# The Experiences of Camouflaging in Canadian Autistic Women

by

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## Abstract

The phenomena of quality of life and camouflaging of autistic individuals have garnered significant attention from academic researchers over the past decade; however, the impact of camouflaging on the quality of life of Canadian autistic women has seldom been assessed. Camouflaging, also referred to as masking, is often used by autistic and non-autistic individuals in an attempt to blend into their social environments, such as by mimicking the behaviours or appearance of others (Hull et al., 2017). Despite literature highlighting the benefits of including the female autistic voice in research, research acknowledging autistic lived experience as expertise is rare (Howard et al., 2019). The present qualitative study aims to understand further the experiences of camouflaging and the implications camouflaging may have on the quality of life of autistic women. Five cis-gendered Canadian autistic women were purposely sampled and interviewed about their camouflaging experiences and the perceived impact of those experiences on their quality of life. Responses were recorded, transcribed, and analysed using Interpretative Phenomenological Analysis to develop themes that address the study's research purpose. The participants described their camouflaging experiences as adaptive, variable, and dependent on degrees of external and internal acceptance of autism. Additionally, the decision to camouflage or not has both benefits and challenges that impact the participants' social, physical, psychological, and environmental quality of life. The findings provide an enhanced understanding of the complexity associated with individual experiences of camouflaging and its impacts on various domains of quality of life. These results inform new understandings of the lived experiences of autistic women highlighting potential avenues for re-allocated supports and more autistic-female-focused programs that address low quality of life.

# Preface

This thesis is an original work by Nicholas Denomey. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “The Experiences of Camouflaging in Canadian Autistic Women”, Pro00100983, October 01, 2020.

# Dedication

This thesis is dedicated to my wife, Katie. Your unconditional love and support are, and always will be, the most influential factors in bringing my seemingly impossible ideas to fruition.

## Acknowledgements

To my supervisor, Heather Brown, thank you for all of the support, guidance, and wisdom you have provided me. Your passion for research and education within the autistic community has taught me the value of humility and collaboration. I will always look back on our time as a meaningful experience that helped me grow as an academic and a person.

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# Chapter One: Introduction

## Background and Rationale

Only one-third of autistic individuals participate in community events with their peers (Shattuck et al., 2011). They also commonly experience fewer post-secondary employment opportunities and poorer post-secondary education outcomes than their neurotypical peers (Shattuck et al., 2012). Likewise, autistic individuals often experience feelings of intense loneliness (Cage et al., 2018; Jackson et al., 2018), and they are seven to nine times more likely to engage in suicidal ideations compared to controls due to co-occurring depression and anxiety (Bauminger & Kasari, 2000; Hirvikoski et al., 2019). In addition, increased prevalence of victimization within school settings (Sterzing et al., 2012), accompanied by poor sleep habits, can result in poor mental health outcomes (Delahaye et al., 2014). Taken together, this suggests that the quality of life (QoL) of autistic individuals is frighteningly poor.

The use of compensation and masking strategies, also known as camouflaging, are often used by individuals with and without autism in an effort to blend into their social surroundings by mimicking the behaviour of others and suppressing internal traits (Hull et al., 2017; Livingston & Happé, 2017; Robinson et al., 2020). This strategy can be used with the intent to improve social relations with others (Hull et al., 2019; Livingston et al., 2020), to avoid bullying or discrimination due to shame of diagnosis (Cage & Troxwell-Whitman, 2019; Hull et al., 2020), to seek out employment opportunities, or to achieve academic success (Livingston et al., 2019).

Recent research has suggested that camouflaging can improve education and employment outcomes (DePape & Lindsay, 2016; Livingston et al., 2019, Webster & Garvis, 2017).

However, some autistic women who regularly camouflage may experience poor physical and psychological outcomes in quality of life (Cage & Troxwell-Whitman, 2019; Livingston et al., 2019; Tint & Weiss, 2018; Tubio-Fungeuriño et al., 2020). This negative impact of camouflaging on the psychological well-being has also been identified as an indirect predictor of suicidal thoughts and behaviours (Cassidy et al., 2019). Moreover, the act of camouflaging itself has been classified as an independent risk factor for suicidality in some autistic women (Cassidy et al., 2018). Recent research uncovering the poor experience of camouflaging indicates the urgency to better understand what those who camouflage, clinical professionals, and the community can do to alleviate these impacts.

Currently, a great deal of literature examines adult women's experiences with camouflaging; similarly, several researchers are examining the QoL of autistic adults. Yet, to date, researchers have not yet explored the impact of camouflaging on the quality of life in Canadian autistic women. The current study will be the first of its kind to analyze the personal accounts of Canadian autistic women and their perspectives on how camouflaging impacts their QoL.

To fully understand the impact that camouflaging may have on autistic women, lived experience of autistic women must be analyzed. Gaining insight into individual experiences will give a voice to those commonly ignored (Pellicano et al., 2014). Furthermore, by actively involving the autistic community in the process of researching this topic, the results can inform change grounded in the needs, concerns, and experiences of the participants.

## Statement of Purpose

The purpose of this qualitative study was to gain a deeper understanding of the camouflaging experiences in autistic women, and the implications camouflaging can have on their quality of life. Specifically, the two research questions that I address are as follows:

## Research Questions

1. What is the experience of camouflaging in autistic women?
2. To what extent does camouflaging impact the quality of life in autistic women?

## Theoretical Frameworks

Theoretical frameworks are the pinnacle of a meaningful research study; the frameworks followed in this study are purposeful for research with autistic female participants. Within this section, I will describe how Feminist Disability Studies, Critical Autism Studies, and the Minority Stress Model are pertinent to understanding the camouflaging experiences of autistic women.

### *Feminist Disability Studies*

At its core, Feminist Disability Studies (FDS) seeks to advocate for a shift in conceptualization and perspectives of disability to be more inclusive of gender intersectionality in societal experiences (Garland-Thomson, 2005). Inaccurate conceptualizations of the autistic female's lived experience impact conceptualizations of what the lived experience of autistic women entails. Assumptions must be challenged and actively incorporate inclusive voices based on lived experiences of disabled women (Garland-Thomson, 2005; Simplician, 2017). These voices can significantly improve our perceptions of what it is like to have a societally deemed disability.

Historically, the term disability has been focused on differentiating people based on their abilities (Goering, 2015). By highlighting how those with disabilities have societally undesirable traits, the power dynamic between the disabled and non-disabled is shifted towards those exhibiting societally desirable traits (Garland-Thomson, 2005). In doing so, the experiences of social exclusion can be partially attributed to social perspectives of disability (Knoll, 2009).

Within an FDS framework, disability is defined as “a vector of socially constructed identity and a form of embodiment that interacts with both the material and the social environments” (Garland-Thomson, 2005, p. 1559). Thus, although a disability can be physical, it is equally important to consider how the appearance of a disability is interpreted in different social environments. In particular, my study seeks to understand how culturally inaccurate definitions of disability apply to the experiences of camouflaging in autistic women. I do this by incorporating the various lived experiences of autistic women. Hence, the conceptualization of the autistic identity and phenomenon of camouflaging are specific to the autistic women in the study.

### ***Critical Autism Studies***

Critical Autism Studies (CAS) utilizes narratives and voices of autistic people to challenge the deficit model of autism. Often, conceptualizations of what autism looks like are birthed from the perspectives of those situated in research and political settings. It can be challenging for autistic voices to be heard and valued when the majority does not believe in the necessity of including new and inclusive understandings of autism. Orsini and Davidson (2013) outlined three main elements of the CAS approach as follows:

> i. Careful attention to how power relations shape the field of autism
> ii. Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy and popular culture; and
> iii. Commitment to develop new analytical frameworks using inclusive and non-reductive methodological and theoretical approaches to study the nature *and* culture of autism. The interdisciplinary (particularly social sciences and humanities) research required demands sensitivity to the kaleidoscopic complexity of this highly individualized, relational (dis)order. (p. 12; original emphasis)

CAS as a formative framework was used within this study for several reasons. First, the study highlights the complexity of the autistic experience from various individuals. Specifically, it highlights the individual experiences of camouflaging as an autistic woman. Second, exploring the camouflaging experiences of autistic women may uncover how the terms ‘ability’ and ‘disability’ are viewed as opposites by employers or those in power. Third, using CAS can facilitate the reconstruction of ‘ability and how these perceptions of ‘disability’ may be pertinent to determining success in academic and vocational environments (MacLeod, 2019). Breaking the stigma surrounding the capabilities of autistic community members starts with addressing the root of the stigma. By formulating new normative assumptions of autism founded on valuing societal diversity, autism acceptance can increase and contribute to equity of opportunity.

Finally, using CAS as a framework for this study unequivocally addresses the epistemic understandings of autism and, by association, Ian Hacking’s looping effect. Hacking (1995) suggests that populations are defined by how they are grouped or classified. If an individual is classified as part of a particular population, the expectations associated with the population will be placed on the individual within that group. Accepting these classifications or categories results in people unconsciously creating more expectations and labels for anyone classified in that population. Furthermore, these expectations may change their individual interpretations of the definition of the population. Consequently, changing the definition will change the categories as others interpret them. Still, the categories will change the definition based on how others perceive them, hence the looping manner of identity attached to a definition. In sum, CAS is used in this study because it ensures that autism is a representative concept and that categories are not discriminative or restricting opportunities for increased well-being (MacLeod, 2019). By acknowledging the voices of autistic women in this study as expertise, this study identifies the definition of autism as explained by the participants.

### ***Minority Stress Model***

The Minority Stress Model (MSM) stems from earlier theories of where and how stress experienced by minorities (i.e., gender, race/ethnicity, sexuality) could result in health disparities (Dressler et al., 2005; Schwartz & Meyer, 2010). Increases in primarily negative health trends (i.e., decreased mental health) are related to increased social stressors. Moreover, research has indicated that these social stressors are directly associated with increased prejudice and discrimination regularly experienced by societal minorities (Botha & Frost, 2020; Dressler et al., 2005; Schwartz & Meyer, 2010).

Botha and Frost (2020) suggest that the decreased social standing of stigmatized minority groups leads to members of such groups “being exposed to more stressful life situations” (p. 22). Yet, at the same time, such individuals have “fewer resources to cope with these events” (p. 22) due to being excluded and discriminated against from accessing social services. Consequently, this reduced access to support or coping mechanisms is a common occurrence in the lives of stigmatized minorities (Schwartz & Meyer, 2010). Moreover, Dressler and colleagues (2005) found that following a psychosocial model of stress, a facet of Social Stress theory, was one of the most conceptually sound approaches to examining where health disparities arise. Using MSM involves explicitly integrating the personal experiences of specific stressors and understanding the implications of long-term continuous stress on individuals' health. Within the current study, I actively listened to the camouflaging experiences from the participants' points of view. Notably, I took note of instances when my participant's described the stress associated with being a neurominority. I also assessed how identifying and being treated as a minority impacted the participants' QoL.

## Study Context

Due to the COVID-19 pandemic that began in late 2019 and lasted throughout this study, this research was completed entirely online. All the communication with the participants occurred via Zoom conferencing software and email. Conducting the study online resulted in participation from only autistic women who had reliable internet and technology access. Notably, although the study objectives involve primarily interpreting the experience of camouflaging in autistic women, the participants expressed that their camouflaging experiences differed within the context of living through a pandemic as opposed to before the pandemic. More detail will be provided on the impact of the pandemic on their camouflaging experience within chapter four.

## Organization of Thesis

This thesis is arranged into five chapters. The first and present chapter, chapter one, provides a detailed overview of the background, purpose, theoretical frameworks, and context applicable to the current study. Chapter two reviews the literature on definitions of disability, understandings and experiences of autism, camouflaging in autistic individuals, and the quality of life of the autistic community. Chapter three outlines the methodological approaches used within the study, including Interpretative Phenomenological Analysis and Community-Based Participatory Research. This chapter also details the data collection, analysis, and ethical considerations for the current study. Chapter four contains in-depth findings in the form of themes and subthemes applicable to answering the research questions. The final chapter, chapter five, discusses the findings, limitations, and implications of the study, along with proposed directions for future research.

# Chapter Two: Literature Review

This literature review contains an overview of the relevant research exploring three critical questions: 1) What is autism? 2) What is camouflaging? 3) What does it mean to experience well-being and quality of life (QoL) for those on the autism spectrum? Within the first section, I will explore the nature and prevalence of autism according to common models of disability (including the medical and social models of disability and the neurodiversity paradigm). I will also explore what it means to be autistic for women. Within the second section, I will begin by describing the phenomenon of camouflaging. Finally, the construct of quality of life is important to understanding the camouflaging experience of autistic women because camouflaging has significant positive and negative impacts on autistic well-being (Hull et al., 2020). Thus, I will begin the final section of the literature review by exploring the concepts of well-being and QoL, explicitly concerning autistic adults. Then I will discuss how camouflaging may lead to higher and lower QoL for autistic women.

## What is Autism?

### *Defining Autism*

Autism has been defined and conceptualized in various ways since Leo Kanner first 'discovered' autism in 1943 (Donvan & Zucker, 2016). In fact, Kanner initially hypothesized that autism was rare (Donvan & Zucker, 2016; Harris, 2018). Today, the Public Health Agency of Canada (2019) reports that 1 in 50 youth is diagnosed with autism. Importantly, as diagnostic rates are seemingly increasing, it is essential to consider how autism is viewed by society. This understanding of autism often depends on which model of disability people agree with the most. Furthermore, this section will first compare how three mainstream models of disability define and conceptualize impairment and disability, followed by autism. Then I will provide brief descriptions of what autism in women entails, including diagnostic bias theories and proposed autistic phenotypes.

### *Impairment and Disability*

The medical model defines impairment as “any loss or abnormality of psychological, physiological, or anatomical structure or function” (World Health Organization, 1980, p. 48). Some examples of relatively common impairments include the loss of a limb or having an auditory impairment. Academics and medical professionals seldom agree on the definition of disability. For example, the World Health Organization (WHO) (1980) views disability as “any restriction or lack (resulting from impairment) of ability to perform an activity in the manner within the range considered normal for a human being” (p. 28).

In contrast, the social model defines disability differently, describing it as a “disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (Union of the Physically Impaired Against Segregation [UPIAS] & The Disability Alliance, 1976, p. 20). Disability, according to both the WHO (1980), UPIAS and The Disability Alliance (1976), is restrictive; however, the causal nature of societal disadvantage is not in consensus. Further in-depth descriptions regarding how each model explicitly conceptualizes disability and autism are provided below.

### *Medical Model of Disability*

The medical model of disability can be explained by a simple equation proposed by Barry (2012, p. 35)

“Disability = Impairment + Profound Limitation”

Currently, an autism diagnosis is received through rigorous observation and assessment based on standards proclaimed by diagnostic manuals. If the impairment they are assessing is determined to be causing a significant limitation to the individual, the diagnosis of a disability is justified. Although the medical model of disability may seem, to some, impartial and righteous in its efforts to identify disability for the sake of remediating it, viewing autism from a medical perspective has significant impacts on autistic individuals. Individuals diagnosed with the disability autism may feel as though their impairment and disadvantage in society are their faults (Krcek, 2013; Pellicano & den Houting, 2021). This disadvantage may result in feeling excluded, undervalued, and stigmatized for being told they significantly diverge from neurotypical standards of being (Goering, 2015; Shaw et al., 2021; Waltz, 2008).

### ***Social Model of Disability***

The social model of disability views disability as a social construct, a political issue based on the notion that society disables the individual, not the impairment (Barry, 2012; Hogan, 2019; Krcek, 2013). The social model of disability’s conceptualization of disability can be explained by this equation (Barry, 2012, p. 36).

“Disability = Impairment + Environment (Negative Treatment)”

Within this model, an autism diagnosis becomes disabling once the impairments are viewed as debilitating within their environment. Considering UPIAS and The Disability Alliance’s (1976) definition of disability, the exclusionary aspect of disability is only prevalent when the impairments are not considered in a social activity. For instance, watching movies in a social gathering with those who are hearing impaired would otherwise be an exclusionary activity without the use of subtitles.

Moreover, the social model of disability claims that the disability label has been irresponsibly placed on autistic individuals (Dawson & Mottron, 2011). Autistic individuals' deficits in social communication, interactions, and imagination may be evident, but they are not disabling. Instead, they become disabling when their social deficits result in a deficiency of opportunities to be social in an environment that is safe, inclusive, and accommodating for the autistic individual (Krcek, 2013). Evidently, even when exhibiting socially desirable traits, autistics can still be considered disabled. Dawson and Mottron (2011) explain this in detail, stating:

> Autistics, like non-autistics, have genuine difficulties in many areas, and like non-autistics, require assistance in areas where their performance is weak… But autistics uniquely are seen as pathological when displaying significant or dramatic strengths, creating for autistics a nearly insurmountable disadvantage or disability not faced by non-autistics (p. 34)

The dire truth regarding autism in the medical or social model is that autism is still viewed as a disability. The main difference between models is the causation of the disability. As Barry (2012) stated, "both models regard disability as something that ought to be gotten rid of, whether that disability is a negative medical state within the person or negative treatment imposed by society" (p. 4). In light of the inability to avoid being viewed as disabled when receiving an autism diagnosis, the neurodiversity paradigm was established to become a promising movement advocating for autistic pride and acceptance in societies (Pellicano & den Houting, 2021).

### *Neurodiversity Paradigm*

The neurodiversity paradigm is quite similar to the social model of disability; disability results from negative perspectives on impairment. However, a notable change is that neurodiversity promotes viewing the diversity of autism as a positive aspect of society. This diversity is valuable, allowing communities to grow exponentially with new approaches to problems, learning to accept that there is not always a correct approach to something (Pellicano & den Houting, 2021).

The neurodiversity paradigm has two aims: (i) depathologize autism; and (ii) advocate for the autonomy of autistic individuals (Pellicano & den Houting, 2021; Shields & Beversdorf, 2020). One way to reach these aims is to highlight autism as not a disability but a way of life (Barry, 2012). Similar to the experiences of those without autism, autistic lived experience is diverse. The environment around autistic individuals is complex; the diverse relationships between physical, social, cognitive, and emotional self and society can significantly impact life's trajectory (Brown et al., 2021; Hughes, 2021). Those who support the neurodiversity movement experience autistic traits as important and the autistic identity as fulfilling. Jim Sinclair (1993), an autistic advocate and activist, eloquently explained what it means to be autistic when he wrote:

> Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with (p. 1).

Within the current study, the neurodiversity paradigm is used as a model of understanding, interpreting, and respecting the participants' autistic identities and their experiences. Similar to Pellicano and den Houting (2021), I recognize their autistic traits as different ways of being human, not less. Additionally, the social model of disability is used within this study, as camouflaging may be an attempt to endure discrimination by hiding the autistic traits that may receive negative responses.

### ***What is Autism in Women?***

It is widely publicized that males are more often diagnosed with autism than females. This worldwide bias of autism diagnosis is prevalent with a ratio of 3-3.5:1 (Loomes et al., 2017; Posserud et al., 2021). Several theories have attempted to uncover the reasoning behind such an evident difference in diagnosis. The following section will outline three theories that address why autism seems to be more prevalent in males than in females.

**Female Protective Effect.** The Female Protective Effect (FPE) suggests that females require an increased autism-specific genetic load to meet diagnostic criteria for autism (Robinson et al., 2013; Tsai et al., 1981). In Tsai and colleagues (1981) research focusing on potential hereditary influences of autism, their results highlighted, within their sample, that autistic females have more relatives with autism than autistic males do. This more common hereditary influence suggests that autism-specific genetic loads more strongly impact autistic females through generations than autistic males (Tsai et al., 1981). Moreover, the higher the autism-specific genetic load within an individual, the more autistic traits are exhibited clearly and distinctly from 'normal' behaviour (Dworzynski et al., 2012; Ferri et al., 2018; Hull et al., 2020; Jacquemont et al., 2014; Robinson et al., 2013; Wigdor et al., 2021; Zhang et al., 2020). Autistic males have more genetic variability with a lessened mutational load than autistic females, ultimately resulting in the autistic traits of autistic males being more noticeable. Therefore, for autistic females to show autistic traits that are visible enough to warrant a diagnosis, the mutational load must be higher to offset the lessened genetic variability (Jacquemont et al., 2014; Robinson et al., 2013; Wigdor et al., 2021; Zhang et al., 2020). Based on the female protective effect, the genetics within females are essentially protecting the individual from receiving an autism diagnosis (Ferri et al., 2018; Wigdor et al., 2021).

**Extreme Male Brain Theory.** Simon Baron-Cohen (2002) proposed his contentious 'Extreme Male Brain theory' (EMB) to explain the gender bias in diagnosing autism. Baron-Cohen (2002) discusses how autistic males are more likely to have high 'systemizing' skills while autistic females have higher 'empathizing' skills. Baron-Cohen (2002) suggests the combination of low empathizing skills with high systemizing skills is common in males (compared to females) and autistic individuals in general (compared to non-autistic individuals). According to the diagnostic criteria of autism, those diagnosed with autism should have poor empathizing skills (e.g., deficits in social skills) and strong systemizing skills (e.g., restricted patterns of behaviour and interests). Therefore, autistic traits are further classified as hyper-masculinized and are more evident and common in masculine individuals (Baron-Cohen, 2009; Baron-Cohen, 2002; Baron-Cohen et al., 2011).

Recent literature confirms the EMB theory, suggesting that autistic males and females are more likely to show higher systemizing over empathizing skills (Greenberg et al., 2018). However, it is important to establish that not all autistic individuals are particularly unempathetic. In fact, Komeda (2015) found in their study on autistic empathy that autistic men and women both show significant empathy towards others, specifically towards other autistic individuals. As this theory highlights that the autistic brain is masculinized, the bias of autistic prevalence towards male-dominated diagnoses results from the assumption that to be autistic, you must be male or have a 'male brain' (Baron-Cohen, 2009; 2002).

**Female Autism Phenotype.** The final theory that may address the gender differences in autism diagnoses is that autistic symptomatology varies in presentation and intensity between males and females. Many of the behavioural variability that females exhibit may be less noticeable and result in a late diagnosis or misdiagnosis. For example, autistic women more often internalize their behaviours, likely due to the societal ideals that females should be passive and social in social settings (Bargiela et al., 2016; Hiller et al., 2014; Holtmann et al., 2007; Hull et al., 2020; Kirkovski et al., 2013; Van Wijngaarden-Cremers et al., 2014). A study conducted in Uganda by Bonney and colleagues (2021) found a statistically significant difference in the age of receiving an autism diagnosis when considering gender. In Uganda, cultural customs do not expect females to express social skills as much as men. These customs likely result in their deficits in social communication and interaction going unnoticed (Bonney et al., 2021). Although the expectations of gender may be different across cultures, autistic traits in women may still not be recognized because they do not explicitly match the diagnostic criteria of autism.

