistic community and I just wondered about your experience with				
A48	Well you know it is kinda like with any social media, and I have talked about this with Lisa actually, at little bit because the loudest voices you hear the most, and so well I follow some people on twitter, but err I feel like a lot of times we feel like, we do want to go on our crusades and we do tend to go on because we have that mindset, because we can't shift to anything else and sometimes I feel like there needs to be more nuanced conversations that don't seem to be happening, like err okay I really like "autistic" Craig, and like Craig he is autistic and you know, no it is not super flattering, but that's not inaccurate, you now half the reason I don't hang out on wrong planet is cause I do here conversations like that and you know if you are not willing to admit that ugliness in yourself I don't really want that much to do with you, and you know the reason I have those two autistic friends is because we knew each other before we knew we were autistic and we justsigh I don't know I just want an autistic friend, errryes that is part of who we are but that is not all of who we are, and I don't know how to go				
R49	Do you have a sense of why that happens, that autistic identity envelopes some people, if you like?				
A49	Because I think it is a special interest and so I think it stuck with them longer than it did with me, and I think that is fair, you know I am not going to judge people for that,				
R50	But it is not the totality				

A50 No and you know sometimes I will get an exchange on twitter with a couple of people and that's nice, and they got it, that one particular thing, but it is not necessarily a meaningful relationship, and so I still feel like I am going it alone a lot of the time, you know it almost a relief with my husband being ADHD cause he can let go and we are more understanding of each other, but like I say that's like cousins, that's not the same and I don't know how to like...i don't know how to find my people within my people, but I have though of going to some of those Aut Coms (for want of a better word) but I feel like even now they can feel performative. [because it is a specific thing?] Yeah and I know that it is like a political identity, it has to be, but then there is just this weird interchange between performing your political identity and not, like one of the things I think about is, you know Roxanne Gay, when she had her surgery, [yes] and like this sort of difficult issue she went through with that and then people getting I can't articulate it, I am deeply uncomfortable with how people are adopting Greta Thumberg, like I respect what she is doing I think it is great, I think she is increasing visibility of autistic girls I feel like they are almost kind of using her as a Joan of Arc figure, cause she hasn't consented to that she is a kid, [ummm how people are using her and the identity and how people are using someones autism and identity] yes I deeply understand the need to reverse diagnose historical figures or characters because you are looking for yourself in other things, I have done that, when I probably shouldn't have done that, but like we have had these lives where we've had so much against our consent, we should know better and I don't think I have meet a lot of people who have under-**R51** There is a real nauce to what you are saying as I am hearing it with the complexitys of both being able to affirm the experience of being a minority, being able to affirm the experience of being discriminated but also being able to see that as one part of a person, and that that doesn't diminish the importance of those other things and how to have that balance, makes a lot of sense to me. Is there anything else you want to say A51 I don't know, as emotional as it has been it has been good to kind of, feel like this has been heard, in a way that is being recorded, being that is what is infuriating about autistic research, it is like fucking listen to us, you know I am sure there will be people who you are interviewing who don't agree with me and that's fine at least you are listening [and that the point that this gets written up and hopefully that this gets spread around as much as possible, to say you know this is what we need to keep touching base with] yes yes [thank you so much]

Appendix viii: Post-interview information sheet

**Post-Interview Information Sheet** 

Study Title: How do autistic women experience and conceptualise camouflaging.

Researcher: Ruth Millman

Supervisor: Prof Digby Tantam

Thank you for giving your time to this research.

The information you have given will be going towards research into further exploring what autistic women experience when they camouflage. This study aims to develop the knowledge around what it means for autistic women to camouflage and what the impact is.

Your interview will be anonymised and written up, and then analysed along with other interviews. This study is part of the researcher's doctorate course in Counselling Psychology and will be written up as a doctoral thesis, and may be published in relevant journals or conferences. The aim is that discussing this research will help clinicians understand and support people better.

If you would like to read the findings of the study when it has been written you will be able to access it through the Middlesex University Repository (<a href="https://eprints.mdx.ac.uk">https://eprints.mdx.ac.uk</a>). If you would like further information on accessing research findings please contact the researcher on the details below.

