

DOCUMENT SUMMARY This 2017 qualitative study from the *Journal of Autism and Developmental Disorders* examines the experience of **social camouflaging** in 92 adults with **Autism Spectrum Conditions (ASC)**. Through thematic analysis, the researchers developed a three-stage model of the camouflaging process. The study identifies the primary motivations for camouflaging (to assimilate and to connect), the techniques used (a combination of **masking** and **compensation**), and the significant negative consequences, including extreme exhaustion, anxiety, and a threatened sense of self or identity.

FILENAME hull_2017_research_report_autism_camouflaging.md

METADATA Category: RESEARCH Type: report Relevance: Core Update Frequency: Static Tags: #autism #asc #camouflaging #masking #social-coping #late-diagnosis #autistic-females #mental-health #identity #qualitative-research Related Docs: None specified Supersedes: None specified

FORMATTED CONTENT

"Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions

Laura Hull, K. V. Petrides, Carrie Allison, Paula Smith, Simon Baron-Cohen, Meng-Chuan Lai, William Mandy

Abstract

Camouflaging of autistic characteristics in social situations is hypothesised as a common social coping strategy for adults with **autism spectrum conditions (ASC)**. **Camouflaging** may impact diagnosis, quality of life, and long-term outcomes, but little is known about it. This qualitative study examined **camouflaging** experiences in 92 adults with **ASC**, with questions focusing on the nature, motivations, and consequences of **camouflaging**. **Thematic analysis** was used to identify key elements of **camouflaging**, which informed development of a three-stage model of the **camouflaging** process. First, motivations for **camouflaging** included fitting in and increasing connections with others. Second, **camouflaging** itself comprised a combination of **masking** and **compensation** techniques. Third, short- and long-term consequences of **camouflaging** included exhaustion, challenging stereotypes, and threats to self-perception.

Keywords: Autism, Camouflaging, Coping, Sex-Gender, Social adaption

Introduction

Autism Spectrum Conditions (ASC) are atypical developmental conditions characterised by impairments in social interaction and communication, alongside unusually restricted/repetitive behaviours and interests, need for sameness, and atypical sensory processing (APA 2013).

ASC is generally viewed as dimensional, with traits found amongst the general population and a specified cut-off point, when present with concurrent functional impairments, used to identify the clinical diagnosis (Baron-Cohen et al. 2001; Constantino 2011). One behaviour associated with

ASC that has recently attracted interest is the development of **camouflaging** or coping strategies for use in social situations (Attwood 2007; Gould and Ashton-Smith 2011; Kopp and Gillberg 2011; Lai et al. 2011; Wing 1981). These strategies may include hiding behaviours associated with their

ASC, using explicit techniques to appear socially competent, and finding ways to prevent others from seeing their social difficulties. In this paper we will refer to these behaviours as '

camouflaging'.

While many neurotypical people, of all genders, manage the way others perceive them in social situations (Izuma et al. 2011), research suggests that individuals with

ASC have a reduced ability to do so (Cage et al. 2013). However, the research in this area has focused on the manipulation of typical social behaviours, rather than how individuals with

ASC may want and be able to adapt their **ASC**-related characteristics.

Camouflaging is likely to exist on a spectrum (similar to autistic traits) in those who have an **ASC** diagnosis and those who are subclinical. However, self-reported evidence suggests possible categorical differences between autistic and non-autistic

camouflaging. For instance,

camouflaging by **ASC** individuals has been reported as extremely effortful and challenging to one's identity (Bargiela et al. 2016), unlike ordinary reputation management in typically developing individuals.

Camouflaging has also been proposed as an explanation for the missed or late diagnosis of females with **ASC**, as part of the **female phenotype** or behavioural presentation (Gould and Ashton-Smith 2011; Kirkovski et al. 2013; Lai et al. 2015). Amongst clinical samples, male to female gender ratios for

ASC diagnosis are generally around 4:1 (Fombonne 2009), but when active case ascertainment is used within the general population, the ratio lowers to around 3:1 (Sun et al. 2014). This discrepancy suggests that there are biases that work against females with

ASC receiving accurate, timely diagnoses from clinical services. Females are less likely to receive a diagnosis of

ASC than males with similar levels of autistic traits (Dworzynski et al. 2012; Russell et al. 2011), and those who receive a diagnosis on average are more likely than males receiving the same diagnosis to be older and have more additional needs, including increased intellectual disability (Shattuck et al. 2009) and behavioural-emotional challenges (Duvekot et al. 2016). Clinical experience suggests that females with

ASC may be more likely than males with **ASC** to have been previously misdiagnosed with other mental health conditions, such as personality disorders or eating disorders (Lai and Baron-Cohen 2015; Mandy and Tchanturia 2015).