Moreover, autistic females may appear more neurotypical than autistic males by presenting 'normal' standards of social behaviours. Autistic females show better non-verbal communication (Rynkiewicz et al., 2016), higher social motivation (Sedgewick et al., 2019b), and less restricted and repetitive patterns of behaviour (Allely, 2019), and more special interests focused on relational topics (Grove et al., 2018). The intelligence quotient (IQ) of autistic females may also play a role in receiving a diagnosis, with several studies suggesting that a higher IQ is associated with being less likely to be diagnosed with autism (Allely, 2019; Ferri et al., 2018; Kirkovski et al., 2013; Siracusano et al., 2021; Van Wijngaarden-Cremers et al., 2014).

Furthermore, there seems to be some evidence suggesting that a female autism phenotype is present, but a plethora of research concludes that findings are inconsistent. In a systematic review conducted by Ferri and colleagues (2018), 19 studies were assessed for significant differences in restrictive and repetitive patterns of behaviours and interests (RRBI). Five studies concluded there was no significant difference in gender expression of RRBIs, while twelve suggested men exhibit more RRBIs than women (Ferri et al., 2018). Likewise, Osório et al. (2021) found females are more likely to be more significantly impacted by stimulating environments than men, while another study found no significant sex difference in sensory phenotypes (Scheerer et al., 2021). And finally, several studies found that autistic women exhibit lower executive functioning skills, while Demetriou et al. (2021) concluded that autistic women scored higher on measures of psychomotor speed, cognitive flexibility, verbal learning, memory, and semantic fluency.

Overall, the distinct gender bias in autism diagnoses is an important factor and can be explained by several research findings like the ones described above. Of course, in theory, any exhibited autistic traits may support a diagnosis of autism, but it can be hard to diagnose autism when an individual camouflages their autistic traits. Camouflaging has been suggested as a core facet of the female autism phenotype and will be discussed later in further detail as to how these traits are hidden or compensated for (Allely, 2019; Bargiela et al., 2016; Hull et al., 2020; Loomes et al., 2017).

## What is Camouflaging?

Camouflaging and masking refer to conscious and unconscious strategies we all use to blend into our social surroundings (Hull et al., 2017; Livingston & Happe, 2017; Robinson et al., 2020). However, autistic women often will feel pressured by society to suppress their internal traits to reduce the presence of autistic traits in a social environment (Hull et al., 2017; Livingston & Happe, 2017; Robinson et al., 2020). The following sections will highlight three main topics of discussion surrounding camouflaging among autistic women: (i) comparing the differences between masking and compensation, which are both terms often used synonymously with the term camouflaging; (ii) the underlying internal and external motivations of camouflaging; and (iii) the direct and indirect impacts of camouflaging on the well-being of autistic women.

### *Camouflaging Techniques*

**Masking.** Both autistic and non-autistic individuals use masking to regulate non-camouflaged social behaviours to fit into society (Livingston et al., 2020). For example, an autistic woman might reduce stimming in a social setting or not overshare or overindulge in a particular interest in public settings; especially if not doing so will decrease their success in fitting in. By wearing a mask and pretending to be someone else to fit in, some autistic individuals can present a different version of themselves to the world. By dampening the autistic traits that are not always accepted in society, one can become partially involved in social settings. For example, an autistic female could go to a party and ‘blend in’ but may not necessarily engage in meaningful conversations or activities. Autistic females may use pragmatic social skills (such as more gestures or long pauses in conversations) to mimic neurotypical social norms (Parish-Morris et al., 2017; Rynkiewicz et al., 2016).

Masking is less cognitively demanding than other camouflaging techniques and generally becomes automatic over time (Livingston et al., 2020). Hull and colleagues (2019) suggest that masking requires individuals to be aware of their impression on others. This approach requires regulating the behaviours they present or inhibit based on their environment. In a study by Hull et al. (2017), ninety-two adults with autism spectrum conditions (ASC) were asked to describe their masking experiences. Several participants suggested that they utilize masking to hide how their condition impacts their daily lives and hide the parts of themselves they were not satisfied with (Hull et al., 2017). Within the study, a typical scenario where autism affects someone's life is utilizing stimming for self-regulation (Hull et al., 2017). Some forms of stimming in the autism community include flapping hands rapidly, repeating words, shaking a knee, or making finger movements (Kapp et al., 2019). This behaviour may seem out of the ordinary for some non-autistic individuals who are unaware of the underlying motivations behind stimming. This notion may result in autistic individuals, who often stim, suppressing these behaviours to fit in and not draw attention to their 'unorthodox' attempts to self-regulate. By masking their diagnosis of autism, their reputation with others is managed, and they can blend into society more effectively.

**Compensation.** Compensation describes explicit alternative strategies that make up for perceived behavioural, social, or communicative skills gaps. For instance, an autistic individual may compensate for lacking social skills by using internal scripts that guide what to say in certain social situations. Compensation can be further examined by assessing the use of both shallow compensation and deep compensation. Shallow compensation involves producing neurotypical behaviour but not necessarily affecting the underlying cognitive difficulty (Livingston et al., 2020). Additionally, Livingston and colleagues (2019) describe shallow compensation as a surface-level compensation that is simple and inflexible. However, this form of compensation is generally more cognitively demanding than deep compensation and does not translate well in social scenarios when there are quick changes in conversation or environment (Livingston & Happé, 2017).

Furthermore, deep compensation is quite like shallow compensation concerning the production of neurotypical behaviour. However, deep compensation involves alternative routes to solve the behavioural, social, or communicative skills gap. This compensation method is much more complex and flexible in various social settings; with time, deep compensatory processes can become automatic and not be explained by a discrepancy in scores. Livingston and Happé (2017) provide an excellent description of the difference between shallow and deep compensation as follows:

> We suggest that 'shallow compensation' is akin to the use of a white stick by the visually impaired. It enables one to avoid obstacles, but does not go further in mimicking vision. By contrast, we suggest that echolocation would be 'deep compensation' as it allows the formation of a rich spatial representation (the end point of vision), albeit via a different route. (p. 735)

Equally important, the descriptions of shallow and deep compensation are not to say that all behaviours conducted by autistic individuals are timed and scripted to the point where they are not genuine. On the contrary, these camouflaging techniques simply support the individual in blending into their surroundings. To act accordingly to social rules by using scripts or guidelines, the individual can gradually learn to do so automatically and still find ways to incorporate their diversity into a social setting.

### *Measuring Camouflaging*

**Discrepancy Approach.** The discrepancy approach explicitly examines the 'discrepancy' between the behaviours presented by autistic individuals and their underlying abilities (Hull et al., 2020; Lai et al., 2018). For example, although autistic women are more likely to self-report autistic traits, these traits are not always present in a behavioural manner (Hull et al., 2017; Lai et al., 2011; Solomon et al., 2012). Additionally, the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS) have been utilized in studies regarding camouflaging and found the measured behaviours were discrepant with self-reported autistic traits (Lai et al., 2018; Lai et al., 2017).

In theory, if the discrepancies are not high, meaning that the autistic traits and behaviours self-reported are consistent with the autistic traits and behaviours observed, there is less reason to believe the individual is camouflaging those characteristics. On the other hand, measuring the discrepancies between self-reported or proxy-reported autistic traits can be hindered by the ability of the reporter to be aware of the characteristics and their impacts on their daily lives. Furthermore, although utilizing self-reports is beneficial for prioritizing the voice of the autistic self, the self-referential skills of the reporter may result in misinterpretation of questions or bias in answers (Kopp & Gilberg, 2011). Considering the limitations of discrepancy approaches, other researchers, including myself in this study, opt to pursue an observational/reflective approach to measuring camouflaging.

**Observational/Reflective Approach.** Measuring camouflaging with an observational/reflective approach includes identifying the camouflaging behaviour and strategies through observation. By doing so, camouflaging can be operationalized in terms of rates, techniques, processes, and experiences expressed by the autistic participants without placing significant value on which autistic traits are being camouflaged. With the observational/reflective approach, comparisons of camouflaging can be made between autistic individuals, specifically those of different gender identifications.

In a study by Hull et al. (2020), gender differences in self-reported camouflaging techniques were assessed using the Camouflaging Autistic Traits Questionnaire (CAT-Q). The CAT-Q, developed from the camouflaging experiences of autistic adults, asks the respondents to reflect on their camouflaging experiences utilizing compensation, masking, and assimilation strategies (Hull et al., 2019). Hull et al. (2020) concluded that autistic females camouflage more than autistic males and non-binary and female autistic participants showed increased use of masking and assimilation strategies. Still, the use of compensatory strategies is similar across genders. In addition, several other studies have supported the findings of gender differences in camouflaging strategies (Dean et al., 2017; Lai et al., 2018; Livingston & Happé, 2017; Schuck et al., 2019; Tubio-Fungeriño et al., 2020).

Overall, the discrepancy approach and the observational/reflective approach to measuring camouflaging are valuable; however, considering that the current study focuses on camouflaging experiences in autistic women, this thesis follows an observational/reflective approach to assessing camouflaging as a concept and phenomenon.

### *Motivations for Camouflaging*

**Internal Motivations.** One internal motivation that received much attention in the existing literature is ‘passing’ as a neurotypical. How individuals change their behaviour, appearance, or identity can vary based on their subjective understanding of what it means to be ‘neurotypical’. Furthermore, to fit into a neurotypical society often requires one to conform to social influences. Lazarro and colleagues (2018) conducted a study that conceptualized public and private conformity and how susceptible those with and without autism are to each concept. Their findings highlight that autistic individuals are similarly susceptible to social influence as neurotypical individuals are (Lazarro et al., 2018).

The difference between private and public conformity could help describe motivations for camouflaging. Specifically, public conformity can be for purely social gain and approval but maintain internal beliefs, while private conformity regards changing inner thoughts based on what others say. Although autistic individuals may do both, one rather than the other, or neither form of conformity, these concepts could explain the underlying motivations for camouflaging autistic traits or hiding an autistic identity (Lazarro et al., 2018).

Another internal motivation for camouflaging is the social motivation to develop and maintain social relationships (Cage & Troxwell-Whitman, 2019; Hull et al., 2017; Tubio-Fungeuriño et al., 2020). These relationships can be familial, peer, or romantic, and each may require camouflaging techniques that vary in effort expenditure. For example, autistic women generally spend more effort developing a relationship with girls than boys because of gossip in female relationships (Bargiela et al., 2016; Milner et al., 2019). The social nuances of gossip, fast conversations, and social conflicts are all noted as barriers to autistic women developing and maintaining relationships (Bargiela et al., 2016; Cook et al., 2018; Cridland et al., 2014; Milner et al., 2019).

The degree of need to utilize compensatory strategies and camouflage autistic traits that may impede the individual’s success with overcoming social inadequacies is much higher in female relationships than in social relationships with males (Bargiela et al., 2016; Cridland et al., 2014). Autistic women report these social relationships as more straightforward and less socially complex (Bargiela et al., 2016). In the case of Cridland et al. (2014), the girls expressed their special interests aligned more closely with the boys than other girls. Due to the reduced effort needed for women to have a social interaction with men rather than with other women, there is less need to camouflage autistic traits (Bargiela et al., 2016). Interestingly enough, Jedrzejewska and Dewey (2021) concluded that camouflaging to develop and maintain friendships is also prevalent throughout online settings. More specifically, male and female autistic individuals will mask autistic traits by conforming to gender and normalcy stereotypes to experience emotional support from their friends and be a part of a community (Jedrzejewska & Dewey, 2021). Overall, by masking socially undesirable behaviours, autistic adults can reduce their chances of standing out.

**External Motivations.** One common external motivation for camouflaging is to avoid bullying or discrimination due to the shame of diagnosis (Cage & Troxwell-Whitman, 2019; Hull et al., 2020). The lack of appreciation for neurodiversity in society is amplified when autistic individuals fear living authentically. Cage et al. (2018) found that 7% of the autistic adult participants in their study (n= 111) felt society generally accepted their autism diagnosis. Where acceptance is limited, being authentically autistic can breed conflict (Aubineau & Blicharska, 2020). One can avoid this conflict by blending in and assimilating to the social constructs.

Furthermore, autistic individuals may camouflage to seek employment opportunities (Livingston et al., 2019). Since autistic individuals often have negative vocational experiences when working in unaccommodating and accepting environments, camouflaging autistic traits can support the individual in accessing and maintaining vocational positions (Black et al., 2018; DePape & Lindsay, 2016; Tint & Weiss, 2018). For example, the expectations of an autistic prospective employee to sound polished and confident during an interview can be challenging to manage for an autistic adult (Sarrett, 2017). For those who decide to camouflage, scripts may be developed to answer common questions in an interview concisely and accurately.

Additionally, camouflaging may also be used to achieve academic success for students (DePape & Lindsay, 2016; Livingston et al., 2019). In an ethnographic analysis conducted by Moyse and Porter (2015), results concluded that there is a 'hidden curriculum' that autistic students may need to consider in addition to the required academic expectations. Navigating varying components of school (i.e., social interaction expectations and differing class rules) was difficult for the three participants in the study (Moyse & Porter, 2015). Evidently, being treated as autistic in schools can be beneficial as the students may receive services or interventions that could support their academic success. However, it can result in the student being segregated from the other students or being labelled as a distraction. Specifically, Moyse and Porter (2015) witnessed that, due to the students camouflaging their autistic traits and need for additional support, the teachers did not have any cause for concern regarding the student. Consequently, the student not being noticed contributed to her success in blending into her environment (Moyse & Porter, 2015).

All in all, an overarching motivation for autistic individuals to camouflage involves the fear of social isolation and discrimination due to the lack of acceptance of autism in the community (Cage & Troxwell-Whitman, 2019; Hull et al., 2020; Hull et al., 2017). The decision to camouflage will be determined by the degree of autism acceptance within the community and how comfortable the individual is with sharing their autism diagnosis (Hull et al., 2020).

### ***Gender Differences in Camouflaging***

Women and girls seem to camouflage more, best exemplified by the Female Autism Phenotype discussed earlier (Cook et al., 2018; Head et al., 2014; Hull et al., 2019; Lai et al., 2011; Tubio-Fungueriño et al., 2020; Wood-Downie et al., 2020). Furthermore, one reason explaining the difference in camouflaging rate is that males are less likely to compensate for their social communication deficits (Cook et al., 2018). This difference is possible due to gendered stereotypes that expect lower social communication from men than women (Cook et al., 2018; Hull et al., 2020). Conversely, autistic women and girls show higher compensation rates at all ages, often exhibiting higher engagement levels with their peers (Dean et al., 2017, Head et al., 2014, Tierney et al., 2016). Autistic girls will also make more attempts to mirror their neurotypical peers’ pragmatic and social reciprocity skills in hopes of establishing social relationships and avoiding discrimination due to their diagnosis (Parish-Morris et al., 2017; Rynkiewicz et al., 2016; van Ommeren et al., 2017).

## **What Does it Mean to Experience Well-Being for those on the Autism Spectrum?**

The construct of quality of life is vital to understanding the camouflaging experience of autistic women because research has suggested that camouflaging regularly significantly impacts the QoL of autistic individuals. Thus, I will begin this section by exploring the concepts of well-being and quality of life (QoL), specifically concerning autistic adults. In other words, I will explore what it means to experience well-being for those on the autism spectrum. Following this, I will discuss how camouflaging may lead to higher and lower QoL for autistic women.

### ***Quality of Life***

Quality of life as a model for well-being has been acknowledged as the best method for identifying and assessing the well-being of autistic individuals (McConachie et al., 2018). Harper (1998) and the World Health Organization Quality of Life (WHOQOL) Group define QoL as “individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (p. 551). Examples of a standard measure of QoL include the WHOQoL assessments, developed by the World Health Organization, to understand the impact of a disease or disorder on individuals' daily lives. For example, the WHOQoL-100 is a quantitative measure consisting of one-hundred questions that ask the individuals or a proxy to assess how their diagnosis impacts several domains of their daily lives, including physical, psychological, level of independence, social relationships, environment, and spiritual/personal beliefs.

A summative assessment can be used instead of the WHOQoL-100, the WHOQoL-BREF, which utilizes QoL domains but offers fewer items within the measure. Furthermore, from completing 26 items, scores will be assigned to the QoL domains of psychological health (e.g., self-esteem, positive/negative feelings, etc.), physical health (e.g., energy, fatigue, etc.), social health (personal relationships, social support, etc.), and environmental health (employment, accessibility to services, etc.). The scores received from completing the measure will ultimately enlighten the individuals about how their diagnoses impact their daily lives.

A subjective approach to understanding and assessing QoL was utilized throughout the current study. Objective QoL, or assessing well-being based on objective standards (i.e., salary, number of friends, etc.), is often used as a proxy report when studying QoL. De Vries and Guerts (2015) found that parents' perspectives of their children's QoL are more valid; however, several other studies state that subjective perspectives of QoL from autistic individuals' may be more reliable (Burgess & Gutstein, 2007; Hong et al., 2016). In addition, several studies have found that parents may view their children's QoL as lower than the child may subjectively respond (Burgess & Gutstein, 2007; Ikeda et al., 2014; Knüppel et al., 2018; van Heijst & Geurts, 2015). Moreover, subjective perspectives of QoL can provide more insight into the individual understanding of well-being than an objective measure of QoL (Smith et al., 2019). For example, an objective measure of QoL may determine that a higher number of friends indicates a higher QoL; however, the objective approach fails to acknowledge the quality of these friendships. Bishop-Fitzpatrick and colleagues (2016) argue this point further, concluding that reaching a good outcome can be achieved through multiple routes.

Although the currently available WHO-QoL measures show good internal consistency and reliability, the measure needs more exploration in the autistic community (McConachie et al., 2018; McConachie et al., 2020). More specifically, these measures often focus only on the objective, explicitly narrow-focused QoL and set standards for what scores indicate high QoL and low QoL (Waldock, 2019). In their review of the WHO-QoL-BREF measure, McConachie and colleagues (2018) highlight that many objective QoL topics can be interpreted differently. For example, a low QoL score may not indicate a low QoL from the respondent but an unsuitable QoL measure for the respondent to complete (McConachie et al., 2018). Therefore, in acknowledgement that QoL is a subjective phenomenon, I used the domains of the WHO-QoL BREF as a framework for understanding the impact of camouflaging on the individualized QoL of the participants. More insight into the process of incorporating subjective perspectives of QoL will be discussed in Chapter Three: Methodology.

### *Quality of Life in Autistic Individuals*

Current research suggests that the QoL of autistic individuals is significantly lower than typically developing adults worldwide (Ayres et al., 2018; Kamio et al., 2012; Mason et al., 2018; Saldaña et al., 2009; van Heijst & Guerts, 2015). In addition, outcomes of autistic individuals across the lifespan are poorer than those who are not autistic (Steinhausen et al., 2016), with autistic children scoring lower on QoL than neurotypical children (de Vries & Guerts, 2015; Ikeda et al., 2014). Moreover, several studies have found that QoL is generally consistent across age trajectories (Mason et al., 2018; van Heijst & Guerts, 2015); however, interventions that explicitly address QoL can lead to improvements in life outcomes (Skevington & Epton, 2018).

### *Impacts of Camouflaging*

**Mental and Physical Health.** Recent research has suggested that, although regular camouflaging can be beneficial in a variety of ways (Cassidy et al., 2019; Livingston et al., 2019; Webster & Garvis., 2017), some autistic women who regularly camouflage may experience issues when navigating how to identify within society (Cage & Troxwell-Whitman., 2019; Lai et al., 2017). The consistent maintenance of this 'façade of normality can result in exhaustion and feelings of worthlessness in autistic individuals (Lai et al., 2011; Livingston et al., 2019; Milton & Sims., 2016; Tint & Weiss., 2018). This dissolution of identity ultimately results in poor mental health, generally low quality of life (Hull et al., 2019), and an increased prevalence of anxiety and depression (Hull et al., 2019; Lai et al., 2011; Milton & Sims, 2016; Tierney et al., 2016; Tubio-Fungeuriño et al., 2020). In addition to the exhaustion experienced by autistic individuals who camouflage regularly (Milner et al., 2019), mimicking social behaviour from others can result in neurotypical males misunderstanding cues (Bargiela et al., 2016). Some participants expressed that their camouflaging attempts to blend in and mask autistic traits sometimes lead to unwanted sexual encounters and rape (Bargiela et al., 2016).

**Accessing and Receiving Services and Accommodations.** Furthermore, camouflaging has been reported to be a barrier to accessing and receiving social support, health care and academic support (Cook et al., 2018; Hull et al., 2017; Milner et al., 2019). By not seeming like they needed help or accommodations for their environment (i.e., reduced harsh lighting), it is difficult for teachers and healthcare workers to recognize autistic individuals may need additional support. More importantly, it is difficult for individuals to acknowledge that the autistic individual's current environment may not be suitable for reaching their full potential or staying healthy without the autistic individual stating so.

**Late Diagnosis.** Equally important, the use of camouflaging strategies has been attributed to the late diagnosis of autistic women (Cage & Troxwell-Whitman, 2019; Head et al., 2014; Hull et al., 2020; Hull et al., 2017; Tierney et al., 2016; Wood-Downie et al., 2020). As a result of camouflaging, clinicians may be reluctant to diagnose an individual with autism who does not, on a surface level, express the traits commonly witnessed in those with a clinical diagnosis. The outcome of a late diagnosis of autism has implications, aside from camouflaging, on the individual's QoL, including reduced access to healthcare services and identity formation complications (Cage & Troxwell-Whitman, 2019; Leedham et al., 2020).

# Chapter Three: Methodology

Qualitative researchers value the subjectivity of diverse and complex life experiences. Additionally, they attempt to understand and interpret data as it forms within a specific context (Braun & Clarke, 2013; Creswell & Poth, 2018). My study is grounded in interpretative phenomenological analysis (IPA), an idiographic approach focusing on how individuals make sense of their experiences, and Community Based Participation Research (CBPR) methods. More specifically, this methodology was chosen as it allowed me to collect a rich, detailed account of how five white female Canadian autistic women experience camouflaging in social environments. The following chapter will discuss four of the study's methodological topics. First, I will discuss the methodology of IPA and how I stayed in accordance with IPA guidelines. Next, I will discuss the Autistic Community Partnership. I will then focus on data collection and will conclude with a discussion on data analysis.

## Interpretative Phenomenological Analysis

IPA was created in response to behaviourism to address epistemological questions in mainstream psychology disciplines (Smith et al., 2009). Recently, it has become a commonly used practice in autism research because it provides a "useful framework for understanding how individuals experience autism" (Howard et al., 2019, p. 1874). IPA is well-suited to understanding the camouflaging experiences of my autistic participants because its approach to interpreting their experience, which treats each person as unique, ensures that each participant is viewed as the expert of their own experiences (Smith et al., 2009). IPA is also theorized to mitigate the double empathy problem (Howard et al., 2019). The double empathy problem suggests the diagnostic social deficit attributed to autism, specifically having difficulties understanding those who are different, is just as applicable to autistic individuals as it is to non-autistic individuals (Milton, 2012). Furthermore, IPA may mitigate the double empathy problem because it recognizes participants' expertise through its double hermeneutic interpretation process and its methodological standards for researcher reflexivity (Howard et al., 2019; Macleod, 2019; Milton, 2012; Pellicano et al., 2018; Smith et al., 2009).