Thank you again and if you have further questions about the research please contact:

Ruth Millman

Email contact: r.millman@alongsideautism.co.uk

Address: NSPC, 61-63 Fortune Green Road, London NW6 1DR

Supervisor details: Digby Tantam Email contact: digby@nspc.com

Tel: 0207 435 8067 or 0203 515 0223

Address: NSPC, 61-63 Fortune Green Road, London NW6 1DR

#### Appendix viiii: Debrief information

#### <u>Information on Autism and Mental Health Services</u>

If you would like more information about autism or how to find support you can contact the following organisations:

- National Autistic Society (NAS)
  - https://www.autism.org.uk
  - NAS Autism Helpline 0808 800 4104
- Information from the NHS:
  - https://www.nhs.uk/conditions/autism/
  - Or you can speak with your GP
- Autism Alliance (A network of 16 autism charities)
  - https://www.autism-alliance.org.uk

#### If you would like more information or support around mental health issues you can:

- Speak to your GP
- Go online find out NHS guidance and information on services:
  - <a href="https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/how-to-access-mental-health-services/">https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/how-to-access-mental-health-services/</a>
- MIND Mental Health Charity
  - https://www.mind.org.uk
  - Helpline 0300 123 3393 (open 9am to 6pm, Monday to Friday; except for bank holidays)
  - info@mind.org.uk
  - Text: 86463
  - Unit 9, Cefn Coed Parc, Nantgarw, Cardiff, CF15 7QQ.
- Rethink Mental Health Charity
  - https://www.rethink.org
  - Phone line 0121 522 7007

### Appendix x: Studies identified in the literature review

	Authors	Methodology	Main findings
	Qualitative		
1	Cook, A., Ogden, J., & Winstone, N. (2018)	Semi-structured interviews (thematic analysis)	Motivation for camouflaging was to have friends, the challenges girls faced (e.g. stress and anxiety), and masking as both a solution and problem.
2	Cook, J., Crane, L., Hull, L., Bourne, L., & Mandy, W. (2021).	Interpersonal Process Recall and thematic analysis	Findings revealed four themes, camouflaging developing over time, intra and interpersonal consequences, the desire for acceptance and connection, and authentic socialising.
3	Halsall, J., Clarke, C., & Crane, L. (2021)	Semi-structured interviews (thematic analysis)	Findings revealed experience of girls in mainstream and specialist classes. Four themes emerged; inconsistencies and conditions in camouflaging, challenges of relationships, consequences of camouflaging and about learning
4	Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017)	Semi-structured interviews (thematic analysis)	Findings identified motivations for camouflaging (fitting in and increasing connections), camouflaging as masking and compensation, consequences (exhaustion, challenging stereotypes, threats to self-perception)
5	Livingston, L. A., Shah, P., & Happe, F. (2019)	Online survey of open-ended questions	Findings revealed multiple compensatory strategies, and individual and environmental factors that modulate use and success, also various positive and negative outcomes.
6	Muggleton, J. T. B., MacMahon, K., & Johnston, K. (2019).	Semi-structured interviews (thematic analysis)	Clinicians conceptualised autism as gender-neutral, but thought girls were viewed to be more socially aware, internalise emotions and alter their presentation, and that culture affect how a person with autism acts.
7	Tierney, S., Burns, J., & Kilbey, E. (2016).	Semi-structured interviews (Interpretative Phenomenological Analysis)	Findings revealed that masking strategies were used to develop and maintain friendships in the increasingly difficult teenage years, leading to positive and negative consequences
8	Schneid, I., & Raz, A. E. (2020)	Semi-structured interviews	Findings discuss the difference between camouflaging and impression management, impression management as a social asset and its limits, and participants ambivalent experience of camouflaging and alternative ways of interacting
	Quantitative		
1	Beck, J. S., Lundwall, R. A., Gabrielsen, T., Cox, J. C., & South, M. (2020)	Quant (self-report) BAPQ / CAT-Q / DASS-21 / SBQ-R / WHODAS 2.0 / ADOS-2 (mod 4)/ SRS-2 / AQ	Camouflaging and autistic traits were predicted psychological distress and functional challenges.
2	Bernardin, C. J., Lewis, T., Bell, D., & Kanne, S. (2021a)	SAT-Q / CAT-Q / DASS-21	Camouflaging was a predictor of depression, anxiety and stress in autistic and non-autistic adolescents, camouflaging more distressing for females.
3	Cage, E., & Troxell-Whitman, Z. (2020).	CAT-Q / RAADS-14 / DIS	Exploring the link between autistic identity and camouflaging Result showed higher autistic identity was linked to less camouflaging via disclosure, although there was also evidence that high autistic identity links to more camouflaging.