In addition to

camouflaging, there are other gender differences in autistic characteristics which may contribute to late diagnosis or misdiagnosis of females. While few significant quantitative sex differences in the core symptoms have been found (Hull et al. 2016; Lai et al. 2015; Mandy et al. 2012; Van Wijngaarden-Cremers et al. 2014), comparisons of associated characteristics have shown differences between the female and male presentations (Kreiser and White 2014; Rivet and Matson 2011). For instance, males with

ASC are more likely to experience externalising difficulties such as hyperactivity and conduct problems, whereas females with **ASC** are more likely to experience internalising problems such as anxiety and depression (May et al. 2012; Oswald et al. 2016). These 'qualitative' differences between male and female presentation, including

camouflaging behaviours, need to be included in measures used to assess **ASC**, as sex differences at a nosological level are likely to have an impact on diagnosis (Lai et al. 2015). Current diagnostic practices focus on the core

ASC characteristics that have been historically established from the behavioural presentation in males, and so do not necessarily reflect the areas in which females with **ASC** may display different behaviours to males. As a result, current assessments of females with

ASC are restricted to the areas in which females are most similar to males, and those females who do not meet the male-typical behavioural descriptions are likely to be missed (Van Wijngaarden-Cremers et al. 2014).

Camouflaging in certain settings may lead to the perception that individuals function well and do not experience any problems, even though those individuals still experience difficulties as a result of the interaction of their **ASC** and the context. For example, it is suggested that girls with

ASC may mimic other socially successful individuals to give the impression that they too are socially successful, but when placed in unknown environments they are not prepared for, they struggle to socialise (Attwood 2006). This may reflect both a stronger motivation to mimic, and itself be the result of a stronger motivation to 'systemize' social behaviour, than is seen in males with

ASC. Teachers or clinicians may therefore be unaware of the difficulties being faced by girls and women with

ASC, whereas family members may see their loved one in a range of situations and so realise the extent of their difficulties.

There is a variety of anecdotal evidence of

camouflaging amongst women with **ASC**. For instance, Liane Holliday Willey describes how she spent her life pre-diagnosis 'pretending to be normal', yet knowing that something was different about her (Holliday Willey 2015). In case studies of girls with

ASC, researchers have suggested that the use of social imitation strategies may lead to missed, late, or questioned diagnoses (Kopp and Gillberg 1992). Essentially, social imitation may be a form of acting, whereby girls with undiagnosed

ASC may be coping without receiving a diagnosis or even needing a diagnosis because their acting is relatively successful. Success here may be defined as simply not having overt functional impairments or raising concerns of teachers or other professionals, even though under the surface or behind maintaining such appearances, females may report high levels of subjective stress, anxiety and exhaustion, and a need to withdraw from social interaction to 're-set'.

Camouflaging is not necessarily a beneficial behaviour, and should not be regularly expected or encouraged for individuals with **ASC**, as this may risk increasing mental health problems. It is therefore important to study

camouflaging in order to better understand the individual differences predicting long-term wellbeing and outcomes for individuals on the autism spectrum.

A small number of studies have recently emerged which directly examine social

camouflaging behaviours in individuals with **ASC**. Tierney, Burns, and Kilbey (2016) interviewed ten adolescent girls with

ASC about their experiences of **camouflaging**, and revealed some common themes including the uncertain, exhausting nature of the social environment; the desire to make friends which motivated **camouflaging** attempts; and using explicit techniques to mask **ASC**-related difficulties. Similar themes were also found during qualitative interviews with late-diagnosed women with

ASC (Bargiela et al. 2016). In particular, the idea of pretending to be normal, which could be achieved through both learned and automatic strategies, and the extensive costs of such strategies, were identified.

Most importantly, studies of

camouflaging in **ASC** cannot progress until a conceptual model of **camouflaging** has been produced, so that subsequent research has strong theoretical grounding. Such a model is best developed from a qualitative analysis of the

camouflaging experiences of individuals with **ASC**. This will ensure that the construct of

camouflaging reflects the real-life experiences of individuals with **ASC** rather than the preconceptions of researchers or clinicians, and that our understanding of **camouflaging** is representative of a broad range of individuals with **ASC**.