### *Theoretical Underpinnings*

**Phenomenology.** Edmund Husserl and Martin Heidegger, 20th-century philosophers, were the pioneers of phenomenological research. Husserl (1970) developed descriptive phenomenology, which is grounded in carefully examining the experiences of an individual so that the essential qualities of their experience can be identified (Smith et al., 2009; Uemura, 2020). This process highlights the value of taking a 'phenomenological attitude,' looking past the objective aspects of the experience and reflecting on the subjective perceptions of individual descriptions of a phenomenon (Sass, 2021).

Husserl believes that the eidetic method of bracketing one's experiences of a phenomenon is crucial to uncovering the essence of the human experience (Smith, Flowers, & Larkin, 2009). To try and understand the nature of the phenomenon, one must separate themself from the world they know and begin to work through phenomenological reductions (Pietkiewicz & Smith, 2014). To start sorting through phenomenological reductions, the researcher takes the broader scope of the constructs and descriptions of a phenomenon and gradually reduces them into smaller units of knowledge (Pietkiewicz & Smith, 2014). Eventually, the researcher can separate the commonalities between their own experience of a phenomenon and the participant's experience and focus on how the experiences differ (Smith, Flowers, & Larkin, 2009). These reductions provide the researcher with a new perspective on the phenomenon that is not entirely clouded by their preconceived assumptions.

On the other hand, Heidegger (1962), a former student of Husserl, built upon Husserl's descriptive phenomenology by conceptualizing a relationship between phenomenology and interpretation. This approach focuses on how individuals attempt to interpret their world, bringing to attention the impact their assumptions and experiences can have on their interpretations of a phenomenon (Smith et al., 2009). While the objective of descriptive phenomenology is to provide a description and understanding of the experience, interpretative phenomenology focuses on how the individual interprets their experience (Smith et al., 2009; Uemura, 2020). According to Heidegger, the human experience is impacted by the consciousness of experience with the phenomena and the world contexts that affect our daily lives (Sass, 2021).

**Hermeneutics.** Hermeneutics, or the theory of interpretation, is primarily associated with the work of three researchers: Schleiermacher, Heidegger, and Gadamer (Smith et al., 2009). The hermeneutic circle, a multifaceted interpretative process, allows phenomenologists to highlight the conceptual 'parts' of an interpretation and how they can make up the whole. Smith and colleagues (2009) describe the double hermeneutic, or the double layer of interpretation, as inherent to an IPA study. This double hermeneutic is evident in an IPA final report where the researcher attempts to interpret and describe a phenomenon previously described by participant(s) that are also interpreting the phenomenon. Furthermore, the double hermeneutic circle includes the participant's first-hand experience and the researcher's interpretation as reported from their experientially-informed lens (Kafle, 2011; Smith et al., 2009). With the researcher and the participant taking on active roles in completing iterative reflections, the interpretations become more comprehensive and meaningful in understanding the analyzed phenomenon.

**Idiography.** Idiography, at its core, is founded on researchers assessing particular cases, enlisting in-depth analysis methods that focus on the personal detail of the experiences of a phenomenon in specific people in specific contexts (Smith et al., 2009). To produce a more insightful analysis in IPA, the researcher must work diligently to uncover the unique experience of one individual before moving on to another's experience using a case-by-case process. For this reason, IPA studies demonstrate their commitment to idiography by recruiting small, reasonably homogenous sample sizes (Smith et al., 2009). For example, within the current research, I ensure that each of the five participants' experiences of camouflaging is individually interpreted and analyzed before moving on to the next case.

#### ***Epistemological Assumptions.***

IPA methodology aligns closely with the theory of social constructivism. Listening to the subjective interpretations of participants' experiences and acknowledging that these experiences are unique, varied, and complex is a vital component of the IPA framework (Creswell & Poth, 2018). It is critical to assume that individual experiences are formed and influenced by their social, historical, and cultural lives. For instance, the experiences and subjective understanding of camouflaging in autistic women will likely differ from my understanding and experiences of camouflaging based on the diversity within our lives. In adherence to social constructivism, my understanding of the phenomenon is grounded in the participants' meanings allocated to the phenomenon (Creswell & Poth, 2018).

Additionally, I am aware of the contexts in which the participants are situated. These contexts differ from the contexts that I regularly experience, and I am mindful of how the difference in context impacts my interpretations based on cultural, personal, and historical experiences. By considering my assumptions when interpreting the experiences shared by the participants, I actively critique my ability to be reflexive in my interpretation.

## Description of Myself in Accordance with IPA

Qualitative research is most efficacious when the researcher is reflexive in their thoughts and interpretations surrounding the experiences of their participants (Goldspink & Engward, 2019; Smith et al., 2009). By actively acknowledging the researcher's prior and current biases, assumptions, and experiences, one can critique how the interpretation and reflection of the data may have been influenced by the self (Creswell & Poth, 2018; Smith et al., 2009). As I attempt to understand the experiences of camouflaging in autistic women, I am aware that my interpretation will be influenced by who I was, who I am, and who I want to become as an individual. Therefore, this section will provide a reflective description of my positionality within the autistic community and how my experiences will influence my understanding of camouflaging experiences in autistic women.

### *Personal Characteristics*

I am a white, cis-gender, heterosexual male in a heterosexual relationship. I do not identify with any official clinical diagnosis, and, notably, I do not have an official diagnosis of autism. I identify with my French-Canadian heritage, and I am a devoted Baptist. I am mindful that because I have privilege as a white, cis-gender, heterosexual male in Alberta, Canada, I do not have a concrete understanding of the experiences of camouflaging in autistic women. Additionally, like many other individuals, I camouflage; I camouflage my insecurities, special interests, religious faith, and political views. I recognize that what and how I camouflage may differ in some ways from others around me. A foundation of my morals is that I am obligated to attempt to understand the experiences of others before judgment. My understanding of autistic experience has been entirely based on the experiences shared by autistic individuals. I hope to continue sharing these experiences with others in an academic setting to encourage other privileged academic researchers to do the same.

### *Socioeconomic Status and Family of Origin*

I grew up in a middle-class neighbourhood in a middle-class family. My parents both held professional positions, my mother a nurse and my father a salesman, contributing to a dual-income household. Although no one in my immediate family has an official autism diagnosis, I am still privy to the impact of having a diagnosis from the DSM-5. More specifically, several of my family members experience mental health concerns and camouflage their concerns in society. I am aware that camouflaging autistic traits and mental health concerns are not comparable. Still, a common link between the two experiences is a personal need to hide a part of oneself to fit into society.

### *Educational, Work, and Volunteer Experiences*

Upon completing my honours undergraduate degree in psychology and youth and children studies, I started working with an academic studying the QoL of autistic families in Southern Ontario. I worked with the data for several months, learning that the quality of life in autistic individuals was shockingly poor. Furthermore, many participants in the study attributed their low QoL to not being entirely accepted in society for their authentic autistic selves.

After learning about the low QoL of autistic individuals, I pursued employment in a group home for autistic adults. Here, I could work to provide care and, hopefully, increase their QoL. It is important to note that this work environment was grounded in a medicalized, deficit model of disability. This experience consisted of improving their functioning, both concerning physical and mental support, so that the men in the home could eventually live independent lifestyles or move back home with family. Working at the group home was crucial to my understanding of autism; I learned that I did not feel comfortable fixing these men, but I would support them in whatever lifestyle that made them happiest. Although this work environment only consisted of working with autistic men, my understanding of QoL in autistic adults was clouded by the assumption that some autistic individuals have a very low QoL. I learned that some autistic individuals would not survive without additional support from staff or family in their homes.

When interpreting the impact camouflaging has on the participants' QoL, I actively bracketed my experience in the group home by reminding myself that each individual is different. I continue to develop my understanding of the QoL in autistic individuals and understand that my interpretation of the QoL of autistic individuals cannot be defined by those I work with and support.

Furthermore, I learned from working with these men that their autistic traits and behaviours were seldom accepted when presented openly in their community. These men did not camouflage their autistic traits; whether they exhibited autistic pride or did not know how to camouflage, I cannot know because they had limited communication skills that I could understand. Moreover, after witnessing these discriminatory social scenarios first-hand, I decided to pursue graduate studies in educational psychology, specifically special education.

As I started my graduate studies, I worked as a child development supervisor and a respite worker for autistic youth. My roles in both these positions were to provide support as expressed by the individuals and their parents, advocate for their needs in the community and social interactions, and continually create environments that are accepting,

My path toward understanding autism more comprehensively began when I started working in a research lab coordinated and established by my supervisor Dr. Heather Brown. As a research assistant in the lab, I began working collaboratively with several autistic research assistants and advocates for autistic acceptance in the community. I quickly learned that Dr. Brown and the autistic individuals associated with the lab all had similar narratives of not being accepted for their autistic selves at one time or another. Through listening to their experiences of social interactions, I learned that to avoid discrimination, they chose to mask their autistic traits, allowing them to blend in. I understand this concept to be synonymous with the phenomenon of camouflaging. However, I recognize that camouflaging is not specific to the autistic community and that I use camouflaging strategies in varying social interactions and environments.

While completing my graduate studies, I have continued to seek opportunities to understand how to support the autistic community. Specifically, I have worked on several research studies that address the first-hand accounts of autistic individuals directly impacted by discrimination and the lack of equity for success in a neurotypical society. I have completed several areas of coursework that outline rigorous methodological procedures that can be utilized to highlight the experiences of neurodivergent individuals. Additionally, I have worked as a research assistant for a study that promotes parent coaching in autistic families to ensure equitable access to services and addresses the individualized needs of all autistic children and youth in Canada. Throughout my graduate studies, I have been a teaching assistant for an undergraduate course that educates students on utilizing a neurodiversity approach to universal design for learning in elementary, middle, and high-school settings. In my experience, I have and will continue to approach situations with a neurodiversity perspective. I am aware of the privilege I hold as a white, male, neurotypical researcher, and I actively seek ways to use this privilege to advocate for the needs expressed by the autistic community.

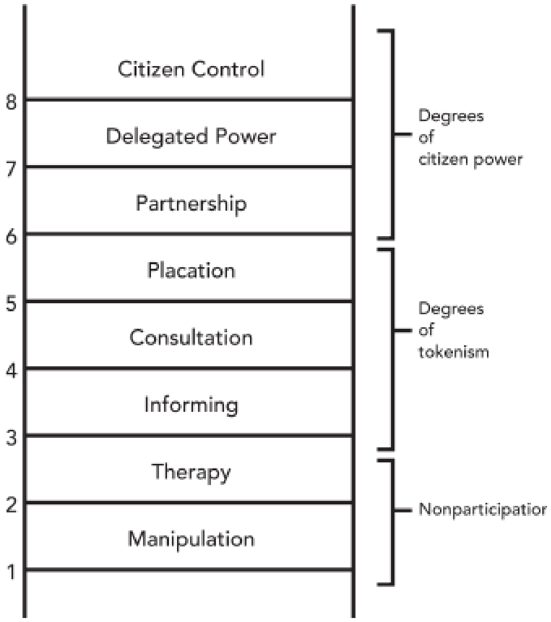
## Autistic Community Partnership

This section will describe the Autistic Community Partnership (ACP) and highlight the justification for establishing and partnering with an ACP and the roles and responsibilities of the partnership. Additionally, I will discuss the procedure for receiving and implementing feedback provided by the members of the partnership and a personal reflection on my experience working with an ACP throughout the study. Before proceeding with descriptions of the ACP, I will describe the model of participatory research that was adhered to within the study.

### *Arnstein's Ladder*

**Figure 1**

*Ladder of Citizen Participation (Arnstein, 1969)*



Arnstein (1969) highlights the value of improving citizen participation in political and community macro and micro system initiatives. For improvements to be evident, power must be given to community members to ensure they participate in a meaningful way. The lower rungs of the Ladder of Citizen Participation diminish the power of community members and ultimately do not allow for active contribution that is meaningful to the participants. However, the Degrees of Citizen Power highlight circumstances where the community members are either partners or have complete control when making decisions that directly affect their livelihood. The current study was developed to provide members of the female autistic community with a partnership where participation was valued, and power was equally shared.

In keeping with the collaborative nature of CBPR and the partnership, a gannt chart outlining the task completion process and who was responsible for completing each task is provided below. Notably, Dr. Heather Brown and Dr. Veronica Smith provided ongoing guidance and editorial support throughout the study.

**Table 1**

*Task Completion and Support*

| | Apr-Jun 2021 | Jul-Sept 2020 | Oct-Dec 2020 | Jan-Mar 2021 | Apr-Jun 2021 | Jul-Sept 2021 | Oct-Dec 2021 | Jan-Mar 2022 | Apr-Jun 2022 | Jul-Aug 2022 |
|---|---|---|---|---|---|---|---|---|---|---|
| **Research Design** | | | | | | | | | | |
| Creation of Study Materials | 🟦 | 🟦 | | | | | | | | |
| Review and Editing of Study Materials | 🟩 | 🟩 | | | | | | | | |
| Recruitment of Participants | | | 🟥 | | | | | | | |
| Development of Ethics Application | 🟩 | 🟩 | | | | | | | | |
| | | | | | | | | | | |
| **Data Collection** | | | | | | | | | | |
| Collection of Camouflaging Journals | | | 🟦 | 🟦 | 🟦 | | | | | |
| Completion of Interviews with participants | | | | 🟨 | 🟨 | 🟨 | | | | |
| | | | | | | | | | | |
| **Data Analysis** | | | | | | | | | | |
| IPA coding and creation of themes | | | | 🟦 | 🟦 | 🟦 | 🟦 | | | |
| Creation of member checking presentations | | | | 🟦 | 🟦 | 🟦 | 🟦 | | | |
| Review of member checking presentations | | | | | | 🟩 | 🟩 | | | |
| Creation of subordinate themes for all participants | | | | | | | | 🟦 | | |
| Review and editing of final data presented in paper | | | | | | | | 🟩 | | |
| | | | | | | | | | | |
| **Writing of Thesis** | | | | 🟦 | 🟦 | 🟦 | 🟦 | 🟦 | 🟦 | 🟦 |

Blue = Tasks I completed alone

Red = Tasks Dr. Brown completed alone

Yellow = Tasks Dr. Brown and I completed

Green = Tasks completed with the ACP and Dr. Brown

## Justification for an Autistic Community Partnership

The decision to establish an Autistic Community Partnership was four-fold. First, as an emerging, non-autistic academic, it seemed appropriate to consult with those who understand the experiences of the study sample. Furthermore, while developing the study, I was unaware of what autistic women wanted to see in research until I listened to what autistic women had to say. Although I do not situate my understanding of autism with the medical model of disability, often, research that fails to acknowledge and celebrate the value of autistic experiences can further stigmatize what it means to be autistic (Fletcher-Watson et al., 2017; Gillespie-Lynch et al., 2017; Nicolaidis, 2012). The ACP members' expertise and guidance through lived experiences is invaluable, as it helps me acknowledge my neurotypical privilege. With the ACP members sharing similar experiences with the participants, I was informed about how autistic women in the community will interpret this study.

Second, collaboration with those who have lived experiences ensures that the study is grounded in and addresses the needs and concerns of autistic women (Howard et al., 2019; MacLeod, 2019). Additionally, the input shared by the ACP helped fine-tune my ability to utilize best practices for working with autistic participants. I will further discuss these best practices below.

Third, all four ACP members expressed their concerns that the current majority of autistic research depicts a largely male-based conversation, resulting in a biased understanding of autism and its manifestations (Milner et al, 2019). They had expressed that there should be more opportunities for autistic women to make a meaningful change to literature that highlights neurodiversity and promotes acceptance of autistic women. Thus, the inclusion of four cis-gender female autistic advisors working collaboratively to disseminate the experiences of autistic women will assist in a meaningful narrative change within the autistic literature.

Finally, the ACP was created to align the study with participatory and Critical Autistic Studies frameworks. As mentioned earlier, studies that utilize these frameworks highlight the vital elements central to meaningful contributions (MacLeod, 2019; Pellicano et al., 2014; Nicolaidis et al., 2011). The purpose of working with the ACP is to ensure this research is making active contributions to a more directed, impactful stream of research for the autistic community.

All ACP members were recruited through previous work experience and already established relationships with my supervisor, Dr. Heather Brown. Dr. Brown and I contacted the ACP members via email and discussed the position's roles, responsibilities and compensation. As a result, only the four members listed below were contacted and recruited. Before I progress to the above topics, the personal descriptions of each ACP member are provided below. I provided some prompts for the members to reflect on (i.e., name, background of research, education, and work experience) and an invitation for them to add any information they thought readers should know about them. Below are the descriptions of Jackie, Laura, Christina, and Emily.

### *Descriptions of ACP Members*

**Jackie.** Jackie is a Ph.D. candidate in Rehabilitation Science at the University of Alberta. Her research is on understanding autonomy and autonomy-support from the perspective of autistic adults with intellectual disabilities using a community-based participatory research approach. She is passionate about the inclusion of autistic people in all that affects them, including research, policy-setting, and service provision. Jackie views autism with a neurodiversity lens and is interested in recent research that calls into question the assumption that autistic individuals struggle with social communication and that perhaps it is a two-way problem.

**Laura.** My name is Laura Gilmour. I am a Ph.D. candidate in educational psychology. I have a Master's degree in special education and a Bachelor's of psychology. I am also autistic. Additionally, I wish for a society where people are respected for the individuals they are versus being expected to assimilate. However, I recognize certain knowledge and behaviours are important for surviving in Canadian society. I am trained mostly in program development in the Psychological Studies in Education program.

My current research focuses on the intersection between autism and culture and creating effective dialogue on diversity in classroom settings.  In addition, I like to have a general awareness of autism research outside of my area so I can understand issues discussed in advocacy groups and where the science stands on these issues. I also think it is important when on an advisory committee to be able to say "I don't know" or "I need to research this further."  Research and life experience bring as much to the table as being autistic, possibly more.

**Christina.** Christina is a Registered Social Service Worker entering her final year in the Disability Studies program at Ryerson University. She has won several awards for her commitment to advancing society's understanding of equality and inclusion. Christina also holds a BA in philosophy from the University of Guelph and is currently enrolled in her 14th psychology course. She dreams of pursuing a Master's degree if she can figure out a way to fund it. She has worked with and for the Autistic community for almost a decade fighting for disability and greater social justice. As a cis, straight, white woman who has had the privilege of pursuing post-secondary education, Christina acknowledges that her lived experience does not represent the diversity of Autistic experience or that of being a woman. She strives to bring an intersectional perspective to this project through her theoretical teachings in school and by following the work of BIPOC and other multiply marginalized Autistic folks.

**Emily.** Emily is an autistic academic researcher currently working at the University of Victoria. Her research interests lay within the progression of autism narratives in academic research. She is passionate about using mixed methods approaches to research, specifically grounded theory and thematic analysis. She aims to provide both a personal autistic and academic lens to this given research project.

### *Roles and Responsibilities of Autistic Community Partners*

The primary roles of the ACP were to co-develop the research study and provide feedback for the varying stages from project development to dissemination. As a partnership, all decisions were made unanimously, and the study stages did not move forward until there was complete agreement. Individual responsibilities, preferences for scheduled meetings, and content for those meetings were established early as a group. The ACP read the content and created notes regarding several components we wanted to ensure. Furthermore, at different stages of the study, suggestions and input were collected from the ACP and incorporated into the study when possible.

## Model of Collaborative Practice

### *Step 1: Develop Study Materials*

To begin, I developed the study materials, including the: consent form, letter of initial contact, camouflaging journal, and interview schedule. This step provided a flexible framework for the committee to work with, offering them materials to critique and adapt to improve the quality of the study for autistic participants.

### *Step 2: Send Documents for Review*

At this stage, I determined what topics I would like to discuss within the upcoming meeting and attached all relevant materials to an email. Within this email, I also provided a semi-structured agenda highlighting what topics were likely to come up, and offered several dates and times that the ACP members could choose that stated their availability.

### *Step 3: Meet with the Autistic Community Partnership*

I began each meeting with casual conversation, asking each ACP member about their current work or research and how they were doing. Once the casual discussion was completed, I briefly outlined the objectives of the meeting. Next, I asked the ACP if there was something specific that they would like to address during the meeting. Furthermore, I organized the meeting based on the specific study materials that the meeting would address. I invited each committee member to open the documents, while I also shared my screen so that anyone having difficulty accessing the file could still see the material. Next, each ACP member would take turns sharing their feedback on the material. I encouraged the ACP members to build on what others were saying conversationally. Also, the group would not move forward until we agreed that moving on to the next item in the agenda was a productive step.

### *Step 4: Listen to and Reflect on Feedback*

Throughout the meeting with the ACP, I listened to the thoughts and constructive feedback that the committee members had for me. As a non-autistic man participating in discussion with autistic women, I reflected on how my perspectives of aspects within the study are interpreted from the ACP's point of view. Finally, I asked for clarification on any feedback proposed that would change study materials.

### *Step 5: Write Down Feedback and Make Necessary Changes*

In this stage, I took all the feedback from the ACP members and applied it to each study material. Additionally, I documented any advice the committee had regarding the interviews with the participants.

**Figure 2**

*Model of Collaborative Practice*

Notably, this cycle of collaborative practice with the ACP was ongoing throughout the study. Once any necessary changes were made to the components of the study, I ensured that I interpreted the feedback correctly by providing the newly adapted material to the ACP again. For example, if they informed me that the material is now appropriate for use with autistic women, I would send it to the participants. If, at any point, feedback was provided for study materials or other aspects of the study, I would begin the cycle once again. Below are some examples of changes that the ACP suggested. These examples are not exhaustive of all proposed changes, but they were quite meaningful in improving the quality of the study.

### ***Examples of ACP Proposed Changes***

**Suggestion 1: Inclusive Language.** One aspect of the study brought to the ACP for consideration was the usage of identity-first language. The language surrounding an autism diagnosis is an important topic to consider as each individual may prefer to be identified in their unique way (Botha et al., 2021). In light of this, there was concern that the title and recruitment materials for the study were not inclusive. If I chose to use person-first language (i.e., woman with autism), the risk of offending or excluding those who prefer to be acknowledged in an identity-first language (i.e. autistic woman) is increased, and vice-versa. Notably, all four ACP members and Dr. Brown identified as 'autistic,' highlighting an identity-first preference.

Moreover, the study's language use discussion revolved around the participants: what would the participants prefer? Therefore, when the participants begin the study, they are asked to state their preferred language. The study used this preferred language throughout all stages when referring to the participants. All the participants expressed that they preferred identity-first language throughout the study; however, if any had expressed that they preferred person-first language, I would have made the necessary adaptations to accommodate their preferences.

**Suggestion 2: Comfort Level of Participants in Interviews.** The second suggestion involved both Dr. Brown and I conducting the interviews together. Dr. Brown and I had considered this idea based on several ethical considerations. The first is that, although I had some experience conducting interviews, this experience was limited, while Dr. Brown's was quite extensive. Secondly, I believed that, ethically, I could understand if an autistic woman would not feel comfortable sharing her experiences of camouflaging one-on-one with a non-autistic male.