4	Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020).	AQ-S / CAT-Q / INQ-15 / PHQ-9 / GAD-7 / SBQ-R	Camouflaging autistic traits is linked to risk of thwarted belongingness and lifetime suicidality.
5	Corbett, B. A., Schwartzman, J. M., Libsack, E. J., Mus- catello, R. A., Lerner, M. D., Simmons, G. L., & White, S. W. (2021).	ADOS-2 / SCQ / WASI-II / NEPSY-II / CASS	Females showing less RRB and more vocal expression. High compensators with higher social communication and rapport. Suggest differences in compensation models linked to individual ability profiles
6	Dean, M., Harwood, R., & Kasari, C. (2017).	ADOS / Stanford- Binet Intelligence scale / playground observation of peer engagement	Girls used more compensatory social behaviours when playing more than boys.
7	Hull, L., Mandy, W., Lai, M. C., Baron- Cohen, S., Allison, C., Smith, P., & Pet- rides, K. V. (2019)	CAT-Q / BAPQ / LSAS / WEMWBS / PHQ- 9 / GAD-7	Validation of novel assessment for camouflaging CAT-Q. 3 factors emerged; assimilation, compensation, masking
8	Hull, L., Lai, M. C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K. V., & Mandy, W. (2020).	CAT-Q / BAPQ	Autistic males scored higher than autistic females, no gender difference in non-autistic participants, no difference in non-binary participants
9	Hull, L., Levy, L., Lai, M. C., Petrides, K. V., Baron-Cohen, S., Allison, C., Allison, C., Smith, P. & Mandy, W. (2021)	CAT-Q / BAPQ / LSAS / GAD-7 / PHQ-9	Camouflaging was associated with greater anxiety, depression, social anxiety, no interaction between camouflaging and gender/
1 0	Hull, L., Petrides, K. V., & Mandy, W. (2021)	CAT-Q / BRIEF-2 / Strange stories (Theory of Mind task) /WASI-II /	Fewer executive functioning difficulties predicted greater camouflaging (but not on masking or assimilation), although variance was small.
1 1	Jorgenson, C., Lewis, T., Rose, C., & Kanne, S. (2020)	SAT-Q / CAT-Q	Females reported higher overall camouflaging, NT participants reported higher levels of masking, autistic females, no difference between autistic and non-autistic on compensation, and effects emerged between age and diagnosis
1 2	Lai, Meng-Chuan; Lombardo, Michael V.; Ruigrok, Amber N. V.; Chakrabarti, Bhismadev; Auyeung, Bonnie; Szatmari, Peter; Happé, Francesca; Baron-Cohen, Simon	ADI-R / FIQ / ADOS / AQ / RMET / BAI / BDI / Go/No go task	Operationalised camouflaging by comparing ADOS and AQ and RMET. Findings revealed females camouflaging more than men, men associated with depression and signal-detection was greater in women.
1 3	Lai, M. C., Lombardo, M. V., Chakrabarti, B., Ruigrok, A. N., Bullmore, E. T., Suckling, J., & Baron-Cohen,	FIQ / ADI-R / ADOS / AQ / RMET / FMRI tasks	Autistic men showed hypoactivity in certain brain regions in comparison to non-autistic men, whilst these differences were not noted between female autistic and non-autistic participants. A lack of impaired neural self-representation and mentalising was noted in autistic women