The present qualitative study examined

camouflaging in a large sample of adults of all self-identified genders who had been diagnosed with **ASC**, using internet-based survey and **thematic analysis**. The aim of the study was to derive a conceptual model of

camouflaging to inform future research. The following research questions were addressed:

1. What is **camouflaging**?
2. What are the techniques used and what do people with **ASC** think **camouflaging** is?
3. Why do people camouflage their **ASC**?
4. What are the consequences of **camouflaging**?

Methods

Participants

Participants were 92 adults of 15 different nationalities (55% British). They were eligible to take part in the study if they were over the age of 16 years and had received a DSM-IV or DSM-V diagnosis from a psychiatrist or clinical psychologist in a recognized specialist clinic of an

ASC, including Autism/Autistic Disorder, Asperger Syndrome/Asperger's Disorder, Autism Spectrum Disorder, Atypical Autism, and Pervasive Development Disorder Not Otherwise Specified.

Table 1: Demographic characteristics of participants and whether they reported camouflaging

| | | | | | | | | |
|---|------------------|------------------|-----------------|------------------|-------------|-------------------------------|----------------------|----------------|
| Female | Male | Other gender | N | Age (mean years) | Age (range) | Age at diagnosis (mean years) | Camouflage? (yes/no) | Nationality |
| 55 | 30 | 7 | 92 | 40.71 (SD 14.14) | 18-68 | 36.98 (SD 14.21) | 51/4 | British |
| 48.03 (SD 16.62) | 40.71 (SD 14.29) | 41.03 (SD 18.08) | 32.67 (SD 9.25) | 28/2 | 7/0 | 6/4 | 0 | North American |
| 12 | 3 | 1 | 7 | 6 | 2 | 6 | 4 | 0 |
| Three male participants reported their natal sex as female. All participants who identified their gender as 'Other' reported their natal sex as female. | | | | | | | | |

Materials

A newly designed questionnaire of

camouflaging was developed by the researchers, in consultation with other experts in **ASC**, including clinicians, researchers, and adults with **ASC**. The questionnaire included 23 closed and 20 open questions, and examined participants' motivations for

camouflaging, the characteristics of their **camouflaging** experiences, the consequences of **camouflaging** (positive and negative), and their attitudes towards **camouflaging**.

Procedure

Early in the questionnaire after demographic data had been ascertained, participants were asked the following question: "Have you ever had the experience of 'camouflaging your autism? A reminder: in this survey we use the term '

camouflaging' to refer to 'coping skills, strategies, and techniques that function to "mask" features of **ASC** during social situations.'. Those who responded 'no' were directed to the end of the questionnaire, where they could leave their thoughts on

camouflaging if they wished. Four females (7% of total number of females) and two males (6% of total males) reported that they had never camouflaged their

ASC in social situations. All seven participants who identified their gender as 'Other' reported **camouflaging** their **ASC**.

Analysis

Analysis followed the six phases of

thematic analysis recommended by Braun and Clarke (2006) with the aim of identifying patterns of information within the data which answered the research questions. This inductive (i.e., data driven) analytic approach was chosen because it does not rely on a rigid theoretical framework for interpretation, and so enables researchers to examine alternative perspectives and identify new information within developing areas of psychology (Willig 2013).

Results

Seven themes, comprising 16 subthemes, were clustered into three stages of the

camouflaging process, as detailed in Fig. 1. Motivations (Assimilation and "To know and be known") describe the reasons why respondents camouflaged their

ASC, including the aims they hoped to achieve as a result. What is

Camouflaging? (

Masking and **Compensation**) describes the concept of **camouflaging** itself, including the techniques used. Finally, the short- and long-term consequences of

camouflaging are described through the themes "I fall to pieces", "People have a stereotyped view", and "I'm not my true self".

Fig. 1: Thematic map of the three stages (motivations, camouflaging, and consequences) of the camouflaging process. Themes are indicated by rectangles; subthemes by ovals

Table 2: Number of participants who referenced each theme

| |
|---|
| Theme Female (n=55) Male (n=30) Other gender (n=7) :--- :--- :--- :--- Assimilation: "hide in plain sight" 49 20 7 "To know and be known" 42 24 5 Compensation: "to exceed what nature has given" 45 22 7 Masking: "I'm hiding behind what I want people to |
|---|

see" | 38 | 18 | 7 | | "I fall to pieces" | 44 | 21 | 7 | | "People have a stereotyped view" | 32 | 6 | 4 |
| "I'm not my true self" | 31 | 15 | 3 |

Motivations for Camouflaging

Assimilation: "Hide in Plain Sight"

Respondents described wanting to camouflage in order to 'blend in with the normals'. Most respondents reported a social expectation from the general population that individuals with

ASC need to change in order to be accepted by others. It was felt that the general population viewed this as unacceptable, and so respondents felt a pressure to change their behaviours in order to seem 'normal enough'.