IPA is most effective when the participant feels comfortable and safe in their surroundings; therefore, having another woman in the interview would likely help them feel more comfortable (Smith et al., 2009). The ACP agreed that this approach to conducting the interviews was the best option. Although the interviews were conducted online, having Dr. Brown present for the interviews fostered an interview environment built on solidarity and validation.

## Data Collection

### *Selection Criteria and Recruitment*

IPA research uses purposeful sampling to conduct an in-depth interpretation of a relatively homogenous sample's experience of a phenomenon (Smith et al., 2009). Unlike other sampling methods, purposeful sampling is not random but is intended to select participants that can provide information-rich data on the research question(s) and objectives (Braun & Clarke, 2013). Generally, the sample sizes in qualitative research are small so that the researcher can provide an in-depth case-by-case analysis of the participants (Pietkiewicz & Smith, 2014; Smith, et al., 2009). Although there is no rigid outline for expected sample sizes in IPA studies, Smith et al. (2009) recommended recruiting three to six participants for newly introduced IPA researchers to avoid being overwhelmed by the amount of data collected.

In the present study, five autistic women, ranging in age from 18 to 35, were recruited. The inclusion criteria for the participants were as follows: (i) cis-gender female; (ii) aged 18-35 years old; (iii) prior diagnosis of autism; and (iv) self-report as 'high camouflagers.' 'High camouflagers' were defined by those who camouflage regularly, indicated on the self-report as answering either "All the time" or "Often." A relatively small age range was selected to ensure that the participants have similar life experiences that are likely to camouflage in various settings such as school, work, home, and other public locations. When using IPA, the sample should be fairly homogenous so that the case-by-case interpretations can be idiographic. Enlisting participants who are as close to similar as possible while still acknowledging that their experiences of camouflaging will differ allows for the interpretation of the phenomenon to be narrowed in on the intricacies of the phenomenon and less on the differences in participants (Smith et al., 2009). For the reasons previously stated, the selection criteria were created.

Participants were recruited via poster advertisements distributed within autism-specific groups on Facebook on January 15, 2021, and April 21, 2021 (Appendix A). Recruitment materials were posted on the following Facebook groups: (1) Autism Canada ASD Central; (2) Autism Society Alberta – Support Group; (3) A4A Ontario; (4) Neurodivergent Graduate Students; and (5) London Autistics Standing Together (L. A. S. T.). Within the second round of recruitment, Dr. Brown identified herself as an autistic researcher to bolster recruitment. As the Facebook groups were not accessible to those without an autism diagnosis or those with an autistic family member, I could not share the recruitment materials with these groups. For these reasons, Dr. Brown supported the recruitment of participants in online settings restricted to members of the autistic community. However, I instructed all interested participants to contact me by email with a statement of interest or any questions. In addition, I sent an information letter (Appendix B) to all prospective participants outlining the nature, objectives, and study tasks and a link to an online screening questionnaire that would further determine eligibility for participation (Appendix C). In total, 20 information letters were sent out to prospective participants, while 13 consent forms were returned (Appendix D).

Additionally, as a token of appreciation, all participants were compensated for their participation with a $50 online gift card of their choice. The compensation of autistic participants has been highlighted as both empowering and essential for increased participatory research (Fletcher-Watson et al., 2019; Gowen et al., 2019). Each participant was informed ahead of time that they would be compensated for their participation, regardless of full completion of study tasks.

### *Participant Journaling*

During the first data collection stage, I asked participants to reflect on their experiences of camouflaging on their own. These entries were submitted to me through Google Forms, and all participants were informed that their journal entries were going to be used to inform the interview process. and share these experiences in an online google form. I used participant journaling in the study to gain further insight into daily experiences. Journal entries often provide richness and detail to the interviews while respecting participant autonomy by providing minimally restrictive prompts and open-ended questions (Meth, 2003).

The camouflaging journals included instructions, asking participants to provide two to three entries about their experiences, feelings, and behaviours related to camouflaging. Four participants completed the journals within a two-week time frame (as I asked), and one completed the journal responses over a six-week period. Participants were provided with an 'information brief' outlining the guidelines they should follow when completing the journal entries (e.g., how often to record, how ideas will be used). The information brief also provided a series of prompts that the participants were invited to use when writing their reflections (Appendix E). Each participant completed three journal entries.

### ***Demographic Survey***

The following demographic descriptors were captured in a pre-interview survey: (i) highest level of education; (ii) employment status; (iii) co-occurring conditions; (iv) how central their autism diagnosis is to their identity; and (v) agreement with camouflaging definition. The demographic survey served two purposes in the study. The first purpose is to provide demographic information on the five autistic women in the study. The second purpose was to provide information I referred to in the interviews. For example, a statement describing camouflaging was provided in addition to the demographic descriptors described above. The participants were asked to express the degree to which they agreed or disagreed. If a participant did not agree with the statement or had another word for camouflaging, I used that information within the interview process.

### ***Semi-Structured Interview***

In the second data collection stage, each participant completed two individual, semi-structured interviews online via Zoom. Each participant was sent the interview schedule before the interview (see Table X. Interview questions) The interview schedule consisted of thirteen open-ended questions, with additional prompts added to facilitate in-depth reflection and discussion.  Norris and colleagues (2020) found that providing autistic individuals with the list of questions ahead of time made participants feel more comfortable and provided more accurate responses. Moreover, the interview schedule was a guide to promote fluid conversation and opportunities for more in-depth follow-up questions to arise.

**Table 2**

*Interview Schedule*

| Question | Follow-Up Question |
|---|---|
| Can you tell me about a recent time when you camouflaged? | What happened? How did you feel while camouflaging? How did you feel after camouflaging? |
| Can you tell me about a time when you attempted to camouflage, and it did not go the way you planned? | How did that make you feel? |
| How do you think people perceive you to be when you act as your authentic, autistic self? | Partner? Close friends? Parents or siblings? Work colleagues? |
| Can you describe how camouflaging affects your relations with other people? | Partner? Friends? Family? Work colleagues? |
| In what settings do you camouflage most? | Where? When? With whom? |
| Can you imagine a world in which you were completely accepted, and there was no need to camouflage? What do you think your life would look like? | |
| Assuming the world remained as it is, how might your life change if you never camouflaged? | |
| Can you describe how camouflaging affects your health? | Imagine a week where you spend a great deal of time camouflaging. Did your need to camouflage a great deal this week have an overall impact on your physical health?... Mental health? |
| Can you describe how camouflaging affects your access to health care (physical and mental)? | Examples of health care professionals may include: dentists, regular physicians, hospitals, massage therapists, pharmacies, etc.<br>How so? Can you tell me about a recent time when this was the case? |
| Can you describe how camouflaging affects the level of social support you receive? | Partner? Close friends? Parents or siblings? Work colleagues?<br>How so? Can you tell me about a recent time when this was the case? |
| How has the COVID-19 pandemic impacted your experience of camouflaging? | |
| If you were to go back in time and give advice to a younger version of yourself regarding camouflaging, what would that advice be? | |

| | |
|---|---|
| In summary, can you please tell me the most important ways camouflaging impacts your life? | |

Smith and colleagues (2009) stress the importance of developing a good rapport with the participant during the interview process because it allows the participant to feel supported, safe, and comfortable sharing their experiences of a phenomenon (Braun & Clarke, 2013; Smith et al., 2009). To build rapport, I began each interview with casual discussion (e.g., how school or work was going). I then assured the participant that confidentiality would be kept and that the interview process would be completed in a conversation-like style. Additionally, I reassured the participants that we would respect their wishes to either move on to the next question or conclude the interview if they felt uncomfortable, as Braun and Clarke (2013) suggested.

To continue, Pietkiewicz and Smith (2014) highlight the importance of being reflexive in the interview process and letting the participants speak about their experiences freely. Moreover, being reflexive or applying flexible thinking contributes to the participants' comfort level in sharing their experiences and my ability to be open-minded when interpreting the experiences within the interview process. To ensure that I was reflexive, I did not interrupt the participant to ask questions and always allowed the participant to speak on whatever came to mind. Finally, I deemed any conversation that arose in the interview valuable to the camouflaging experience. I did this because the participant discussing it implies that it is, in some way, related and meaningful to their understanding and interpretation of camouflaging in their life.

### *Social Responsiveness Scale (Second Edition)*

Following the interview, I sent each participant the Social Responsiveness Scale Second Edition (SRS-2) (Constantino & Gruber, 2012) to provide additional information on the participants' autistic traits. Notably, the individual results did not act as an exclusionary item of criteria but rather an additional demographic measure. The SRS-2 is a 65-item identifies the degree of social impairment by providing a T-score associated with five subscales: social awareness, social cognition, social communication, social motivation, and restricted interests and repetitive behaviour. Furthermore, each subscale has its respective questions. For example, the social motivation subscale total score is determined by the results of eleven items on the survey (e.g., 'I feel self-confident when interacting with others'). In comparison, twenty-two items explicitly examine social communication (e.g., 'I tend to be inflexible') (Constantino & Gruber, 2012). In addition to the individual score of the five subscales, the SRS-2 total score determines the degree of social deficits exhibited by the respondent (Bruni, 2014; Constantino & Gruber, 2012). A score of 60 or higher indicates that the person likely has autism.

## Data Analysis

When I approached the data analysis stage, I continually engaged myself in the data and idiographic research processes. Each case was treated as unique; therefore, each case was analyzed separately. While there are no explicit rules for data analysis when conducting an IPA study, Smith and colleagues (2009) provide five broad steps that I used to address my research objectives. I will outline these steps and provide examples of working through these steps below.

### *Step 1: Reading and Listening to the Participant Experience*

Before interpreting the data, I completely immersed myself in the data. This step included reading and re-reading the transcript and listening to the recorded interview to engage in the narrative actively. At this point in the analysis, I consulted notes that I made immediately after the interviews, highlighting my initial thoughts, feelings, and understandings of what I had just heard from the participant.

### *Step 2: Noting and Commenting on Participant Experience*

The second step involved directly commenting on the participant's experience, examining semantic content and language in an exploratory nature (Smith et al., 2009). Within this stage, Smith et al. (2009) provide suggestions for noting. They suggest I use three types of comments: descriptive, linguistic, and conceptual comments (Smith et al., 2009).

When creating descriptive comments, I described content that I interpreted as valuable to the experience of camouflaging. I took everything at face value with descriptive comments, highlighting how the participant described their experiences. As for linguistic comments, these notations pertained to the use of language by the participant throughout the interview. I highlighted and analyzed the usage of identifying information (i.e., autistic), metaphors and similes, and the diversity of language used to describe the experiences and impacts of camouflaging.

Finally, I applied conceptual comments throughout the transcript. These comments explicitly highlight the potential conceptual frameworks, motivations, or emotions associated with the experience. With conceptual comments, I was aware that veering away from explicit statements by the participant increases the chances of my experiences, previous knowledge, and beliefs impacting my analytic interpretations. I framed all of my conceptual comments as questions because it reminded me that the 'whole' of the experience can be divided into 'parts' that may address these questions.

For example, a conceptual note that highlights associations between autistic identity and camouflaging (the 'whole') may be addressed by other comments previously discussed in the interview (the 'parts'). Specifically, some examples may include the process described throughout the experience of receiving an autism diagnosis, the levels of acceptance when being their authentic autistic self, and feelings of self-worth as an individual.

### *Step 3: Developing Emergent Themes for Participant Experience*

Next, I reviewed and reflected on my annotations from the previous step, focusing on similarities between each comment to address the overarching research questions. Notably, I worked with both the transcript and my notes to conceptualize the participant's experience by using phrases from the participant's excerpts (Pietkiewicz & Smith, 2014). At this point, the emergent themes created were representative of the participant's experience begin to answer the research questions

Furthermore, the double hermeneutic described above becomes relevant, specifically with the positions of emic and etic within IPA analysis. While in the emic position, I prioritize the participant's view of the world and their interpretation of camouflaging experiences (Reid et al., 2005). As for the etic position, another hermeneutic circle becomes prominent when I begin to make sense of the participant's experiences to answer the research questions (Reid et al., 2005).

### *Step 4: Connecting Emergent Themes and Developing Subordinate Themes*

For this step, I made a list of all the emergent themes and created definitions for each theme. Additionally, I accompanied each theme with an excerpt from the transcript most representative of the participant's experience. This list of emergent themes and examples was created to keep track of all the data up to this point, reflect on which pieces overlap, and ensure that the participant's experience was still central to the data analysis steps.

At this point, I placed the emergent themes in chronological order and began assessing similarly defined themes. I moved forward with this process by eliminating themes that, in hindsight, did not accurately address the research questions and grouping themes that had similar definitions or answered identical components of the research questions. These themes were grouped, and subordinate themes were developed through abstraction. By assessing the summaries of the emergent themes, I grouped the similar themes into a more abstract conceptualization that more effectively answered the respective research question. Once the subordinate themes were developed, they were listed separately, and relevant excerpts from the transcripts were attached to them.

### *Step 5: Idiographic Analysis and Comparison Across Cases*

Aligning with the idiographic nature of IPA, once I completed the data analysis of the first participant, I moved on to the data analysis of the next participant and so on. All four steps previously outlined were completed with all participants. Once the data analysis stages were conducted with all five participants, I compared the subordinate themes of each participant's experiences, looking for similarities and differences in how they understand, experience, and interpret their respective camouflaging experiences. These subordinate themes were combined through abstraction to address the research questions by accurately representing the diversity and similarities between camouflage experiences and including relevant statements from the transcripts that most effectively reflect their individual experiences.

## Analyzing Data with the Autistic Community Partnership

In keeping collaborative with the ACP throughout all stages of the study, the ACP members were engaged in data analysis. Through discussions with the ACP members, it was determined that the ideal data analysis process was for me to complete the preliminary IPA data analysis steps listed above. Once the subordinate themes for each case were finished, I sent the data summaries to the ACP members and scheduled meetings to discuss the cases. During these meetings, we discussed four main topics: (i) was there anything in the data that interested or surprised the ACP members regarding camouflaging; (ii) how much did the experiences of camouflaging align with the ACP members' experiences of camouflaging; (iii) are there any similarities or differences noticed between the participants' experiences of camouflaging; and (iv) is any of the summarized data going to be detrimental to the autism community if disseminated.

The ACP members shared their insights and concerns with the data throughout the meetings. Notably, one finding from the research was determined to be of high "ick" factor by the ACP members, indicating that it could cause more harm than good for the autistic community if the finding were disseminated to the community. Therefore, this finding is not present in this thesis and will not be discussed in the future dissemination of this research.

In conclusion, the ACP members' feedback on the results aligned closely with my interpretations of the data. No changes were suggested regarding how I interpreted the data, but there were suggestions regarding which findings were most important to highlight in the research results. Chapter four highlights the current study's findings, and it is important to note that these findings were organized in collaboration with the ACP.

## Trustworthiness of Study

Next, I will describe how I addressed Yardley's (2000) four principles to ensure the study is trustworthy. These principles include: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

### *Sensitivity to Context*

I ensured that my study met this principle in three ways. First, I completed an up-to-date literature review of camouflaging in autistic communities and the quality of life of autistic women. This literature review above echoes several findings within the study and contributes to what is known thus far regarding the phenomenon of camouflaging. Secondly, I ensured that I was sensitive to the interactional nature of the interview process (Smith et al., 2009). I paid close attention to how the study context impacted the participant and treated the data analysis through an idiographic approach. When completing the data analysis, I kept the cases separate to specify the particular context for each camouflaging experience (Smith et al., 2009). Finally, I was sensitive to the study context by selecting verbatim excerpts from the participants' interviews when connecting their experiences to the research questions.

### *Commitment and Rigour*

Smith and colleagues (2009) describe commitment as the researcher's ability to be attentive to their participants throughout the study's data collection and analysis phases. I demonstrated commitment during data collection by regularly ensuring the participant was comfortable providing their camouflaging experiences. Also, I established an online setting that was supportive of the participant's needs by making sure the participants felt comfortable expressing any concerns they had. I also incorporated accommodations for the participants who wanted the questions ahead of time or needed additional time to answer the interview questions.

Furthermore, the study was conducted with a high degree of rigour through my ability to follow the outlined methodology as closely as possible. When establishing selection criteria for participants, I recruited an appropriate size and sample that could address the study objectives of understanding camouflaging experiences in autistic women. Additionally, I remained consistent with my interview process, allowing each participant to speak freely while staying relatively close to the interview schedule provided to the participants ahead of time. Finally, I stayed aligned with the idiographic component of IPA, addressing all five experiences of camouflaging separately to value the contextual differences in experiences and provide an in-depth analysis of individual experiences of camouflaging and the impact camouflaging has on their QoL.

### ***Transparency and Coherence***

In this paper, specifically this methodology chapter, I address transparency by providing a detailed description of the use of IPA for this research and outlining the steps I took throughout each step in the study. In addition, I have provided tables and models that summarize the participants' features, the process of working with the ACP, and the interview schedule.

Additionally, throughout this chapter, I present a coherent argument that using IPA is a logical approach to answering the research questions. Finally, throughout the research, I also discuss the similarities and differences between the participants' experiences, highlighting the themes that apply to some participants but not all.

### *Impact and Importance*

Yardley (2000) describes this principle of quality research as to how vital, engaging, and insightful the study is to the reader and literature. As mentioned within the literature review, there is a need to understand the experiences of camouflaging in autistic women and research to assess the impact that camouflaging can have on their QoL. With this study, although with a small sample, this research will make an impactful contribution to further understanding the experiences of camouflaging in autistic women, the impacts of camouflaging on QoL, and the benefits of providing autistic women with a voice in a research setting.

## **Ethical Considerations**

The current study received ethics approval from the University of Alberta's Research Ethics Board (REB 2). In adherence to ethical guidelines, all participants were treated with respect and dignity and informed that their study participation was completely voluntary. Each participant signed and returned a consent form outlining the study's description, purpose, procedures, risks and benefits, compensation, and commitment to confidentiality and anonymity. These consent forms and all other files containing identifying information were kept secure within a password-protected Google Drive folder. Each participant was reminded that they could stop the interview at any time or skip a question if necessary. All the transcriptions have been anonymized of any identifying information, and each participant chose a pseudonym to represent themselves within the study. Finally, all participants were informed that they would be compensated for their participation in the study. If they decided to withdraw, they would still be compensated, and all their data would be destroyed.

# Chapter Four: Results

This chapter details my interpretation of the experiences of camouflaging from five autistic women. In addition, this chapter will also report my interpretations of how camouflaging impacts the participants' quality of life. First, I will provide a demographic summary of the participants then summarize the themes that emerged from the interviews. Participants were identified by using "CAM" for camouflaging and a number that coincided with the order in which they were interviewed. When collecting data, 11 participants were interviewed as part of a larger study. In creating homogenous samples, five of the eleven participants were chosen for this study. The number attached to the participants' ID indicates the order in which they were interviewed. While some participants were comfortable sharing their name, I made the decision to de-identify the participants to ensure anonymity for those not comfortable sharing their names.

**Table 3**

*Demographic Information*

| Participant ID | Age Range | Province | Occupation | Highest Degree of Education | Co-Occurring Conditions |
|---|---|---|---|---|---|
| CAM 2 | 18-23 | British Columbia | Educator | High school | • Anxiety<br>• Depression<br>• Generalized Anxiety Disorder |
| CAM 3 | 24-29 | Ontario | Social Worker | Bachelors Degree | • Anxiety<br>• Generalized Anxiety Disorder<br>• Learning Disability (math) |

| | | | | | |
|---|---|---|---|---|---|
| CAM 6 | 24-29 | Ontario | Customer Service | College Diploma | - ADHD |
| CAM 7 | 18-23 | Alberta | Healthcare worker | Bachelors Degree | - Anxiety<br>- Depression<br>- Post-Traumatic Stress Disorder |
| CAM 11 | 24-29 | Nova Scotia | Customer Service | Bachelors Degree | - Anxiety<br>- Depression |

All five of my participants identified as cis-gendered females and preferred identity-first language. The participants ranged in age from 18 to 29 years old, with two participants between the ages of 18 and 23 and three participants between the ages of 24 and 29. All five women were attending post-secondary education in Canada while also working. Their places of employment varied significantly; one participant worked as an EMT while others were in customer service, educational or community support roles. All participants had at least one co-occurring condition, while three had three conditions. The most common co-occurring conditions are anxiety (n=4) and depression (n=3). All five participants met the threshold for autism according to their responses on the SRS-2 (i.e., all participants has SRS-2 Total T-Score at 75 or higher).

## Themes

Five themes emerged to answer the first research question, including: (i) descriptions of the phenomenon; (ii) motivations for camouflaging; (iii) learning to camouflage; (iv) camouflaging techniques; (v) navigating your autistic identity. The impacts were summarized across four domains from the WHO-QoL: (i) physical QoL; (ii) psychological QoL; (iii) social QoL; and (iv) environmental QoL. An additional theme regarding the experience of camouflaging when accessing healthcare is also included. Although all of the above subordinate themes are present in the experiences of all five participants, some emergent themes within each subordinate theme are not. Therefore, I will outline how common each emergent theme is present and which participants highlighted each of these themes in their shared individual experiences of camouflaging. Tables 4-9 illustrate the number of participants who endorsed each emergent theme.

**Table 4**

*Number of Participants Endorsing Emergent Themes from Theme 1*

| Participant ID | Camouflaging is Adaptive | Camouflaging is Subconscious | Camouflaging is a Privilege |
|---|---|---|---|
| CAM 2 | • | | • |
| CAM 3 | • | • | • |
| CAM 6 | • | | • |
| CAM 7 | • | • | • |
| CAM 11 | • | • | • |

**Table 5**

*Number of Participants Endorsing Emergent Themes from Theme 2*

| Participant ID | Avoidance | Fitting in | Camouflaging for Others | Camouflaging for Safety |
|---|---|---|---|---|
| CAM 2 | • | | • | |
| CAM 3 | • | • | • | • |
| CAM 6 | • | | • | • |
| CAM 7 | • | • | • | • |
| CAM 11 | • | • | • | • |

**Table 6**

*Number of Participants Endorsing Emergent Themes from Theme 3*

| Participant ID | Learning Expectations | Preparation and Routine |
|---|---|---|
| CAM 2 | • | • |
| CAM 3 | • | |
| CAM 6 | • | • |
| CAM 7 | • | • |
| CAM 11 | • | • |

**Table 7**

*Number of Participants Endorsing Emergent Themes from Theme 4*

| Participant ID | Suppressing Behaviours | Partial Camouflaging | Shallow Compensation | Deep Compensation | Regulating Intense Emotions | Masking |
|---|---|---|---|---|---|---|
| CAM 2 | • | • | • | | • | • |
| CAM 3 | • | • | • | • | • | |
| CAM 6 | • | | • | • | • | • |
| CAM 7 | • | • | • | • | • | • |
| CAM 11 | • | • | • | • | • | • |

**Table 8**

*Number of Participants Endorsing Emergent Themes from Theme 5*

| Participant ID | Autism is Central to Identity | External Acceptance | Neurodiverse Relatedness | Reducing Camouflaging |
|---|---|---|---|---|
| CAM 2 | • | • | • | • |
| CAM 3 | • | • | • | • |
| CAM 6 | • | • | • | • |
| CAM 7 | • | • | • | • |
| CAM 11 | • | • | • | • |

**Table 9**

*Number of Participants Endorsing Emergent Themes from Theme 6*

| Participant ID | Physical QoL | Psychological QoL | Camouflaging and Healthcare | Social QoL (Social Relationships) | Social QoL (Romantic Relationships) | Environmental QoL |
|---|---|---|---|---|---|---|
| CAM 2 | • | • | • | • | | • |
| CAM 3 | • | • | • | • | • | • |
| CAM 6 | • | • | • | • | • | • |
| CAM 7 | • | • | • | • | • | • |
| CAM 11 | • | • | • | • | • | • |

## Research Question 1

### Theme 1: Descriptions of Phenomenon

Within the first subordinate theme, three emergent themes identify the intricate and idiographic nature of how the participant describes the phenomenon of camouflaging. Therefore, this section will first summarize how each participant individually conceptualizes the phenomenon of camouflaging. Following these summaries, findings regarding three emergent themes will be presented. These three emergent themes are: (i) camouflaging is adaptive; (ii) camouflaging is subconscious; and (iii) camouflaging is a privilege.