1	Lehnhardt, FG.,	AQ/SQ/EQ/	Sex-related differences in cognitive profile, males had
4	Falter, C. M., Gawronski, A., Pfeif- fer, K., Tepest, R., Franklin, J., & Voge-	Eyes-ToM / WAIS- II / TMT / WCST / COWAT	higher verbal abilities, and females had higher processing speed and executive functions, suggest ed that these result were linked to sex-related differences in camouflaging.
1 5	Livingston, L. A., Colvert, E., Bolton, P., & Happé, F. (2019).	ADOS / WASI / self report anxiety scale / series of cognitive tasks (measuring ToM and EF)	Findings revealed that high compensators demonstrated better IQ and EF, but also higher anxiety, compensation not linked to severity of ASD.
1 6	Livingston, L. A., Shah, P., Milner, V. & Happe, F. (2020)	Novel Compensa- tion Checklist / AQ / ISCE	Higher compensation related to autism diagnosis, more autistic traits and higher eduction. No link with sex or age of diagnosis.
1 7	Martin De Lassalle, C., Lerens, E., Mous- set, E., Kurzeja, N., Poncin, F., Charlier, D., & Wintgens, A.	Retrospective study of clinical data / diagnoses / AQ scores / IQ	Findings revealed with participants with high intellectual potential profiles autistic traits were more easily observed in the ADOS and informal assessments than other standard analysis, and argue high IQ is linked to camouflaging.
1 8	McQuaid, G., Lee, N. R., & Wallace, G. (2021	AQ / CAT-Q	Gender diverse adults reported elevated compensation (sub scale) compared to cisgender, adult diagnosed reported higher assimilation and compensation compared to child/adolescent diagnosed individuals.
1 9	Perry, E., Mandy, W., Hull, L., & Cage, E. (2021)	Nario-Redmond et al's measure of individual & col- lective strategy use / Stigma Con- sciousness Scale / CAT-Q / WEM- WBS / RAADS-14	Higher camouflaging passively associated with autism-related stigma and individualistic and collective strategy use. Stigma was associated with lower wellbeing not mediated by camouflaging.
2 0	Ratto, A. B., Kenworthy, L., Yerys, B. E., Bascom, J., Wieckowski, A. T., White, S. W., Wallace, G. L., Pugliese, C., Schultz, R. T., Ollendick, T. H., Scarpa, A., Seese, S., Register-Brown, K., Martin, A., & Anthony, L. G. (2018)	ADOS-2 / SRS / ADI-R / Parent- report Adaptive Behaviour inter- view	Female and males rated similarly on the diagnostic measures overall, but females with higher IQ were less likely to meet ADI-R, suggesting masking of symptoms.
2	Robinson, Erin; Hull, Laura; Petrides, K. V. (2020)	BFI / TEIQue / CAT-Q	Camouflaging was positively related to neuroticism, and negatively to extroversion, agreeableness, conscientiousness, and emotional intelligence.
2 2	Rynkiewicz, A., Janas-Kozik, M., & Słopień, A. (2019).	ADOS-2 / AQ Child / Faces Test / SCQ	Girls used more gestures than boys, but but more mistakes on the faces test, suggesting that high functioning females may camouflage diagnostic features
2 3	Somerville, M., Mac- Pherson, S. E., & Fletcher-Watson, S. (2019).	CAT-Q / DASS / AQ / Berg card sorting test . Col- our-Word Stroop task / WAIS-IV	Camouflaging predicted increase mental health symptoms, but didn't correlate with executive function, autistic traits didn't correlate with mental health when camouflaging was controlled for