[I camouflage] to reduce the threat of feeling uncomfortable through being unable to measure up to social expectations. (Male, 62)

I don't want to draw attention to myself by appearing to be different. (Female, 30)

A more pragmatic aspect of this motivation was the desire to obtain jobs and qualifications, which respondents felt were less accessible when they were more visibly 'autistic'. The desire for

assimilation was also prompted by concerns for their own safety and wellbeing. Many described being ostracised, verbally or emotionally attacked, and some even reported physical assaults when they had not camouflaged their

ASC.

When I was younger and more obviously odd and strange I was thought of as stupid and also badly physically and mentally bullied. I also lost employment. I want to avoid the bullying mostly. I have even been spat at in the street. (Female, 49)

"I Want to Know and Be Known"

The other key motivation for

camouflaging was to increase connections and relationships with others. Due to their inherent social difficulties, many respondents reported struggling to make friends and form romantic attachments, despite this being a strong desire.

Camouflaging was seen as one way to overcome the initial obstacles to connection and allow for future relationships to develop.

Connections have to be made initially on neurotypical terms. Then, hopefully, on my terms as well. (Female, 46)

For some, the risk of failure and associated embarrassment created severe anxiety during social interactions; by

camouflaging and using structured techniques, respondents could reduce some of this uncertainty and so were more confident in their ability to socialise.

What is Camouflaging?

Masking: "I'm Hiding Behind What I Want People to See"

Masking encompasses the aspects of **camouflaging** that focus on hiding one's **ASC** characteristics and developing different personas or characters to use during social situations.

Camouflaging was partly performed through suppressing, hiding, or otherwise controlling behaviours associated with **ASC** that were seen as inappropriate in the situation. Respondents described attempting to minimise their self-soothing or 'stimming' behaviours, and their responses to sensory overstimulation, in order to make their condition less obvious to others.

I prevent myself from doing any particularly visible or otherwise noticeable stims...
(Female, 20)

Masking enabled respondents to present a different identity to the outside world, one that covered up those parts of themselves they were not happy with. In some cases, this went as far as portraying an entirely different character, and several respondents likened it to acting or performing a role, complete with costumes. One way to easily identify the appropriate role to play was to mimic the behaviours of others during a social interaction. Behaviours could be copied directly from the person in front of them, or could be identified and learned from observing others interacting, and even from watching television and films.

Compensation: "To Exceed What Nature has Given"

The other aspects of

camouflaging centre around developing explicit strategies to meet the social and communication gaps resulting from an individual's **ASC**, which we call **compensation**. These

camouflaging techniques include specific non-verbal communication strategies and guidelines for successful conversations with others. Explicit, compensatory strategies were reported by many respondents as a vital way to improve non-verbal communication with others. Forcing and maintaining appropriate eye contact, or attempting to look as close to another's eyes as possible was a common compensatory technique reported.

In addition to these non-verbal techniques, respondents reported developing rules or guidelines to compensate for some of the social difficulties they experienced during conversations. One rule was to ask questions of the other people. Explanations for this varied between respondents, but included minimising the amount of time they had to speak, giving them more time to prepare things to say, and ensuring the

ASC individual did not take over the conversation by talking about themselves or their own interests. Respondents also described spending time before an interaction to prepare topics of conversation, including questions to ask, anecdotes to relate, and potential responses to others.

Consequences of Camouflaging

"I Fall to Pieces"

By far the most consistent consequence of

camouflaging described by respondents was exhaustion.

Camouflaging was frequently described as being mentally, physically, and emotionally draining; requiring intensive concentration, self-control, and management of discomfort. Many respondents reported needing time to recover after

camouflaging, where they could be alone and release all of the behaviours they had been suppressing.

It's exhausting! I feel the need to seek solitude so I can 'be myself and not have to think about how I am perceived by others. (Other, 30)

In addition to this exhaustion, after a

camouflaging session was over some respondents would experience extreme anxiety and stress. Respondents felt significant pressure, whether from themselves or others, to camouflage successfully, but many were uncertain of how effective their

camouflaging strategies were.