#### *Individual Descriptions and Environments of Camouflaging*

**CAM 2.** CAM 2 described camouflaging in a variety of ways. CAM 2 understands the phenomenon of camouflaging as a mode utilized for "talking to people in a certain way.” The expectation of talking to people in a specific way was common in several environments, such as school, work, and with her roommates. However, she expressed that she does not camouflage as much at home by herself or with her family members, particularly her mother. She also defined camouflaging as a way to "separate [herself] from being autistic.” This interpretation of camouflaging is quite literal and highlights that she is not only hiding her autistic traits but actively separating herself from the autistic identity. This understanding may be evident when she decides to camouflage in a work or school setting where autism is not entirely accepted.

**CAM 3.** CAM 3 describes camouflaging as “going inconspicuously into any environment and adapting to it." This definition highlights how CAM 3 will camouflage in environments where there is a possibility that autistic traits or an autistic identity will draw unwanted attention to herself. The environments where CAM 3 camouflages are broad; aside from experiences with parents, she will camouflage regularly. For example, she shared that she will camouflage in various public settings, such as "when I'm grocery shopping, when I'm waiting for the bus, when I'm walking around campus." In addition, CAM 3 regularly camouflages at work and with her partner, stating: "I always camouflage… I don't think it's ever 100% not there. Unless I'm home by myself.” Although all five participants expressed that they camouflage all the time, CAM 3 is one participant that fully embodied that declaration through her camouflaging experiences shared in her interview.

**CAM 6.** CAM 6 described camouflaging as "pretending to be a person" and "learning how to be a part of the world." These camouflage descriptions highlight her feeling alienated from those who do not share the same lived experiences as her. She identifies camouflaging as a way to make her look like a person; she understands that external perceptions of autism include seeing autistic women as not equal or a part of the world. Camouflaging for CAM 6 is changing how she communicates with others to blend into the world and be recognized as a person. She sees camouflaging as a form of communication, stating: "I am not camouflaging my autism, I'm learning to speak neurotypical." Within her shared experiences of camouflaging, it is evident that her views on society are dichotomous; there are neurotypical people and neurodivergent people. If one is neurodivergent, they must use camouflaging to pretend to be a neurotypical individual and, if done successfully, they are accepted as "part of the world." She shared that she regularly camouflages during online school, work, with family, and essentially "anytime that I go outside… public transit, grocery shopping, anything that is very difficult and stressful.”

**CAM 7.** For CAM 7, camouflaging was defined as "pretending you're not who you are" and "acting the way" others expected her to act. Considering that CAM 7 believes that autism is central to her identity, camouflaging is a way to hide the autistic aspects of her identity and act differently. This acting is directly associated with meeting the expectations other people may hold for her in specific social interactions. Still, in doing so, CAM 7 acknowledges that to act "autistic" is not acceptable for that situation.

CAM 7 shared that she camouflages regularly in settings where people view autism as negative or weak, specifically in her work setting as a health care professional. She also described feelings of obligation to camouflage in school but not with her autistic sister and partner. However, she does camouflage with her family, stating that "none of my family has ever witnessed who I really am," indicating that she upholds her original definition of camouflaging by pretending to be someone else.

**CAM 11.** CAM 11 described camouflaging as "altering goal choices and activities to maybe lessen or hide autistic qualities." This camouflaging definition highlights that she will actively change her behaviours, plans, or aspirations for a particular event to create an ideal environment where autistic qualities are less visible.

CAM 11 also shared that she camouflages regularly in various settings, such as school, work, and in public. Regarding her camouflaging with family, she will camouflage more if there are other people with her, stating:

> If I'm around other people, so at that barbecue, we were with some family friends, so I was camouflaging then, but if it's just me and the family, I don't camouflage. We make a lot of jokes and everything, so it's great. We joke about a lot of things, so I'm allowed to talk nonsense or quote movies or flap my hands.

For CAM 11, camouflaging involves "faking it," acting like a "chameleon," and "pretending that everything is fine." As a result, if she camouflages by altering her behaviours to give the impression of "I know what I'm doing," she can subjectively succeed in school and work environments.

### ***Camouflaging is Adaptive***

Participants described camouflaging as an adaptive mechanism to blend into social surroundings. This behaviour may involve adapting how they present themselves, depending on the people they are with, the 'in the moment' threat of conflict, and what is said in the conversation. For example, CAM 3 described how she might adapt her camouflaging while on a date, stating:

> I know how much to camouflage based on a person's reaction, right? Like if I say, let's suppose I'm on a date, and the guy, I say, 'I'm autistic,' and he goes, [in a disgusted tone] 'oh … okay', like obviously, I'm not going to, I'm going to completely camouflage myself. Or if I got, if I have one who says, 'oh, that's cool, my sister's autistic,' or 'I have a

> friend who's on the spectrum,’ I can completely just let myself be and not, I don't have to camouflage

Likewise, CAM 2 and CAM 11 agreed that they adapt their camouflaging by changing their behaviours or language to be pleasant for those around them, specifically those who may cause conflict. CAM 2 described further how she might adapt her camouflaging with her roommates by choosing not to use chewlery to regulate intense emotions. However, if her roommates aren't home or in the room, she will use chewlery as she wishes.

According to the participants, camouflaging requires one to adapt to avoid negative experiences or to meet the changing expectations of others. It is a fluid social skill, and the adaptation that may surface because of the expectations of others will be different depending on the environment. CAM 7 highlighted this in her descriptions of what it was like to camouflage with people who didn't clearly understand what autism entailed, sharing that she uses camouflaging to "adapt to who I thought they wanted me to be."

Finally, CAM 6 echoed the value of adaptive camouflaging expressed by the other participants, stating that although she may "find new social situations challenging" and she's "the most unsettled by socializing… [she] can also adapt to it quickly.” This lack of comfort experienced in new social settings can be somewhat diminished by finding innovative and relatively unnoticeable ways to adapt behaviour to support them in completing a successful social interaction.

### ***Camouflaging is Subconscious***

Participants found that although camouflaging may take a lot of effort, they rarely notice if they are camouflaging their autistic traits in the first place. For example, CAM 7 shared that she had been camouflaging for four years in her job and "for the first three and a half years, [she] had no idea [she] was actually doing it." CAM 11 described camouflaging as a "habit" and "instinct," sharing that she has to "consciously think about not camouflaging" with people she feels comfortable sharing her autistic identity.

Finally, CAM 3 shared this experience: "I don't know that I'm doing it, because it's such a part of my being now, it's subconscious." Camouflaging consistently for years in most environments has made it difficult to discern at what point camouflaging starts and stops throughout a day of interacting. The subconscious nature of camouflaging is reflected in the habits of the participants, with CAM 7 sharing that camouflaging is "almost automatic" and does not require a lot of "conscious thought" to be successful.

### ***Camouflaging is a Privilege***

All participants viewed the ability to camouflage as a privilege; as CAM 3 stated, it’s "important to me and autistic people in general." CAM 2 discussed how her ability to camouflage helps her potentially avoid more negative perceptions of others, stating that for those that can't camouflage as well or as often, it likely "has affected how people perceive them even more." CAM 11 echoed this as she noticed a difference in how people perceived her when she camouflaged less than how often she camouflages now. She, like many of the other participants, described herself as more "socially developed" than others, and that helps her avoid some perceptions that other people may have if she stopped "working 150% on them" and started working "on them like 80%.”

CAM 7 described camouflaging as a privilege because it helps those overloaded with sensory draw less attention to themselves. The additional attention brought to someone having a meltdown due to excess negative stimulation would only cause more stimulation and make the scenario worse for the autistic individual. CAM 7 went on to share how camouflaging has been a privilege to her, stating

> being able to hide that [overstimulation] has given me the life I have today. Like, if I wasn't able to hide that, people, people can't always camouflage, and they can't always camouflage as well as I do. Like, it's huge impact on who I am

Finally, CAM 6 discussed how camouflaging as an autistic woman comes with its own concerns and "trauma," but in thinking long-term, "having the ability to do it is something that's always going to be a benefit." The concept of camouflage ability came up frequently as a descriptor of camouflaging across all participants' experiences. Camouflaging is a skill, and the ability to hide certain parts of oneself to have more enjoyable and productive social interactions is something the participants don't take for granted.

## Theme 2: Motivations for Camouflaging

### *Internal Motivations to Camouflage*

**Avoidance.** All participants expressed that an internal motivation to camouflage involved avoiding a negative experience. In the opinion of CAM 3, there is shame associated with stimming and displaying autistic traits. She decides to camouflage in specific scenarios because, as she stated, "it's embarrassing to see how people stare at us, or make off-handed comments, and you know they're commenting on it." The shame associated with choosing not to camouflage ultimately motivated CAM 3 to camouflage more. This experience was highlighted as well by CAM 6, where she avoids the negative emotions that may come with others, such as teachers, saying that her stimming was "a distraction."

CAM 7 discussed that often she will camouflage to avoid conflict with others. She went on to share how she feels when she tries to share her opinions with others, stating

> There's no point in arguing and making your life more difficult to actually like, say what you believe… because, these people, they don't… or even the way you are, you don't get the same respect for the opinions you have. You, it's just way easier to just be 'yeah, sure. Whatever'. Like, it's just easier

Finally, both CAM 2 and CAM 11 shared that they camouflage to avoid being "alienated" or to "bring attention" to themselves in a negative way. Specifically, CAM 11 shared that she experienced being alienated in the past, resulting in her being left out of future social interactions or treated differently when she was seldom included. She elaborated on this worry of being treated differently, stating, "I just don't want people to see the absolute worst side of me." Evidently, CAM 11 camouflages to avoid being avoided by her peers, while CAM 2 shared that she camouflages to avoid bringing unwanted attention to herself and being labelled with negative autistic labels.

**Fitting in.** All the participants expressed the decision to camouflage to fit in. CAM 2 shared that she explicitly "masked to fit in" in previous social interactions. Of course, the concept of pretending to be someone else was not an ideal option for the participants. CAM 3 summarized in her interview that sometimes, "you go along to get along" and CAM 6 echoed this, stating,

> Mostly, I think that it's just trying to survive in a world that wasn't really built for people who think the way you do and that you shouldn't feel bad about doing what you have to do to get through that… really depends on the situation

For CAM 7, the motivation to fit in was strong because she felt that who she was when not camouflaging would not be included. She elaborated, "I learned it because I was constantly trying to fit in. I was constantly trying to not be this weird person that I thought I was.” This feeling of being different from others when not camouflaging was also mentioned by CAM 11, stating that she knew her social skills needed work and she needed to work on that because she "wanted to fit in"

### *External Motivations to Camouflage*

**Camouflaging for Others.** There was a strong motivation to camouflage certain autistic traits, particularly stimming, in the presence of others for the benefit of others. All five participants stimmed regularly and acknowledged that stimming around neurotypical people could make those around them feel "uncomfortable." For these reasons, CAM 3 and CAM 6 specifically mentioned that they camouflage to avoid making other people uncomfortable. At the same time, CAM 2 shared that she camouflages her stimming around her young nephew because she doesn't "want to scare him yet."

CAM 11 did mention that she camouflages her stimming regularly. Still, she also shared that she will camouflage the negative feelings she may be experiencing to make other people feel better. Specifically, she shared an experience with her co-worker, stating:

> Even if we just like start off and, like, I can, say if I go up to my friend, I could already tell that she's kind of like in a down and out mood. Then I could, I can shift my attitude to be like more up beat and cheery, to try and help her. So even if I'm feeling pretty shitty myself like I still do that for her

CAM 7 elaborated on how the motivation to camouflage for the benefit of others may seem noble, but it's not always the best option for the individual camouflaging. Considering the effort required to camouflage to ensure everyone around her is having the experience that they should or need to be having, she shared that she does it, but went on to say, "if I didn't have to, I wouldn't."

**Camouflaging for Safety.** All but one participant shared that a solid motivation to camouflage involves safety. Specifically, CAM 3 highlighted how her decision to camouflage keeps her safe, stating:

> I think it keeps me safe [nods]. I think it keeps me safe. Um, I think I, I get, it's kind of like a, it's like a curtain, and it disguises, it hides me from … I guess the prying eyes of people who are not as educated, or judgmental, or not as informed about autism, or really anyone different in general.

CAM 6 elaborated further regarding how camouflaging as an autistic female can provide additional safety for her and others.

> It's also like a safety thing. And I think that there's this weird intersection of like the fact that I present as really feminine. The fact that I'm white, that I live in like an upper-class neighborhood, if I'm, if I ever lose the ability to camouflage, I'm also protected by those things. I'm never a threat. And being able to camouflage on top of that just adds to the level of protection that like I don't really have to worry about the things other people have to worry about.

As CAM 3 and CAM 6 shared that camouflaging can provide safety in the moment of a social interaction, CAM 7 and CAM 11 discussed how camouflaging could keep them safe until they get to a safe environment. CAM 7 and CAM 11 both shared that when they experience sensory overload, they need a safe place to be themselves and manage the stress they endured in the moment. Specifically, CAM 7 shared an experience of going into sensory overload and managing the pain to a certain extent, stating, "as soon as I'm in a safe place, I shut down, I have a meltdown." Likewise, CAM 11 shared that she likes being in her lab because it doesn't provide too much sensory overload, "it's quiet," and she doesn't "have to bother with people," making it "safe" to be her "autistic self."

## Theme 3: Learning to Camouflage

### *Learning Expectations*

All participants expressed that one of the first steps to learning how to camouflage is understanding what expectations need to be met in specific social interactions. For some participants, like CAM 2 and CAM 6, these expectations are learned with the help of roommates. CAM 2 had a less positive experience than CAM 6 when learning social expectations, sharing, "my roommates, they said a very interesting thing, where I have to make eye contact with them, or else I'm being very rude." These were expectations that the roommates had for CAM 2, and she shared that she has taken this suggestion and applied it to other social interactions. CAM 6's experience of learning expectations with the help of roommates was focused on online social interactions. She shared her experiences of learning expectations for texting, also describing her confusion with the logic behind the expectation.

> The other day, my roommate told me that people, if they're texting somebody, and the person doesn't reply for a little while, and then they reply late at night, you're not supposed to text them back immediately, even if you have already seen their text. And I

> think that that's dumb, because if I wanted to, to get a response tomorrow, I would have sent a carrier pigeon, not a text message

For the other participants, the learning of social expectations came without explicit support from others; they had to learn on their own through their experiences. For example, CAM 11 shared that she spent her time "studying other people to learn social patterns." In contrast, CAM 7 shared that after spending time in a previously unsuccessful relationship, she knows "what not to do now, like don't do that."

CAM 3 and CAM 11 elaborated on how difficult it can be to learn these social expectations. As the only participant who camouflaged in the United Kingdom (UK), CAM 11 frequently discussed that the contextual differences in social expectations between the UK and Canada made it difficult to camouflage successfully. CAM 3 elaborated on the challenges of camouflaging successfully by highlighting the strict and complicated expectations that someone who camouflages regularly needs to consider, stating "you don't do this, you don't do this, you don't do this, you don't do this, you don't do this, you can do this, but you can't do this.” CAM 3 learned how to discern what to do and what not to do through her experience with cadets. She elaborated on how her experience with cadets helped her learn how to camouflage, stating, "cadets in a way kind of gave me a manual for how to interact with other people and how to disguise my autism, which sounds really toxic and negative but it wasn't. It gave me survival skills."

The experience of learning expectations through experience was also mentioned by CAM 6 and CAM 11. CAM 6 shared that throughout her work in customer service, she has determined that specific scripts yield more successful camouflaging experiences. In contrast, other scripts may not achieve the outcome she is hoping for. By gaining experience, she has learned the social expectations and camouflaging strategies that are best to use in each social scenario. Likewise, CAM 11 learned through watching media, observing what characters on a reality tv show said and did, and gradually learned how each expectation the character was experiencing was addressed with a social skill. As a result, the social skills she watched others use became camouflaging techniques, and she now uses them regularly.

### ***Preparation and Routine***

Camouflaging preparation and routines were a big part of the camouflaging experiences of the participants. Through practice and learning how to camouflage, routines are developed to improve camouflaging success rate. Additionally, preparation for social interactions requiring camouflaging was considered necessary as it kept all participants ready for the various social interactions they could encounter in a social environment. For example, CAM 6 shared that before she goes out on a date, she will get together with her roommates and discuss the possibilities for how the date could go. She elaborated, describing the questions she and her roommates might consider asking: "how do we handle this? Like, what, what signals am I looking for? Are we supposed to hold hands? And are we going to kiss at this date?"

CAM 2 and CAM 6 had a similar approach to preparing for a social interaction where they may need to camouflage. For example, CAM 2 discussed that she has "prepared for the 'tell me about yourself" question before job interviews and other questions that may come up. Additionally, CAM 7 shared that preparing for camouflaging involved "a lot of playing, like conversations in my head, and attempting to see every possible direction they could go in and have a response for that."

Camouflaging preparation for CAM 11 looked similar to CAM 7's approach to preparing for a period of camouflaging; however, CAM 11 described hers in great detail. She described it as such:

> I can like picture somebody and I could have like a whole conversation with them planning out what I want to say if, for instance, if I want to talk to my professor about something I'll like picture in my head and like make a script basically of exactly what I want to say and kind of project what he likely will react with because I know him well enough to do that. And then, with again the flow chart that's basically just another program with my language so just, I could probably actually write it in coding language but basically if group then one, you know. If no group, then zero equals zero. So that's like a whole other length, it's just a code, I see as a code almost.

Recognizing that the context of this study takes place during the COVID-19 pandemic, the concept of routine change was discussed. All participants shared that the COVID-19 pandemic significantly impacted their camouflaging experiences because the preparation and routine aspects of camouflaging were, as CAM 11 put it, "obliterated." Before COVID-19, the routines were well established, and preparation was not impacted by constantly changing public health restrictions. During data collection, the participants were settled into their new routines based on COVID-19 lifestyles.

## Theme 4: Camouflaging Techniques

### *Suppressing Behaviours*

All participants shared that they regularly camouflage by suppressing behaviours. These behaviours were often described as those that others found odd or were considered socially inappropriate for the situation. For example, all the participants shared that they suppressed their stimming, while CAM 3 described when she suppressed her disgust towards a particular smell. CAM 3 had to suppress the urge to "gag cause of the smell," with the knowledge that gagging in a public place would draw unwanted attention.

### ***Partial Camouflaging***

Several of the participants shared that they utilized some form of partial camouflaging throughout their camouflaging experiences. Partial camouflaging may include camouflaging certain aspects of one's behaviour or identity but not others. CAM 11 described her camouflaging experiences as "baseline camouflaging" and "added camouflaging." She elaborates, stating

> I sort of have like a base, so I think what you're talking about it's like a baseline camouflaging. As what I would call it, where I basically just it's mostly just checking the stimming as much as, I still stim, but not as much as if I was alone. Then the added, the added camouflaging would be like completely trying to hide my stimming like 100% and then also adding the verbal filters on. And also trying to hide any processing issues

CAM 2 described how she partially camouflages, stating that she will often mask her autistic traits but "bring up autism a lot in the conversation" as a way of "not masking, but masking." CAM 7 takes a similar approach by not stimming around people "unless it's like a very, like something people can't recognize as stimming."

CAM 3 has been working towards developing her partial camouflaging skills, sharing that she is starting to camouflage less with her partner. She states

> I've gotten better, I've actually made myself stim in front of him, and we just watched television. And I do small stims, but my big stims, like my violently rocking back and

> forth [rocks back and forth], or my skipping, or my flapping of my hands [flaps hands]. And um there are times when I'm overwhelmed and I do that all [that] in front of him, but I don't do it on a regular basis in front of him

Partial camouflaging looked different for each participant, and it was discussed as a technique used more frequently with people they felt somewhat comfortable sharing their autistic identity with. It may also be a technique used when energy levels are low, and the effort required to camouflage fully is not feasible to use for the participant.

### *Shallow Compensation*

All the participants expressed that they utilized shallow compensation, either through scripts or, in the case of CAM 7 and CAM 11, changing the tone of their voices. CAM 6 highlighted that scripts were beneficial "when you have an interaction that you have, repeatedly." CAM 3 gave an example of a script, sharing that "when someone says hi, you don't start talking about dinosaurs at a million miles an hour, I say hi back." CAM 11 also mentioned that the tone of voice could change based on the scenario, stating an adaptive aspect of the decision to use shallow compensation. In an example she shared, she said, "if I'm reading that you're angry, I can quickly change my tone of voice, I can quickly change my conversation, I can figure out strategies to help defuse the situation."

### *Deep Compensation*

Several of the participants expressed that they use either “manuals,” “journals,” or “flowcharts” as ways to camouflage in social interactions. For example, for CAM 7, she would be prepared to take part in social interactions, and when she is asked a question, she will think, “I have already played this whole scenario out in my head, every step has like 97 different possibilities, and I thought of what I will say to each and every one of those." Another example of using deep compensation was shared by CAM 3, stating that the structure and expectations she learned in cadets became her "manual for how to interact with people."

Finally, CAM 6 discussed how she had journals that were her guide to approaching social interactions, but since she has had them for so long, she has "integrated that knowledge into [her] daily routine. Deep compensation is a high-quality camouflaging technique that can take a long time to perfect. However, four of the participants discussed how they have gradually perfected it over time and continue to add to their "manuals" and "flowcharts" as new social interactions are experienced.

### ***Regulating Intense Emotions***

All participants found that they used various ways to regulate intense emotions without drawing unwanted attention. For CAM 2 and CAM 6, the excessive sound in specific environments (i.e., movie theatre or dental office) would require their ears to be covered by their hands or "earplugs." CAM 6 specified that attempts to regulate intense emotions often needed explanations. An example included her telling the dentist, "I'm going to put in earplugs. I need this thing to be here in a comfortable way."