2 4	Schuck, R. K., Flores, R. E., & Fung, L. K. (2019)	AQ / RAADS-R / BEQ / SPAI / FSIQ	Camouflaging was found to be more common in females, not linked to social phobia, and negatively correlated to emotional expressivity in females but not males.	
2 5	Wiskerke, J., Stern, H., & Igelström, K. (2018)	AQ / self-rated questionnaire on repetitive move- ments / self-rated multiple choice questionnaire on camouflaging	Findings reveal camouflaging of RM in diagnosed and non-diagnosed participants across all genders.	
	Mixed Methods			
1	Bernardin, C. J., Mason, E., Lewis, T., & Kanne, S. (2021b).	CAT-Q / semi structured inter- views	Findings reveal motivations, positive and negative consequences of camouflaging, and trends linked to sex and diagnosis.	
2	Cage, E., & Troxell- Whitman, Z. (2019)	CAT-Q / DASS-21 / RAADS-14 / some open questions "other reasons for comparisons"	Gender difference in reasons to camouflage, high camouflagers and "switchers" had poorer mental health outcomes	
3	Jedrzejewska, A., & Dewey, J. (2021)	CAT-Q / CATO-Q / Social Media In- tensity / Social Media Prior Con- tacts vs Meeting New People scale / Passive vs active social me- dia use scale / semi-structured interview (6 parti-	Offline autistic adolescents camouflage more than non-autistic, online autisitc participants camouflage less than they do offline, females camouflage more than males.	
4	Wood-Downie, H., Wong, B., Kovshoff, H., Mandy, W., Hull, L., & Hadwin, J. A. (2021)	SCDC / WASI-II / IDT / Reading the Mind in the Eyes test	Similar levels of social reciprocity in autistic and neurotypical females, autistic males with lower than neurotypical males, autistic males and females had similar theory of mind skills, the evidence support that there is more camouflaging in autistic females.	
	Review and commentaries			
1	Alleley, C. S. (2018)	A systematic PRISMA review	Camouflaging can lead to social success in women, but also under diagnosis and high levels of stress and anxiety, more research into camouflaging and measuring camouflaging is needed.	
2	Dell'Osso, L., Loren- zi, P., & Carpita, B. (2020)	General comment - no methodology used	The growing body of literature may lead to new understandings of gender discrepancies in autism diagnosis, also how camouflaging strategies may be shared in the general population, and across over psychiatric disorders as a transdiagnostic element	
3	Hull, L., Petrides, K. V., & Mandy, W. (2020).	A narrative literat- ure review	That evidence supports a female autism phenotype of which camouflage is distinguishing component, although more research across all genders is required.	
4	Livingston, L. A., & Happé, F. (2017).	A general review - no specific meth- odology	They propose a transdiagnostic model of compensation and argue further research in to definitions and impact across neurodevelopmental conditions is required.	

5	Tubío-Fungueiriño, M., Cruz, S., Sam- paio, A., Carracedo, A., & Fernández-Pri- eto, M. (2020).	A systematic PRISMA review	Camouflaging seems to be an adaptive mechanism, that has negative implications such as anxiety and loss of identity	
6	Pearson, A., & Rose, K. (2021)	Conceptual Analysis	Examine how social identity theory can inform understanding of camouflaging. Suggest future research should be examined through a sociodevelopmental lens, taking account of individual presentation and intersectionality.	
7	Fombonne, E (2020)	Editoral Com- mentary	Further research is needed to define and measure camou- flaging, and it should be seen in the context of the indi- vidual and is not a feature of autism per se.	
8	Gould, J. (2017)	Commentary	Personal commentary on the under diagnosis of women and girls and masking	
9	Mandy W. (2019)	Commentary	Personal commentary on camouflaging research to date.	
1 0	McPartland, J. C. (2019).	Commentary	Critiques Livingston et al. 2018 study and highlights the consequences of camouflaging on diagnosis	
Articles did not explore camouflaging specifically, but noted in discussions				
1	Baldwin, S., & Costley, D. (2016)	The experiences and needs of female adults with high-functioning autism spectrum disorder.		
2	Tint, A., & Weiss, J. A. (2018)	A qualitative study of the service experiences of women with autism spectrum disorder.		
3	Cage, E., Di Monaco, J., & Newell, V. (2018)	Experiences of autism acceptance and mental health in autistic adults		