"People Have a Stereotyped View"

Many respondents felt that, because their

camouflaging changed the way they presented themselves to others, they did not meet the 'stereotype of an autistic person' when they camouflaged. Some also reported that this enabled them to challenge commonly held views of autism, especially for women.

So many people have a stereotyped view of what **ASC** looks like... They don't realise that women with **ASC** tend to internalise things much more and do have empathy and insight, and are very careful not to make hurtful remarks. (Female, 56)

However, there were also negative consequences to not appearing autistic to others. The most striking was that for some respondents their

camouflaging, even if it was involuntary, resulted in a delay or questioning of their **ASC** diagnosis. In addition to this, respondents described failing to receive adequate support or allowances for their

ASC difficulties, because these difficulties were often hidden behind the mask of **camouflaging**.

"I'm Not My True Self"

The final consequence reported by respondents was that

camouflaging affected their perception of themselves, in particular how they represented themselves to the outside world and their sense of authenticity. For many respondents, by

camouflaging their 'true' or natural behaviours they were lying about who they were.

like the weight of a black cloud is hanging on me having to be this fake version of me. (Female, 48)

For some respondents their

camouflaging behaviours contradicted the important role they attributed to **ASC** in shaping their identity. These individuals felt that by hiding their

ASC characteristics, they were betraying the **ASC** community as a whole. Some respondents felt that the relationships they formed through

camouflaging were based on deception, and therefore the relationships themselves were false. This reinforced experiences of loneliness and isolation, as they felt no one truly knew them or understood them. The situations in which respondents camouflaged were so extensive for some, they felt that they were losing sense of who they truly were.

Discussion

This study identified key themes underlying the motivations, techniques, and consequences associated with social

camouflaging amongst adults with **ASC**. The vast majority of participants (male, female, and of other genders) reported

camouflaging to some degree, although there was significant variation in individual experiences of **camouflaging**. The results were combined into a model of the

camouflaging process, which we hope will contribute to the generation of testable hypotheses and identification of avenues for future research.

The themes revealed two key motivations for **camouflaging**;

assimilation and connection. This suggests that

camouflaging behaviours come from multiple sources. They may be internally driven by the individual to accomplish specific goals such as friendships, but they may also be produced as a response to external demands placed on how a person should behave in society. The two main themes found here,

masking and **compensation**, appear to relate to the motivations of fitting in and forming connections respectively.

There was extensive variation in the consequences of

camouflaging reported, but one of the most striking findings was that the vast majority of participants reported some unpleasant and unwanted consequences of **camouflaging**. These included the exhaustion experienced during and after

camouflaging, which has been identified in previous research (Tierney et al. 2016). In addition, a profound consequence of

camouflaging was a change in self-perceptions, as detailed by the theme 'I'm not my true self'.

Camouflaging appears to challenge many participants' views towards themselves, and produce negative emotions and attitudes, such as being a 'fake' or losing their identity.

Previous researchers have suggested that

camouflaging by females with **ASC** might account for the gender disparity in diagnosis (Gould and Ashton-Smith 2011; Kreiser and White 2014; Lai et al. 2015). Our study is not designed to directly test this idea. We found that relatively equal numbers of males and females, and all individuals of other genders, reported

camouflaging, and no consistent patterns of differences in **camouflaging** behaviours between males and females were identified. However, some female and other-gender participants argued that

camouflaging was a specific reason for their own or others' late diagnosis, suggesting that society places higher demands on social ability and **assimilation** for people perceived as female.

Strengths and Limitations

One strength of this study was the high proportion of females and those of non-binary gender, many of whom were diagnosed later in life. This is an under-represented population, and it is important to include their voices and insights, which may be different to those of the majority male, younger samples included in previous research. However, because of this our sample was not fully representative of the entire

ASC community. The cognitive and self-reflecting abilities required to complete the survey may also mean that our sample were better able to perform successful

camouflaging behaviours than others on the autism spectrum. As a result, our findings cannot be said to represent the views of those with

ASC who also have intellectual disability, or who cannot express themselves in written English.

Conclusions

This study demonstrates that

camouflaging of **ASC**-related characteristics in social situations may be a common behaviour amongst adults with **ASC**.

Camouflaging is motivated by the desire to fit in with others and to make connections. The behaviours themselves can be grouped into

masking and **compensation** strategies. In the short term,

camouflaging results in extreme exhaustion and anxiety; although the aims of **camouflaging** are often achieved, in the long-term there are also severe negative consequences affecting individuals' mental health, self-perception, and access to support. Our findings demonstrate that

camouflaging is an important aspect in the lives of many individuals with **ASC**.