CAM 3 discussed how self-talk is associated with her camouflaging experience when regulating her intense emotions. Notably, in a new social environment, she shares her thought process of experiencing a lot of emotions and finding ways to regulate them:

> So I know when I feel anxious, I also know I want to stim because it helps to get rid of that anxiety. So when I suppress it… I have all these butterflies and I'm like 'stay down butterflies'… so for last night when I was handing out toiletries, and I had all these odors,

> and sounds, and a lot of people around me all at once, and I was kind of in a new situation, I was like, ‘wow, this is a lot’… like, ‘this is really new and I'm feeling a lot of things right now’ and excitement, and I'm a little bit frightened, and I’m also really happy. And I'm, and I'm, I'm overwhelmed. So I want to kind of run around and, and then camouflaging, my part of me that wanted to camouflage was like, ‘okay, we're just gonna, we're going to take it here, and we're going to bring it down here. So we're just going to put it down, just push it down a little bit’

CAM 7 and CAM 11 had similar approaches to regulating their intense emotions; they hid so they could have their “mental breakdown” privately. For CAM 7, she is “careful to remove [herself] from the situation” when she is in “sensory overload.” CAM 11, while in an online meeting, found ways to hide her intense emotions. She shared her experience as such:

> So I was actually having a bit of a meltdown, so they would ask a question, I’d answer it, I’d turn off my mic, have my meltdown until they asked another question, turn on my mic, answer the question. And I just did that, over and over again for like a good half hour. They didn't notice like, yeah so it was sort of like, have it like, switching on and off my camouflaging every five or so minutes, like the teary meltdown and then just being like yes, the material does this and that, and then yeah

For many participants, the regulation of intense emotions was used until they got to a safe environment where they could have their meltdown. Additionally, the emotions experienced in various scenarios are independent of each participant; some participants were more open to experiencing louder sounds but needed to camouflage more in the presence of intense odours. Therefore, the process of regulating intense emotions differed for each participant, but they all had the same goal.

### *Masking*

For many of the participants, masking was used as a camouflaging technique. For CAM 6, this included making a lot of eye contact with those she is engaged in social interaction with, even though she prefers not to. CAM 2 expressed that she often holds back her thoughts with people talking about autism. CAM 6 will also hold thoughts back and mask by mimicking others, whether their behaviours, language or simply "telling them what they want to hear."

CAM 11 discussed her approach to masking in a very detailed manner. She states,

> my first day, my boss said to me, because he knew I was autistic, and he had had experience working with autistic people. And he noticed that I was not scaring off customers, but I definitely wasn't as pleasant, as I could have been, for you know for waitressing. So he came up to me and he said [name] the best advice, anyone can ever give you whilst waitressing is to act like a Disney princess. So you know go to the table smile say only the most pleasant things. Look like fluffy around the restaurant like a little princess. And it absolutely worked. Like people, the customers, where we like always seem to like it. So her name is [name] so I also noticed that people were a lot more comfortable with the just saying [name] rather than [name] a lot more people are using [name]…Um so yeah this is so that's the personality that I put on"

Through her experience mimicking a Disney Princess, she acted as someone she had seen through media. Also, changing her name to accommodate for the comfort levels of those around her was a novel approach to hiding her autistic identity.

## Theme 5: Navigating Your Autistic Identity

### *Autism is Central to Identity*

The concept that autism is central to their identity was expressed by all the participants. Some described themselves as “my autistic self,” while others (CAM 2 and CAM 3) shared that being autistic is “literally who I am.” CAM 3 elaborated on how she navigates the decision to identify with her autism and share it with others, stating,

> The first thing is that that's who I am as a person. A lot of people like to say, you know, you shouldn't say ‘I am autistic’, you should say ‘you have autism’. I don't like that. That's my personal opinion. That's a very heated debate in the autistic community. I like to say ‘I am autistic’ because I am my autism. If you had a magical pill and it took away my autism, I would be a completely different human being. So I, and I'm proud to be defined by my autism. I think I'm not ashamed of it. I think it's, it's really cool. I love autistic people, we have an amazing, we're very compassionate and empathetic and, and kind and um … I'm very proud to be a part of this community

CAM 11 also shared that she is “proud” of her autism and that her autistic identity is a “really important part of [her] life.” For CAM 6, although she shared similar notions about being proud of her autism, she wishes she could be more “honest with them” and that camouflaging is a barrier to being “authentic with people.” The opposite of camouflaging for the participants is being authentic; complete authenticity is the end goal for those who share their autistic identity with others unequivocally.

### *External Acceptance*

The degree of external acceptance of autism was discussed as a barrier to successfully navigating the decision to share their autistic identity with others. CAM 3 describes it as "throwing a dice," elaborating that the response to her sharing that she is autistic could "have a serious impact on my future and what happens to me." For many participants, at least one environment they spend considerable time in does not promote complete acceptance. CAM 11 described how she feels accepted at her work with an autism organization, but at school, "disabilities just aren't accepted yet." This feeling was echoed by CAM 7, stating that in her experience at work, "the world isn't ready for acceptance, unfortunately… I only know like one, maybe two people who would accept my autistic self."

Acceptance of an autistic identity is a primary motivator for sharing autistic identities with people. However, CAM 6 highlighted that acceptance is a broader concept for her, sharing,

> Let's say that autism is like entirely accepted. So that means to me that like we've created social structures that make it easier for autistic people to function. So you'll probably have less crowded spaces, less of the bright lights. Maybe like just like general accessibility, like bus schedules and whatever would be easier to read, like there would just be things in public that like public spaces would be easier to access for people with different sensory needs, I think. And not because like, we didn't have to camouflage, like, I still don't want people to melt down in public, even if they're allowed to, do you know what I mean? Like, if people know that you have autism, and that you're like, you know, freaked out about something, I still don't want people to be freaked out, even if they're going to be accepting of it.

For CAM 6, full acceptance is not on a personal level but on a societal level, and even if that were to happen, she still would camouflage her sensory needs. The thought of camouflaging in an accepting environment was discussed by CAM 2 as well when she mentioned that camouflaging an identity is paradoxical to her. She explains by stating,

> People think they're treating me like [name] when they don't know I'm autistic but I know they're not treating me like [name]. But if I tell them I'm autistic, um I feel like I'm treating myself as [name], but they may not be. Best case scenario, they can treat me as [name]

The degree of external acceptance is a pivotal determinant of whether all five participants would decide to camouflage or not. As mentioned previously, if in the presence of those that are not entirely accepting of autism, they would camouflage to avoid conflict, negative emotions, alienation, or being treated differently.

### ***Neurodiverse Relatedness***

All of the participants expressed that it was easier to be their autistic selves when around other people who are neurodivergent. Spending time with other neurodivergent people is “fun” for CAM 2, while CAM 3, CAM 6, and CAM 7 described that others having first-hand experience is very helpful. CAM 3 elaborated, “if someone says their autistic, I just do my thing, because they get it, I don’t have to explain myself to them.” The explanation for behaviour showed when not camouflaging was discussed by CAM 6 and CAM 7 as well, with CAM 7 sharing that it’s a “non-judgmental” experience.

CAM 11 went on to describe spending time with neurodivergent people as autistic oxygen, explaining it as such:

> like when you're with neurotypical people sometimes it might feel that your out of oxygen you're like a little bit, almost drowning a little bit in like camouflaging so she said, you know when you get to see other neurodivergent people, then you get that kind of that breath of oxygen because you don't need to camouflage as much, and you can also meet people who are just as weird as you are

In addition, all the participants shared that at least one member of their inner circle, either friends, siblings, parents, or partners, were neurodivergent. This shared experience between participants and loved ones facilitated a safe environment at home where all the participants expressed they could be their autistic selves without fear of judgment.

### ***Reducing Camouflaging***

All participants expressed an interest in reducing or completely stopping their camouflaging in the future. For CAM 3, this looked like making a “resolution” to “not camouflage as much as [she] used to,” while CAM 6 shared she is looking for “people who are okay” with answering her questions when others are not. CAM 7 discussed how she is ready for a change, stating,

> I'm trying really hard to not mask anymore. I don't want those relationships in my life where I can't be who I am. I will do it strategically when I need to, to you know, keep my job, but if you can't accept me for what I need to be then I don't want that relationship

For CAM 11, reducing camouflaging is important, but it’s not an easy task. Due to camouflaging being such a “habit,” she mentioned that she has to “consciously think about not camouflaging” with someone. CAM 2 offered an approach that she is planning to use to reduce her camouflaging, sharing, “if I do stop masking, I would do it slowly because then people psychologically start to get used to it slowly, and then they don't think anything of it if I do it more."

## Research Question 2

### Physical Impact of Camouflaging

Each participant expressed a physical impact of camouflaging on their QoL. All participants shared that camouflaging causes a lot of exhaustion, with CAM 2 and CAM 3 mentioning that after a long day of camouflaging, they will "sleep more hours." CAM 3 also shared how camouflaging impacts her eating, stating,

> I feel like if I stim a lot and I'm healthy, and I feel good, I don't eat as much, but if I'm having to mask, camouflage for a very long period of time, I feel like I eat a lot more the next day, or I even eat a lot during it, because I'm trying to manage uh my anxiety levels

For CAM 2 and CAM 6, camouflaging causes shoulder pain, as they feel they have to maintain a particular posture throughout the day, and the stress of pretending to be someone else builds up in the neck area. CAM 7 highlighted how much of an impact camouflaging has on her physical QoL, stating, "it's insane how like, physically ill it'll make you, just pretending you're not who you are." CAM 11 discussed the impact of camouflaging as well, sharing that because she is not encouraged to stim in a non-injurious way (i.e., flapping hands), she was forced to find an alternative which happened to be scratching her thigh. She went on to describe that she now has "quite the pain tolerance" and that the expectation of enduring loud noises has resulted in her learning to decide not to "say anything."

## Psychological Impact of Camouflaging

For all the participants, camouflaging significantly impacted their psychological QoL. All five participants made the common points of stress, anxiety and depression. CAM 11 shared that she will “get more migraines” when school stress and family members come over because these circumstances require additional camouflaging. CAM 2 elaborated that camouflaging makes her “sad” and “it does take a big toll on [her] mental health.”

For CAM 6, she described that camouflaging may not be the explicit reason for psychological health concerns, but because “when you're spending so much time focused on that one thing, sometimes other things fall behind, like, you know, you forget to do other stuff that should have been done, and then that's stressful.” CAM 7 highlighted that camouflaging for a day can put her in a “debilitating mental lockdown,” while CAM 3 shared that the thought of camouflaging all day would result in her “mental health in shambles.”

### *Camouflaging and Healthcare*

The experiences of healthcare when camouflaging were discussed in great detail by all the participants; some had positive experiences, while others had less than ideal experiences. All the participants brought up being dismissed as an autistic female when accessing healthcare. Common experiences involved “not being taken seriously,” hearing “you can’t have autism,” or, as CAM 2 shared that if she’s camouflaging,

> they might be more concerned if they're looking at my health, they might see me not masking as a symptom of my health and then they'll talk about it and, like they'll be like ‘let's unpack that’ when I, in reality, I just want them to deal with my teeth or I want them to deal with my injured ankle or something

All participants shared that they have camouflaged with healthcare professionals at some point in their lives. Still, if they know their healthcare provider accepts autism, they are more likely to reduce their camouflaging with them. For example, CAM 7 shared how she switched her "dismissive" to a "new GP [that] is a young female doctor fresh out of school, extremely open-minded and very helpful."

For CAM 6, her experiences with healthcare often resulted in her being dismissed, even when she advocated for her needs. She feels this happened because, even when she camouflages by not stimming and making eye contact, she does not have a lot of voice expression. She elaborates further, stating,

> I tend not to have a lot of like, voice expression, and people tell me I'm really monotone… And then like facial expression as well. And I think that that makes it difficult for me to be taken seriously sometimes. And in healthcare settings. That's really, because if I'm like, 'hey, this is causing me a lot of pain, and I'm really unhappy with it in my day to day'… and doctors go 'sure'. Like, it's not, you can't express a heavy emotion with like that kind of weighted language and not also have a tone that backs it up. Neurotypicals don't understand things that don't have tone."

Advocating for needs was a topic that came up in CAM 3's discussion of her experiences of camouflaging in healthcare settings. She shared that she will camouflage in environments like a dental office, but because her "doctor's super chill," she can ask for things, and they will be done.

It is also important to note that all participants believe their camouflaging in healthcare directly impacted their late diagnoses of autism. For example, CAM 7 shared that even when she wasn’t camouflaging, professionals would say, “Oh, she’s just shy. Oh, like, that’s how a woman should be. She’s, she’s being the proper woman.” CAM 2 echoed this experience, sharing how people saw her as “a normal girl” and “that definitely made [her] diagnosis much later.”

## Social Impact of Camouflaging

### *Social Relationships*

The impact of camouflaging on social relationships was high for all the participants. In many cases, the participants shared that their friends don’t share their whole autistic identity with others, and as CAM 7 said, “you don’t actually know who I am. You just know who I want you to see.” CAM 3 and CAM 11 expressed that they have both experienced circumstances where their friends have either “alienated” them when they showed their autistic traits or treated them differently. However, CAM 3 shared that in her experience in an environment where “autism was celebrated” she was able to be herself, resulting in her receiving “a huge friend group.”

When discussing the direct impacts camouflaging can have on social relationships, CAM 2 and CAM 11 shared that if one is camouflaging for a long day, they “end up ending things earlier.” However, all participants shared that camouflaging helps them develop social relationships in the beginning stages, but eventually, they have the motivation to reduce camouflaging over time. The decision to reduce camouflaging with a friend is considered challenging by all the participants. Still, CAM 6 believes that reducing camouflaging is necessary to create “a much more dynamic [and] like stable relationship.”

### *Romantic Relationships*

For several participants, camouflaging at the beginning of a romantic relationship was a shared experience. Mainly, camouflaging is done on the first date to get a sense of how the person they are dating may react if they found out the participant was autistic or “different.” For example, CAM 6 shared that she will use scripts on a date consisting of questions that allow the other person to talk more than her. This approach helps her understand who the person is while supporting her preference to listen rather than talk.

In some instances, camouflaging is not done in romantic relationships, as CAM 3 shared, to “weed out the jerks.” CAM 11 has a similar approach to dating, stating that she will tell people she is autistic on the first date to confirm whether they will accept her for who she is. In the case of CAM 3 and CAM 7, their partners are neurodivergent, which was one of the reasons they believe the relationships work. As mentioned earlier, neurodiverse relatedness is beneficial as it allows the participants to feel safe and accepted in their homes.

## Environmental Impact of Camouflaging

All participants expressed that camouflaging has an impact on their environmental QoL. When discussing whether to camouflage in employment settings, all participants shared that they camouflaged to receive their current job. CAM 2 elaborated on why she continues to camouflage in her employment setting, stating,

> because I'm the sole authority and they put a lot of trust in me. And I feel like if I, even though I'm technically lying by masking, um, I feel like they might not take me seriously if I'm stimming. And, and so I definitely try to mask there

All participants shared that they believed if they did not camouflage, they would lose out on many opportunities. For CAM 7, she described her perception of what she thinks her life would look like if she did not camouflage,

> I can guarantee I wouldn't have a job... Um, and that's strictly on other people's perception on what I can handle… I may not even be able to have owned my own house because I would have been seen as um … incapable

CAM 6 echoed that being in a customer service position and deciding not to camouflage would result in people "misunderstanding" her. This is true for CAM 3 when she shared that not camouflaging would likely result in people not believing she can complete the job at high standards.

Educational opportunities were also discussed, as CAM 2 and CAM 11 shared that they achieved higher academic standards when they chose to camouflage. CAM 6 also highlighted that camouflaging could "allow more opportunities in [her] education." However, with some participants working remotely due to the pandemic, and all students completing school online, the impacts of camouflaging were different than before COVID-19. CAM 11 describes this well, stating that the ability to

> turn off my mic, as I said in like if my camera isn't showing then that's fine. But also, I find that I tend to get more anxious when I'm talking to people online just because there's less body language for me to read. So it kind of causes more meltdowns, but I can hide the meltdowns more. So it's yeah it's kind of a double-edged sword in that respect.

When considering the costs and benefits of camouflaging, the participants shared that sometimes the scale is tipped one way or another, and sometimes it's even. Sometimes, the benefits, such as getting a job and developing a relationship, take precedence over physical and psychological QoL impacts. However, when the exhaustion, depression, anxiety, and headaches become too intense, the participant suggests the costs or camouflaging outweigh the benefits.

# Chapter Five: Discussion, Implications, and Conclusion

The current study aimed to explore the subjective camouflaging experiences of five cis-gendered Canadian autistic women and ask them to reflect on how camouflaging impacts their QoL. Notably, this study was conducted during the COVID-19 pandemic, resulting in context-specific findings. The camouflaging experiences of the participants are further explained by how they describe camouflaging; the motivations they have to camouflage (or not); how they learn(ed) to camouflage; the camouflaging techniques that they regularly use; and navigating the relationship between their camouflaging experiences and their autistic identity. To determine how the participants' camouflaging experiences impact their QoL, the impacts were assessed across their physical, psychological, social, and environmental QoL. The findings revealed that the camouflaging experiences of the autistic women in this study are adaptive, variable, and dependent on degrees of external and internal acceptance of autism. Additionally, for the participants, camouflaging has benefits and challenges that impact various domains of their QoL. Importantly, the participants emphasized that their experiences with healthcare were variable and being dismissed as an autistic female was a pretty common scenario. In this chapter, I will first discuss the findings of this study and how they are situated in the current literature. Next, I will highlight and discuss the current study's limitations and then I will propose directions for future research and methodological approaches with autistic samples. Finally, I will discuss the implications for policymakers, educators, and employers.

## Discussion of Findings

### *Descriptions of Phenomenon*

All participants described camouflaging as separating themselves from their autistic identity. As a subconscious, sometimes automatic, approach to pretending to be someone different, the participants were adaptive to their environments. Consistent with current literature, camouflaging environments are varied, but common scenarios include social settings like school, work, and community (Livingston et al., 2019; Moyse & Porter, 2015; Tint & Weiss, 2018). The participants noted that these environments often have respective social expectations, environmental sensory demands (e.g., loud noises, bright lights, etc.), and unclear degrees of autism acceptance from the participants within the setting.

With the lack of consistency in environmental and social contexts for certain settings, particularly during a global pandemic, a significant aspect of camouflaging is that it adapts to the context. Throughout this study, the participants experienced multiple public health restriction changes, all coming with new expectations for socializing within public settings. These changes required the participant to regularly adapt their camouflaging techniques to the social expectations of the environments where they found themselves.

The experience of adapting their camouflaging within environments that regularly, yet seemingly randomly, had changing social expectations was challenging for the participants. These findings align closely with the work of Maljaars and colleagues (2022) in their review of the impact COVID-19 pandemic on autistic adults. Although camouflaging was described as adaptive due to the COVID-19 pandemic, the participants also shared that one must adapt their behaviours to the responses they receive in social interactions to camouflage successfully. For example, suppose they choose to mask their stimming, yet those in the social interaction still notice the masking technique. In that case, the participant will adapt their behaviours to improve their success of not drawing attention to themselves. The description of camouflaging as adaptive aligns closely with Lawson's (2020) conceptualization of camouflaging as autistic morphing. Adapting by changing behaviours and hiding traits can be extremely beneficial towards meeting social expectations and, consequently, addressing the motivations for camouflaging (Lawson, 2020).

Additionally, all five participants expresssed that their ability to camouflage is a privilege. According to the participants, camouflaging ability, although similar across the five within the study, is also variable within the autistic community. All five participants acknowledged that having the ability to camouflage successfully is beneficial, while not having the ability to camouflage can have negative impacts on social, vocational, and relational aspects of life. The specific benefits and costs of camouflaging within this study are discussed below. Notably, camouflaging allows them to reap the benefits of pretending to be neurotypical while avoiding the potential concerns that come with acting autistic in a non-accepting society.

Furthermore, although the descriptions of camouflaging provided by the participants are somewhat similar, the individual experiences of camouflaging offer unique opportunities for the conceptualization of camouflaging to be continually updated. All the participants expressed that their understandings, experiences, and conceptualizations of camouflaging as an autistic woman have changed since the COVID-19 pandemic began. In conclusion, camouflaging may be adaptive, subconscious, and a privilege for the five participants within the study; however, these descriptions may change with age, experience and the significance of impacts camouflaging has over time.

### *Motivations for Camouflaging*

According to the participants, the motivations to camouflage or not depend on the perceived environmental demands, social expectations, and level of social acceptance of autism within the particular environment. Both internal and external motivations arose from the camouflaging experiences shared. However, the motivations are not explicitly distinct from one another; internal and external motivations often overlap as both directly impact one another. Furthermore, the participants and other autistic women camouflage to avoid stigma and how the stigma makes the participants feel (Cage & Troxwell-Whitman, 2019; Hull et al., 2020; Perry et al., 2021). One component of autism stigma that all the participants shared is being alienated because of their autistic traits and identity (Radulski, 2022). So naturally, the participants camouflaged autistic traits that they worried would draw negative attention to themselves to fit in.

Some participants shared that the negative perceptions of autism that they try to avoid are often imposed by those who are not accepting of autism or are misinformed about autism. As Radulski (2022) highlights, neurotypical hegemony can significantly impact the perception of autism. Neurotypical hegemony "means that the Neuromajority have the benefit of shaping cultural norms for society and communication that reflect their own traits and characteristics, rather than the minoritized characteristics of Autistic culture and communication" (Radulski, 2022, p. 120). Due to the lack of inclusivity in conceptualizations of autism and where it fits on the spectrum of cultural norms, the internal and external perceptions of autism vary. To avoid negative perceptions of autism, the participants pretend to be neurotypical. Similar findings have been reported by Lazarro and colleagues (2018), who indicated that autistic individuals might camouflage to conform to neurotypical social influences. In doing so, they become subjectively neurotypical in the view of the majority, ultimately increasing their success in fitting in with neurotypical people around them.

Additionally, camouflaging to develop and improve relationships is quite a common motivation for autistic women (Bargiela et al., 2016; Cage & Troxwell-Whitman, 2019; Hull et al., 2017; Tubio-Fungeuriño et al., 2020). The results from this study also highlight the motivation of camouflaging for others. Wigfield and colleagues (2022) discuss how an essential tenet to meaningful interaction between people is the degree of positive attitude and the reciprocal value placed on the needs of those in the social interaction. For all five participants, camouflaging to meet the needs of others was a significant motivation, regardless of the impact on the participant. Notably, in recognizing that those around them would be distracted or feel uncomfortable around specific stims, the participants camouflaged their stimming. They realize that others can experience certain stims as distracting in a classroom setting or scary to those that perceive stims with big movements as dangerous.

Moreover, external perceptions of autistic stimming are assumed by the participants. Although stimming helps them manage stressful social interactions, they feel pressure to act in a way that meets the needs of those around them. This empathetic motivation for camouflaging is also seen in the participants' experiences of camouflaging negative feelings to make others feel better. In the past, literature has suggested that autistic individuals do not have strong empathy for others, best exemplified by the theories of mind-blindness, monotropism, and theory of mind (Baron-Cohen, 2002; Baron-Cohen et al., 1985; Murray et al., 2005). Recently, the notion that autistic individuals are not empathetic has been dismissed (Botha et al., 2020; Fletcher-Watson & Bird, 2020; Nicolaidis et al., 2019; Stroth et al., 2019). Specifically, many participants in this study had expressed empathy for those around them and, as Crompton and colleagues (2020) concluded, mask their autistic traits to make others more comfortable. The current study's finding that autistic women are not only empathetic but act on their feelings of empathy, regardless of the impact it has on their own QoL, is an important step forward in addressing public autism misconceptions.

Finally, four participants spoke of the motivation to camouflage for their safety. Autistic women are often the victims of crime and being taken advantage of, often due to others seeing them as vulnerable (Forster & Pearson, 2020). In addition, the participants discussed how deciding not to camouflage opens them up to stigma or the misconception that they may be a threat to those around them. One participant spoke about how the intersectionality of being an autistic female with privilege keeps her safe, yet camouflaging is another "level of protection." Sedgewick and colleagues (2019) found that 80% of their sample of 19 autistic women have experienced sexual assault. Additionally, supporting literature reports higher rates of sexual assault, rape, and domestic abuse than non-autistic individuals (Bargiela et al., 2016; Weiss & Fardella, 2018). With data suggesting that autistic women are at high risk for abuse, stigma, and assault when choosing not to camouflage, it is no surprise that the participants camouflage regularly for safety (Hull et al., 2017; Radulski, 2022).

As I interpreted the internal and external motivations for camouflaging, Damian Milton's (2012) 'double empathy problem' aligned closely with the participants' experiences. The double empathy problem addresses the misconception that misunderstandings and lack of empathy between autistic and non-autistic individuals are entirely due to the autistic individual's social deficits. Many of the participant's motivations align with their attempts to get neurotypical individuals to understand autism and, in some cases, their autistic communication style better. However, all five participants expressed that they are often the individuals making more of an effort to understand those different from them. Similarly, current literature suggests camouflaging may be a direct response to acknowledging that an autistic identity or visible autistic traits will not be socially accepted (Cook et al., 2021; Mitchell et al., 2019; Mitchell et al., 2021). Expending significant effort to feel included and welcomed in social interactions is already challenging. What makes it even more difficult is doing so when the others in the interaction unconsciously (or consciously) support neurotypical hegemony and do not try to understand autistic individuals better. These feelings of being excluded and pressured to camouflage their autistic identity can have significant implications on the quality of life of autistic women (Mitchell et al., 2021).

In conclusion, the motivations for camouflaging expressed by participants are highly supported in academic literature. However, although the motivations behind camouflaging are generally agreed upon within the sample, the emphasis placed on each motivation varies based on personal experience and degrees of empathy for others. For example, autistic women may endure some negative impacts of camouflaging to benefit their family members, but not those who are not close to them. To conclude, camouflaging experiences are unique to social relationship dynamics; these dynamics ultimately determine when and where camouflaging is felt as necessary.

### *Learning to Camouflage*

Although the process of explicit learning to camouflage is rarely cited in academic literature, many social skills development programs are available for autistic individuals (Gates et al., 2017; Tse et al., 2007). Many of these programs will seek to improve social competence in autistic youth and apply those skills to non-clinical environments such as school, family and work (Gates et al., 2017). All of the participants expressed that, at one point in their life, they had completed some degree of social skills training. For some, these learning opportunities were more formal at autism-focused centres or schools, while others learned informally from family members or friends. All in all, the participants shared that one crucial approach to learning how to camouflage is first identifying expectations for the social interaction in the specific environment.

To learn the expectations of social interactions, one can experience it first-hand and adapt behaviours through feedback. All of the participants shared how they often learned how to socialize with others by trying to mimic what they see in media. In these scenarios, they expect a particular outcome based on the decisions they make socially, however, if the social interaction goes poorly, they will take that feedback and apply it to the next social interaction. The use of media, particularly television shows, Facebook and YouTube, has been suggested to support the development of social skills for autistic and non-autistic individuals (Bargiela et al., 2016; Gwynette et al., 2017; Raj et al., 2019). Similar to mimicking the social interactions portrayed in media, autistic women will learn to camouflage by mimicking the behaviours of their peers. Tierney and colleagues (2016) reported that one participant in their study pretended to read a book in the library when really they were just listening and watching social rules play out. Many participants in the current study shared that they often watch others socialize and then mimic it in their social interactions.

For some of the participants, the camouflaging learning process was much more explicit. Three of the participants ask their peers for support in improving their social skills when camouflaging, while one participant learned through the strict social rules of cadet training. Often this learning with others is accompanied by an “if this, then that” role-play scenario, specifically what happens if one does not seem engaged in the social interaction. In alignment with previous literature, each participant was motivated to learn how to camouflage by becoming familiar with social patterns (Bargiela et al., 2016; Tierney et al., 2016). One participant described these social patterns as a coding language that they could mentally refer to when found in familiar social interactions. All the participants shared that they have an individualized ‘manual’ that they have learned and developed through personal experience, media, and support from those within their social circle.

Notably, the ‘how’ of camouflaging was described as an ongoing learning process by all the participants. All five women expressed that they consistently update their ‘manuals’ when they meet new people and experience new social outings in new environments. However, two factors critical to the success of camouflaging are the preparation and routines associated with their individualized camouflaging. For some, this meant preparing particular camouflaging techniques or scripts when they knew they would be in scenarios that required them. Specifically, all of the participants shared that they have scripts that they will utilize at work. Likewise, they will apply specific camouflaging techniques when they go on dates, in grocery stores, or to school. The value of consistency in social interactions and environments is reflected in the participants' experiences and current literature (Hull et al., 2020; Maljaars et al., 2022).

When the COVID-19 pandemic arose, all the participants shared that their camouflage routines were destroyed, and they felt immense pressure to re-learn how to camouflage. As the participants shared that one factor of successfully camouflaging is consistent practice, the social isolation instructed by public health restrictions significantly impacted their ability to keep their camouflaging skills at a level they were satisfied with. Furthermore, the social expectations of each environment were changed, resulting in all five participants feeling pressure to learn how to camouflage in new scenarios while being aware that what they learn one day may not be applicable a week later. As the study came to a close, the public health restrictions within Canada were beginning to stabilize, which was celebrated by the participants as they could now re-establish a camouflaging routine. Several studies have indicated that the COVID-19 pandemic had significant implications on the autistic community, yet this study is the first to acknowledge the impact the COVID-19 pandemic had on the camouflaging experiences of autistic women in Canada (Baweja et al., 2022; Maljaars et al., 2022).

### *Camouflaging Techniques*

According to the participants, various camouflaging techniques are used regularly depending on the people they are with, the expectations of the social environment and the amount of energy the participant has. Like Livingston et al. (2019) findings, all five participants expressed that they masked their autistic traits around others in an effort to blend in. For some autistic individuals, this can be exhibited by adding more gestures and pauses in the conversation (Parish-Morris et al., 2017; Rynkiewicz et al., 2016). All five participants were very aware of how others were perceiving their behaviour, which led them to find innovative ways to hide behaviour that is subjectively inappropriate. Examples included the suppression of stims and regulating intense emotions in public.

When regulating intense emotions, the participants shared that they often hide the impact social expectations and environmental sensory demands have on them until they can get to a safe space to vent. For some participants, this meant regulating emotions by internalizing symptoms of stress, anxiety, and guilt for hours. This camouflaging technique aligns closely with conscious masking, referring to the recognition that they need to mask until they feel safe enough not to do so anymore (Sedgewick et al., 2022). As many of the participants shared, pretending everything is alright when it is not often resulted in feeling worse. Van der Cruijsen & Boyer (2020) highlight the implications of autistic individuals internalizing mental health concerns, suggesting that the self-esteem of the individual may decrease. Considering that all the participants spoke on how they must be confident in their ability to carry out the camouflaging technique, the self-esteem of the individual can be a contributing factor to the success of the social interaction. More research will be required to better understand the relationships between camouflaging and self-esteem.

Additionally, another common camouflaging technique shared across the participants was the use of shallow and deep compensation. Existing literature aligns closely with the experiences of using compensation in social interactions; shallow compensation is useful but only to a certain extent (Livingston et al., 2019; Livingston et al., 2020). All the participants shared that although the use of scripts can help them succeed in a basic, short social interaction, the technique loses its value when the conversational topic changes quickly or they are meeting someone for the first time. Therefore, all the participants strive to perfect and utilize deep compensation for social interactions. As mentioned earlier, many of the participants use a ‘manual’ that they may refer to when engaged in a social interaction. As Livingston & Happé (2017) highlight in their analysis of camouflaging techniques, with time and practice, deep compensation can become automatic and provide more flexibility for those that use it. Deep compensation has recently been aligned with Sedgewick and colleagues (2022) conceptualization of ingrained masking, a learned response that was once conscious but now “an embedded ‘subroutine’” (p. 23).

Finally, partial camouflaging is used by all five participants, specifically as a combination of motivations of blending into society, hiding autistic traits, yet still being partially authentic. Partial camouflaging can take many forms, as it is individualized to specific aspects of autism each person is comfortable sharing and which characteristics they feel need to be hidden. For example, one participant shared that although she always has a “baseline” camouflaging level, she may camouflage additional autistic traits if the environment calls for that degree of camouflaging. Partial camouflaging may also entail disclosing a diagnosis but not stimming in public. Frost and colleagues (2019) that one factor autistic individuals take into consideration when deciding to disclose their autistic identity is the degree of acceptance around them. It is important to note that all five participants in the current study partially camouflaged with those they felt comfortable around. These include family members, close friends, and other neurodivergent individuals, aligning with the results of current literature (Frost et al., 2019; Romualdez et al., 2021).

Overall, the camouflaging techniques shared by the participants align closely with previous literature findings (Hull et al., 2017; Tubio-Fungeuriño et al., 2020). However, it is crucial to highlight the uniqueness of camouflaging experiences as techniques are often closely associated with the underlying motivations for camouflaging. The techniques may also depend on the individual's self-esteem and societal expectations. Of course, some individuals may choose to be more authentically autistic by not using masking or compensation strategies. By partially camouflaging, one can meet the expectations of their social interaction while still staying true to their autistic identity.

### ***Navigating Autistic Identity***

All five participants expressed that autism is central to their identity and that they are proud of their diagnosis. However, the internal acceptance of autism is not always met with the external acceptance of autism. With some demographics, particularly those that are neurodivergent, the participants shared that they feel more accepted for their neurodiversity. Moreover, all participants shared that they camouflage less with others for two reasons: (i) they feel more comfortable sharing their identities; and (ii) there is less pressure to act neurotypical. Many of the participants highlighted that if they experience less autism acceptance they feel like they need to camouflage their autism more, resulting in identity crises. Current literature concurs that autistic women are prone to identity crises, especially when theories (i.e., Extreme Male Brain) directly contradict the notion of intersectionality (Botha & Gillespie-Lynch, 2022; Frost et al., 2019).

According to some participants, the perception that autism is a male diagnosis and that being autistic means that you are more male than female is another layer of intersectionality they must endure. And when a public narrative of what autism entails does not match one's interpretation of their autism, they may become further alienated from their diagnosis. The participants expressed that the autistic identity gaslighting is a significant barrier to disclosing their autistic identity. Concurrent with the work of Stevenson et al. (2011), one participant noted that the infantilization of autism is a factor to consider when deciding whether to share their autistic identity.

Moreover, all participants expressed that a negative experience of sharing autistic traits and facing stigma ultimately diminished the value they held for their own autistic identity. This phenomenon is echoed by Botha, Dibb & Frost (2020), highlighting the concern that autistic individuals may accept externally stereotyped views of autism if they are not addressed as wrong. In recognizing that certain autistic traits would not be accepted within specific social interactions, the participants unconsciously labelled these autistic traits as threats to performing successfully in a social interaction.

As one participant explicitly shared in their camouflaging experiences, full acceptance of autism is a societal challenge that must be addressed. To fully accept, we must reduce environmental sensory demands (i.e., bright lights) and improve accessibility to information (i.e., easier-to-read bus schedules). Current literature suggests that society is working towards improving the experience of autistic individuals, particularly in work, health care, and school settings, yet there is still work to be done (Khalifa et al., 2020; Mason et al., 2019; Petcu et al., 2021). As camouflaging has also been reported as a barrier to receiving accommodations in work, health care, and school settings, increasing the external acceptance of autism is crucial for the well-being of autistic women (Cook et al., 2018; Hull et al., 2017; Milner et al., 2019).

Furthermore, one approach the participants actively take to promote the external acceptance of autism is reducing their camouflaging. All five participants camouflage 'almost always', yet all expressed that they are gradually working towards finding ways to become more authentically autistic. Botha and colleagues (2020) highlight that reducing camouflaging by being publicly authentic may remind the neurotypical hegemony that although autistic individuals are in the minority, their experiences still matter. As all the participants shared, they strive to educate non-autistic individuals by advocating for preferred language use and challenging the stigma associated with autism by highlighting autistic success.

All in all, navigating an autistic identity is complex, mainly when there is immense pressure to act in a way that is not reflective of your identity. Disclosing autism is a complicated process that can significantly affect life experiences, outcomes, and opportunities (Frost et al., 2019). As the participants shared, even though they may camouflage regularly, autism is still central to their identity. Therefore, they will always seek out opportunities to share their identity with those who are accepting and non-judgmental. All the participants stated that they would never completely stop camouflaging; however, they will all find ways to navigate the perceptions and assumptions that accommodate a female autism diagnosis.

### *QoL and Access to Healthcare*

Camouflaging was reported by the participants to have both positive and negative impacts on their physical, psychological, social, and environmental quality of life. All participants expressed that camouflaging for long periods can result in feelings of exhaustion, anxiety, depression, and guilt for not being authentic. This finding is consistent with literature that more camouflaging may be associated with higher reports of anxiety, depression, and stress in autistic adults (Cage et al., 2018; Lai et al., 2020; Lai et al., 2017). Similar to the findings of Crompton and colleagues (2020), autistic women who camouflage often will sleep more. One novel finding from the current study includes perceived increases in eating after camouflaging for a long time. Although not with an autistic sample, research has suggested that participating in stressful social interactions is associated with increased caloric intake in a sample of 41 women (Tyron et al., 2013). Therefore, it is not surprising that after being mentally on edge and pretending to be someone else for an extended period, one would resort to comfort foods that are proven to reduce stress (Tomiyama et al., 2011). On the other hand, camouflaging for long periods has also been associated with restricted eating patterns in forty-nine autistic individuals (Leedham et al., 2021). The relationship between eating patterns and camouflaging warrants more research to provide conclusive evidence of potential associations and implications.

In addition to the physical and psychological impacts of camouflaging listed above, some participants suggested that camouflaging for long periods causes shoulder and back pain. This pain is likely due to increased stress when camouflaging in social interactions and can significantly impact one’s overall quality of life (Kemp et al., 2011). The participants discussed other experiences of physical pain, such as stomach aches and resorting to physically harmful alternatives to outward stimming, as associated with camouflaging.

As physical and psychological concerns for QoL are prominent in the experiences of camouflaging in the study's sample, it is unfortunate that autistic women often report significant concerns accessing healthcare that is non-dismissive of their concerns (Malik-Soni et al., 2021; Nicolaidis et al., 2015). All five participants shared that they have resorted to internalizing symptoms to avoid being misunderstood and gaslit by health care professionals. Specifically, the participants shared that they have two options. First, they disclose their autism and hope that the health care professional knows autism and will acknowledge that the patient's needs are legitimate. The second option is to camouflage in hopes that the hidden autism diagnosis will allow the healthcare professional to focus on the issue they came for instead of the autism. As all five participants shared, they more often than not will resort to the latter option.

Some participants have healthcare professionals they do not camouflage with, and these relationships are described as valuable and validating. However, when receiving support such as a diagnosis of autism, the participants all shared that they believe camouflaging resulted in them receiving a late diagnosis, a missed diagnosis, or both. In addition to camouflaging, all the participants expressed that male-focused descriptions of autism also contributed to late diagnosis. This finding is consistent with literature suggesting that clinicians are less likely to diagnose autism in those that do not meet the male-dominated surface-level standards of behaviour that autism 'usually' presents (Leedham et al., 2020). As the Female Autism Phenotype theory suggests, camouflaging is often part of being an autistic female. Considering that late diagnoses can negatively impact the QoL in autistic women, it is vital to address that camouflaging autism is not the issue; not recognizing that camouflaging is a characteristic of an autism diagnosis is (Leedham et al., 2020). All in all, there is a clear need to improve the quality of healthcare as the internalization of symptoms can lead to further low quality of life, increased suicidal ideations, and increased mortality in the autism community (Bernardin et al., 2021; Mitchell et al., 2021; Walsh et al., 2021).

Regarding social QoL, the participants shared that social and romantic relationship development is supported by camouflaging, but eventually, the camouflaging must be reduced. Frost, Bailey & Ingersoll (2019) found in their study of factors contributing to disclosing autism diagnoses that autistic individuals are more likely to disclose with long-term friends and those that are also neurodivergent. All five participants shared that there are people in their life that they did not share their autistic traits with until they felt comfortable doing so. The concern of telling new acquaintances early is that they are unsure how others will act when they see autistic traits or hear about a diagnosis. Camouflaging allows them to, in the beginning, gauge the degree of acceptance they may receive from their new peers, and eventually provide an opportunity to share a part of their identity once the relationship is solidified (Frost et al., 2019). As social relationships develop while the participant is camouflaging, they may become exhausted from expending so much effort within the interactions. According to the participants, this exhaustion will often lead to them leaving early, ultimately impacting the relationship and potentially opening up an unwanted conversation around reasons for leaving.

Regarding the perceived impact camouflaging has on social and romantic relationships, the benefits of camouflaging to develop relationships are valued more than the challenges that may arise with camouflaging in relationships. Of course, all five of the participants have, at least once, shared their autistic identity with someone they began camouflaging with in the beginning. In all five cases shared, there was no negative feedback regarding disclosing at a later date. This experience is not always the case for autistic individuals, as isolation and loneliness are common feelings in the autism community (Bauminger & Kasari, 2000; Howlin et al., 2013; Shattuck et a., 2011).

Finally, all five participants expressed that camouflaging has been beneficial in providing more positive opportunities in academic and vocational environments. Current literature highlights concerns that autistic individuals have when deciding to camouflage or not in vocational settings. For example, choosing not to camouflage autistic traits in non-accepting environments can sometimes lead to experiencing stigma, discrimination, and, in some cases, termination of employment (Black et al., 2018; DePape & Lindsay, 2016; Tint & Weiss, 2018). All of the participants within this study had experienced stigma in the workplace and actively camouflage in their employment positions to avoid more stigma and discrimination.

Livingston, Shah & Happé (2019) found in their study assessing the use of compensatory strategies in autistic adults that camouflaging was associated with more positive employment experiences. By utilizing camouflaging strategies in social interactions with colleagues and regulating intense emotions when work gets challenging, albeit adhering to the external pressures to act neurotypical, they were more likely to gain employment (Livingston et al., 2019). Unfortunately, the employment trends and lived experiences of autistic individuals suggest that employment is difficult to maintain (Chen et al., 2015; Livingston et al., 2019). Many of the participants shared how the external perceptions of autism from colleagues, sensory demands, and accessibility to accommodations are all factors that contribute to poor employment experiences. In a scoping review of 161 articles conducted by Harmuth and colleagues (2018), the acceptance of diversity and willingness to accommodate and learn about the autistic lived experience was associated with higher rates of autistic wellbeing in the workplace. As the participants expressed, camouflaging in the workplace can provide opportunities to receive employment and maintain it for a short period; however, they all are optimistic that the environment can become more inclusive. If the environment is more inclusive, the well-being of autistic employees will be higher, and companies can grow with a new-found respect for diversity (Black et al., 2018; DePape & Lindsay, 2016; Harmuth et al., 2018; Tint & Weiss, 2018)

Similar to the findings of Moyse & Porter (2015), all the participants spoke of the hidden curriculum that autistic individuals feel pressure to adhere to in school. However, as all of the participants were students and were completing school online, the pressure to camouflage was lessened. Many participants shared that they would turn off their microphones and cameras so they did not need to maintain a particular facial expression or tone of voice throughout the sessions. Additionally, all of the participants shared that they could stim more in online school settings, specifically when the camera could not see them during synchronous sessions.

Furthermore, camouflaging has been acknowledged as a way to achieve academic success for autistic students (DePape & Lindsay, 2016; Livingston et al., 2019). Some of the participants shared that they felt they achieved higher standards of education as their ability to camouflage supported them in staying in the classroom. Brede et al. (2017) assessed the lived experience of nine autistic youth in schools, and the results indicated that a common concern is that teachers will get frustrated with autistic traits and kick them out of the room. Inclusive education has made immense improvements in Canada (Bunch, 2015); however, a classroom is not genuinely inclusive if the students feel the need to camouflage to be successful. These findings of the experience of camouflaging in academic settings during the COVID-19 pandemic contribute new information to the body of literature on camouflaging. However, as students are returning to in-person education at the time of writing, more research is necessary to fully comprehend the experience of education when going from an online to in-person setting.

Overall, according to the participants, regularly camouflaging has benefits and costs. Of course, the impacts of camouflaging in the current study are not representative of the autistic community's experience of camouflaging, yet the findings are valuable to the literature. Like the descriptions of camouflaging provided in work by Frost and colleagues (2019), one participant shared that camouflaging is a 'double-edged sword.' There may be benefits to camouflaging such as developing relationships with others and becoming employed, yet the negative physical and psychological impacts are still present. How one views the impact of camouflaging on QoL is dependent on their own experiences and values. If the camouflaging costs outweigh the benefits, the individual will not camouflage as much; however, as all the participants shared, the benefits outweigh the costs, which is why they continue to camouflage.

Before any conclusions are made on the impact of camouflaging on QoL in autistic women, two final points need to be addressed. First, the participants shared that they view the impacts of camouflaging on their quality of life like a scale. Sometimes it tips towards the benefits, sometimes towards the costs, and sometimes it is even. As the participants expressed, they do not conclude that the impact of camouflaging is positive or negative based on minimal experiences. Some impacts are short-term while others are long-term; the participants weigh the pros and cons of camouflaging by looking at the 'big picture' of all the experiences together. Second, as Bernardin and colleagues (2021) suggest, the causality direction of camouflaging is unclear. This study does not conclude causality or objective associations between camouflaging experiences. For some individuals, their high camouflage rate may be associated with more anxiety, depression and stress (Cage et al., 2018; Hull, Lai, et al., 2020; Lai et al., 2017).

However, it is unclear whether those that have poorer psychological QoL result in people camouflaging more (Bernardin et al., 2021). Although the current study further contributes to the body of literature on camouflaging and QoL, further research is required to accurately identify how camouflaging impacts the objective physical, psychological, social, and environmental domains of QoL.

## Limitations

The present study used IPA to explore the experiences and impacts of camouflaging in five Canadian autistic women. As the methodological standards for IPA suggest small, homogenous sample sizes, the results of this study are not generalizable or representative of the autistic camouflaging experience. Moreover, the use of purposeful sampling resulted in the participant sample consisting of all white, cis-gendered, heterosexual adult Canadian women between the ages of 18 and 29 years old. Even though generalization of research findings is not a key facet of IPA, the experiences and impacts of camouflaging may be similar to the lived-experience of other autistic individuals. However, IPA's idiographic approach to analysis is not conducive to conclusive statements regarding the lived experience of a specific demographic or community. The results of the current study contribute to the autistic camouflaging literature; however, more inclusive research will need to be completed to gradually improve our understanding of camouflaging experiences and how they impact QoL.

Second, as the study was completed during the COVID-19 pandemic, the camouflaging experiences of the participants are not reflective of 'normal' camouflaging experiences. The consistently changing social expectations in environments due to public health restrictions resulted in many camouflaging experiences changing from one interview to the next. Additionally, with all the participants living in different provinces, except for two living in

Alberta, the camouflaging experiences often reflected the public health restrictions within their home province. Alberta, British Columbia, Ontario, and Nova Scotia all experienced the COVID-19 pandemic differently at one point; therefore, the context of the camouflaging experiences and impacts should always be considered.

Finally, in using CBPR and an ACP, the study did not include some of the data presented by the participants. Although the camouflaging experiences and impacts of camouflaging shared within the study were meaningful to the participant, it was decided by the ACP members and myself that if the data was presented in academic literature, it would further stigmatize the autism community, causing more harm than good. Good IPA research highlights the individual experience as expertise while good CBPR advocates for lived experience of community-based partners to be viewed expertise. As a result of the misalignment in methodological understanding of valuable lived experience as expertise, some data was removed from the results. This decision was made with the best of intentions for the autistic community as a whole; however, the efficacy of utilizing IPA and an ACP when completing autism-focused warrants further investigation.

## Future Directions of Research and Methodology

Considering this study's results, three research directions and methodology could improve our understanding of camouflaging and its implication for the quality of life in the autistic community. First, this study only looked at the lived experiences of autistic women in Canada between the ages of 18 and 29. Even within a homogenous sample size, there are still unique experiences and perspectives of camouflaging among the five participants in this study. For example, some participants started to camouflage at a younger age, while others only started to camouflage after they recently received their autism diagnosis. Therefore, future research should explore the experience of camouflaging in various demographics. Some suggestions that were not possible in this study could include those in the LGBTQ community, older autistic individuals, and those in countries and cultures where autism is viewed differently.

Second, as the participants suggested that their camouflaging experiences have changed since the pandemic's beginning, a longitudinal study would merit a unique opportunity for a deeper understanding of how camouflaging changes over time. Hickey and colleagues (2018) recently completed a study assessing the experiences of thirteen autistic individuals older than fifty. The experiences of their participants highlighted how loneliness and isolation are still common concerns because they feel like others don’t accept them for their autism (Hickey et al., 2018). As the autistic community ages, the experiences of those camouflaging now and growing up could lead to important findings in community, clinical, and educational approaches to improving outcomes (Hickey et al., 2018; Wise, 2019).

Finally, using mixed methods could be more useful in providing a more comprehensive understanding of how camouflaging impacts quality of life. As quality of life is subjective, measures indicating mental and physical health outcomes, employment and educational settings, and relationships with others could outline where resources should be allocated. As this study found, there are perceived benefits and costs to camouflaging regularly; highlighting which aspects of camouflaging can be addressed to improve the frequency of benefits could significantly impact the camouflaging experiences. On the other hand, mixed methods approaches should be used to assess further the relationship between internal and external autism acceptance with camouflaging experiences and impacts of camouflaging on QoL.

## Implications

The implications of this study are three-fold. First, as much of the current research surrounding autism is focused on cis-gendered male children, a male-biased understanding of autism has emerged. By exploring the experiences of autistic women in social settings, this study becomes a platform to share the lived experience of autistic women. As a non-autistic male, my understanding of the lived experience of autistic women is limited; however, after hearing the stories and perspectives of social interactions from the participants, my understanding has improved. By sharing the lived experiences of autistic women, those that are not autistic or women, may gain a better understanding of autism and, hopefully, more acceptance for neurodiversity.

Second, given that all the participants expressed that there are costs to camouflaging, community initiatives dedicated to supporting the community's wellbeing should target autistic women who camouflage regularly. Educators should be aware that even if an autistic student is ‘acting like everyone else’, that does not mean that the student is necessarily doing well. They could be camouflaging and exerting a lot of their energy into pretending to be someone else rather than focusing on the lesson. This concept of seeming fine when autistic individuals are actually struggling to keep their camouflaging mask on may also apply to employers. Community spaces like school, work, and other public settings, should regularly check in on the mental health of autistic individuals while also providing a safe and inclusive space where everyone feels comfortable being themselves.

Finally, after working with an Autistic Community Partnership, it is clear that this research approach is highly beneficial to the quality of the work and alignment of the implications with the needs and concerns expressed by the autistic community. I found the experience of working collaboratively with the ACP incredibly enlightening. Together, we created some best practices for participatory research that I can apply in the future. These best practices include: (i) promote collaborative efforts; (ii) avoid ableist language; and (iii) consider privilege and power dynamics between researcher and participant. The engagement, commitment and investment of the ACP members genuinely inspired and pushed me to work harder to complete and disseminate meaningful research.

## Conclusion

The purpose of this study was to contribute to a growing body of literature that explores the camouflaging experiences of autistic women, and the implications camouflaging may have on autistic quality of life. Overall, the results support the notion that camouflaging experiences differ based on several factors, including perceived level of social acceptance of autism, environmental demands, and the degree to which camouflaging is beneficial or harmful to their quality of life. By providing five autistic Canadian women the opportunity to share their unique camouflaging experiences, the literature becomes closer to providing a more comprehensive description of the phenomenon of camouflaging. Of course, the results of this study are not reflective of the experience of camouflaging within autistic women worldwide. However, to my best knowledge, this study is the first to explore the camouflaging experiences and implications of camouflaging on autistic QoL during the COVID-19 pandemic and within a Canadian context. Also, by following the combination of theoretical frameworks of FDS, CAS, and MSM, the results of this study are unique to understanding the phenomenon of camouflaging. Furthermore, the findings of this study highlight the amount of effort autistic women expend to fit into a society that is not entirely accepting of their autistic traits. This study is a stepping stone to future research and advocacy endeavours, a call to action for improved acceptance of neurodiversity in society and continuous reassurance that authenticity is attainable under the right circumstances.

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## Appendix A – Recruitment Materials

### Participants Needed for a Research Study!

The Experiences of Camouflaging in Canadian Autistic Women

Women who identify as autistic are invited to participate in a study that aims to better understand the experience of camouflaging autistic traits and it's impacts on their overall wellbeing.

Camouflaging can be defined as: strategies used by individuals with and without autism in an attempt to blend into their social surroundings by mimicking the behavior of others and, in the case of people with autism, to suppress autistic traits

The study involves two 60-minute interviews, each of which will take place online through video conferencing. Each participant will also be asked to keep a "camouflaging journal", which asks each participant to reflect on their experience of camouflaging for two weeks. It is estimated that each reflection will take approximately 15 minutes to complete. For the completion of these activities, participants will receive a $50 gift card.

We are seeking 18-35-year-old women who:

1. Have a diagnosis of Autism
2. Camouflage often or regularly
3. Speak English as their primary language

For more information, please contact:

Nick Denomey, M.Ed. Student

Dept. of Educational Psychology

University of Alberta

denomey@ualberta.ca

Pro: 00100983

## Appendix B – Letter of Initial Contact

RE: The Experience of Camouflaging in Canadian Autistic Women

Hello [NAME]

You are receiving this letter because you have expressed interest in participating in our study.

From this research, we wish to understand your perspective and your experience of camouflaging in your life. We will do this by listening to your stories and your suggestions on how to make the lives of people with autism better. It is anticipated that, through the results of this study, we can spark change grounded in the needs, concerns, and experiences of the autism community.

If you wish to participate in this study, please complete the screener survey attached to the bottom of this letter. This screener survey should take approximately 10 minutes to complete.

The survey will ask you questions about your:

- Age
- Gender
- Diagnosis
- Person-first or identity-first preference
  - Comfort using the online conferencing technology “Zoom” and with having your voice audio recorded

In addition to the information we collect from you, you will be asked to report how often you camouflage. Camouflaging and masking strategies are often used by individuals with and without autism to blend into social surroundings. They may copy the behaviour of others but, in the case of people with autism, it may mean hiding their autism (Robinson et al. 2020).

The following is an excerpt of an individual with autism expressing their experience with camouflaging:

> ***“I have to be hyper aware - almost 100% of the time – in order to successfully hide and suppress my natural autistic tendencies – Wherever I am – at home with my family – at school – at work, I am required to ‘mask my weird’ and attempt to pass as ‘normal’ or ‘neurotypical’”***

Based on the results of the screener, you may receive an invitation to participate in the larger study. All of your responses will be kept confidential. If you are not chosen to participate in the study, all of your information will be deleted.

Once we receive your response, we will contact you within 72-hours to provide more information about study participation.

If you have any questions, please feel free to contact us at aidanlab@ualberta.ca

Kind regards,

Nick Denomey

## Appendix C – Screening Questionnaire

Screening Questionnaire
This questionnaire will collect personal information that will determine if you are eligible to participate in our study

You will be asked to answer the following questions to the best of your abilities. If you do not feel comfortable answering any of the questions, feel free to select the option "I would rather not say".

Do you agree to complete the screener?

- Yes
- No

Question 1
You will now be asked to place your age in one of the following age ranges. For example, if your age is 25 years old, you should pick the range "25-29". If you feel uncomfortable answering this question, feel free to choose the answer "I would rather not say"

What is your current age?

- Under 18
- 18-23
- 24-29
- 30-36
- 37-43
- 44-50
- 50 or above
- I would rather not say

Do you have a legal guardian?

- Yes
- No

Question 2
You will now be asked to state your gender. If you feel uncomfortable answering this question, feel free to choose the answer "I would rather not say"

What is your gender?

- Man
- Woman
- Transgender
- Gender Non-Conforming
- Gender Non-Binary
- Gender Queer
- I would rather not say
- Other ____________

Question 3

You will now be asked to specify which diagnosis you identify with. If you feel uncomfortable answering this question, feel free to choose the answer "I would rather not say"

What diagnosis do you identify with?

- Autism Spectrum Disorder
- Autistic Disorder
- Autistic
- Asperger's Syndrome
- Asperger's
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder Not Otherwise Specified
- I would rather not say
- Other___________

Question 4

You will now be asked to state your preference on how you would like to be identified. If you feel uncomfortable answering this question, feel free to choose the answer "I would rather not say"

How do you identify?

- Person-first (e.g., person with autism)
- Identity-first (e.g., autistic person)
- I would rather not say
- Other __________

Question 5

You will now be asked to state your comfort level with the following aspects of the study

Are you comfortable with having your interviews audio recorded?

- Yes
- No

Are you comfortable with using the online conferencing program "Zoom" for the interviews?

- Yes
- No

Question 6

You will now be asked to report how often you use camouflaging techniques within your daily life. Camouflaging can mean many things to different people. For the sake of this study, camouflaging refers to using strategies to minimize the appearance of autistic characteristics within a social setting (Hull et al., 2019)

How often do you camouflage your autistic traits?

- Never
- Rarely

- Sometimes
- Often
- Always

# Appendix D – Information Letter and Consent Form

## *INFORMATION LETTER and CONSENT FORM*

The Experiences of Camouflaging within Canadian Autistic Women

| | |
|---|---|
| **Research Investigator:** | **Nick Denomey (M.Ed. Student)**<br>Dept. of Educational Psychology<br>University of Alberta<br>Edmonton, AB T6G 2G5<br>Tel. 905-516-3300<br>Email: denomey@ualberta.ca |
| **Supervisor:** | **Dr. Heather Brown (Assistant Professor)**<br>Dept. of Educational Psychology<br>University of Alberta<br>Edmonton, AB T6G 2G5<br>Tel. 780-243-3334<br>Email: heather2@ualberta.ca |

### *Background*

You are being invited to participate in this study because you have expressed interest in discussing your experience of camouflaging. This study is about understanding camouflaging and its impacts on your wellbeing. Camouflaging is often used by individuals with and without autism to blend into social surroundings. They may copy the behaviour of others but, in the case of autistic individuals, it may mean hiding their autism (Robinson et al. 2020). Sometimes, camouflaging can be used to improve social relationships, get a job, or do better in school. On the other hand, hiding their autism may impact their quality of life in a negative way. Someone's quality of life is measured by how happy they are with their life. It is also measured by how well people believe they are doing compared to others.

Our goal is to understand your experience of camouflaging. We will do this by listening to your stories. It is anticipated that, through the results of this study, we can spark change grounded in the needs, concerns, and experiences of the autistic community.

I will use the results of this study as part of my Master's thesis in the Educational Psychology, Special Education program at the University of Alberta. This project was supported financially by the Autism Edmonton & Autism Research Center graduate student grant, and by the Support for the Advancement of Scholarship grant from the University of Alberta, which was awarded to my supervisor.

Before you make a decision, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

*Purpose*

The purpose of this new study is to explore the experience of autistic women who use camouflaging strategies. We will also explore the positives and negatives of relying on camouflaging strategies, specifically in relation to your overall quality of life.

*Study Procedures*

If you consent to participate in this study, you will be asked to take part in a variety of tasks. First, we will ask you to keep track of your camouflaging experiences for two weeks. These journal entries will be completed online through Google Forms. Each journal entry will take close to 20 minutes to complete, but you are free to use more or less time to complete the task. All the journal entries from this task will be transferred to a password protected folder on the researcher's computer. Once the journal entries are transferred to the primary researcher's computer, the journal entries will be deleted from Google servers. The journal entries may be uploaded to a server outside of Canada, and as such may be subject to the privacy laws of that jurisdiction.

Next, two interviews will be conducted with you through video call. Each interview will take close to one hour of your time. These interviews will be completed on Zoom and cloud recorded. The recording may be uploaded to a server outside of Canada, and as such may be subject to the privacy laws of that jurisdiction. We will ask you questions about your camouflaging experiences and how it impacts your well-being. The researchers will give you an opportunity to review your data so that we can be sure that what you said is what you meant.

You will be asked if you agree to be video recorded for the individual interviews. If you agree to be video recorded, the clip could be used in a summary video. If we decide to use the clip in the summary video, you will be contacted to get your explicit written consent before we use it. This video will be used to describe the experience of camouflaging in a more artistic way. The goal of using multiple approaches to collecting information is to provide multiple ways of communicating the experience of camouflaging.

Once we have analyzed the data from your interviews, we will contact you with an opportunity to participate in a focus group discussion. This focus group will be used to make sure that the findings we have are interpreted correctly.

*Benefits*

There may be no direct benefits to participating in this study. However, you may feel a greater sense of 'autistic pride' and a better understanding of your wellbeing after discussing your experience of camouflaging.

We hope that the information we get from doing this study will help us better understand the female experience of autism. We hope the results of this study can further advocate for a reduced level of stigmatization surrounding the autistic identity by promoting neurodiversity, acceptance, and understanding of autism within the community.

### *Risk*

Participating in this project involves only minimal risk. You may feel vulnerable or uncomfortable discussing your experience of camouflaging. We will make every effort to make you feel comfortable during the interview. We would like to emphasize that you are free to not answer any questions we ask. We will respond to the unique needs of those involved and ensure that all parties give informed consent.

### *Compensation*

You will be compensated a total of $50 for your participation in this phase of the study. If you decide to withdraw from the study, you will still receive compensation for your participation.

### *Voluntary Participation*

You are under no obligation to participate in this study. The participation in this research is completely voluntary. In addition to being able to refuse to answer any questions during any of the interviews, you can withdraw completely any time from the beginning of the study until up to four weeks after your second interview. If you choose to withdraw from the study, you may contact the primary investigator with your statement of withdrawal.

### *Confidentiality & Anonymity*

The research collected from this study will be used for the main researcher's thesis. We will write a research article and publish the findings in academic journals with the data from this study. This research will also be presented at conferences. At all times, your name, and all personal information you provide will be kept confidential. You may request that your identifying information be made public. If you would prefer that your name is attached to the materials you create, we will respect your wishes and put your name on your work.

Only the main researcher and research assistants will have access to the data from this study. All confidential material, including study data, will be kept on a secure computer, and all digital media will be password protected. All research assistants will sign a form to ensure that they will keep your information private. All information will be destroyed after 5 years from the date you sign this consent form.

If you wish to withdraw from the study, all of your data will be deleted. All hard copies that you have submitted for the study will be shredded and any copies on the computer will be permanently deleted.

There are certain situations in which we may be required to break confidentiality by reporting to law enforcement or another agency. These include:

a) if you are at risk of imminent harm to yourself or someone else, or;

b) if a child is at risk for harm.

If this type of information comes up during the interview, we will work with you to access suitable supports.

*Contact Information*

If you have any questions or concerns about the research, please feel free to contact the study's Principal Investigator:

**Nick Denomey, BA Honours**

Dept. of Educational Psychology

University of Alberta

Edmonton, AB T6G 2G5

Email: denomey@ualberta.ca

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615. This office is independent of the researchers

***Consent Statement***

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

____________________________________________

Participant's Name (printed) and Signature

____________________________________________

Date

____________________________________________

Name (printed) and Signature of Person Obtaining Consent

____________________________________________

Date

I agree to have my real name used in the study. If yes, please complete the lines below. If no, please print "N/A" in the lines below

____________________________________________

Participant's Name (printed) and Signature

____________________________________________

Date

____________________________________________

Name (printed) and Signature of Person Obtaining Consent

____________________________________________

Date

I agree to be video recorded during the interviews. If yes, please complete the lines below. If no, please print "N/A" in the lines below.

____________________________________________

Participant's Name (printed) and Signature

____________________________________________

Date

____________________________________________

Name (printed) and Signature of Person Obtaining Consent

____________________________________________

Date

I agree to be audio recorded during the interviews. If yes, please complete the lines below. If no, please print “N/A” in the lines below.

____________________________________________

Participant’s Name (printed) and Signature

____________________________________________

Date

____________________________________________

Name (printed) and Signature of Person Obtaining Consent

____________________________________________

Date

## Appendix E – Journal Entries and Demographic Survey Prompts

Camouflaging Journal & Demographic Information

For this activity you will be asked to answer the following questions to the best of your abilities.

Demographic Questions

What is the highest degree or level of school you have completed? If you are currently enrolled in school, please indicate the highest degree you have received?

- Less than a high school diploma
- High school degree or equivalent
- Trades school
- College diploma
- Bachelor's degree (e.g., BA, BSc)
- Master's degree (e.g., MA, MSc, MEd)
- Doctorate degree (e.g., PhD, EdD)
- Prefer not to say
- Other: __________

What is your current employment status? Select all that apply.

- Employed full-time (40+hours per week)
- Employed part-time (less than 40 hours per week)
- Unemployed (currently looking for work)
- Unemployed (not currently looking for work)
- Student
- Retired
- Self-employed
- Unable to work
- Prefer not to say
- Other: ________

Do you have any comorbid conditions? If so, please choose all that apply. If you do not have any comorbid conditions, please select the option “Not applicable”

- Anxiety
- ADHD
- Bipolar
- Borderline personality disorder
- Depression
- Eating disorder
- Epilepsy
- Generalized anxiety disorder
- Learning disability (reading and/or writing)
- Learning disability (math
- Obsessive compulsive disorder
- Panic attacks
- Post traumatic stress disorder

- Social anxiety disorder
- Tourette's syndrome
- Prefer not to say
- Not applicable
- Other: _________

Autism Acceptance and Identity

"Autism is not an appendage. Autism isn't something a person has, or a "shell" that a person is trapped inside. There is no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person - and if it were possible, the person you'd have left would not be the same person you started with"

How much do you agree with this statement?
- Totally disagree
- Somewhat disagree
- Neither agree or disagree
- Somewhat agree
- Totally agree

Is your diagnosis of autism central to your identity?
- Yes
- No

Camouflaging

Camouflaging and masking strategies are often used by individuals with and without autism in an attempt to blend into their social surroundings by mimicking the behavior of others and, in the case of people with autism, to suppress autistic traits"

How much do you agree with this statement?
- Totally disagree
- Somewhat disagree
- Neither agree or disagree
- Somewhat agree
- Totally agree

If your definition of camouflaging is different, please describe the ways our definition is different than the one provided above.

______________________________________________________________________________
______________________________________________________________________________
_________________________________________________________________________

Do you wish to continue with this activity?
- Yes
- No

1. Hi! How are you? How was your day today?
    - Very bad
    - Bad
    - Fairly bad
    - Neutral
    - Fairly good
    - Good
    - Very good
2. Did you camouflage today?
    - Yes
    - No

Questions answered if they say “No” to Question 2

We ask that you reflect on why you did not feel the need to camouflage today. We have provided you with a lot of space to write, however, you are not obligated to fill the box.

3. Why did you not camouflage today?

________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

We ask that you reflect on how not camouflaging today made you feel. We have provided you with a lot of space to write, however, you are not obligated to fill the box.

4. How did not camouflaging today make you feel?

________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

We ask now that you please reflect on any benefits and/or costs that resulted from you not camouflaging today. We have provided you with a lot of space to write, however, you are not obligated to fill the box.

5. What were the benefits and/or consequences of not camouflaging today?

____________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

Questions Answered if they say “Yes” to Question 2

We ask that you reflect on what setting you felt the need to camouflage in today. Choose all that apply. If where you camouflaged is not an option, feel free to write it down under the "Other" category

3. Where did you camouflage today?

- School
- Work
- Home
- Shopping Centre/store
- Public transit
- Park
- Restaurant
- Other _________

We ask that you reflect on your experience of camouflaging today. We have provided you with a lot of space to write, however, you are not obligated to fill the box. We have also provided you with some ideas you may want to write about, however, you are not obligated to answer each of the prompt questions:

What aspects/traits did you choose to camouflage today?
Why did you camouflage these aspects/traits?
From whom did you feel the need to camouflage in front of today?
What strategies did you use to camouflage today?

4. Please describe your camouflaging experience today

_____________________________________________________________________________
_____________________________________________________________________________
_________________________________________________________________

We now ask if you could please add anything else about your camouflage experience today that we did not touch on in the previous questions. If there is nothing else you would like to add, feel free to just leave this question blank.

5. Is there anything else you would like to say about your camouflaging experience today?
_____________________________________________________________________________
_____________________________________________________________________________
_________________________________________________________________