"I Don't Mind People Hugging Me When I'm Happy." Autistic Individuals' Experience of Emotions on Their Sensory World: An Interpretative Phenomenological Analysis

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by
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Abstract

After the recent change in the diagnostic criteria of autism, sensory issues have been acknowledged as more than just an associated symptom of the condition. Current literature explored the social, emotional, and physical consequences of unusual sensory experiences on the lives of autistic individuals and gave an insight into the needs of this population. Literature also suggested a possible effect of emotional states on the sensory experiences of autistic individuals. In order to explore autistic individuals' experience of emotions on their sensory world, three autistic individuals were recruited and interviewed through semi-structured interviews, in person and via Skype. Interpretative Phenomenological Analysis was used to analyse the data and four main themes emerged: (1) experiencing sensations and emotions, (2) coping with consequences, (3) making sense: "the base part of what I have to do in my everyday life", and (4) the process of describing. The findings were discussed in the context of existing literature and theories. The key finding was that negative and extreme positive emotions increase sensory sensitivity in autistic individuals, whereas mild positive emotions decrease sensory sensitivity. The intensity and unpredictability of situations and stimuli also increase sensory sensitivity. The effect reported by participants was consistent with previous studies, but also provided new insight regarding the impact of positive emotional states on sensory experience in autism. Any implications for practice and an evaluation of the study were discussed and recommendations for future research were made.

Keywords: autism, sensory, emotions, qualitative, semi-structured interviews

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Table of Abbreviations

Table 1

Terms and abbreviations

Term	Abbreviation
Adolescent/Adult Sensory Profile	AASP
American Psychiatric Association	APA
Asperger syndrome	AS
Autism spectrum disorder	ASD
Central coherence	CC
Counselling psychology	CoP
Diagnostic and Statistical Manual of Mental Disorders	DSM
Grounded Theory	GT
High functioning autism	HFA
Intellectual disability	ID
International Classification of Diseases	ICD
Interpretative Phenomenological Analysis	IPA
Negative sensory experiences	NSEs
Pervasive developmental disorder not otherwise specified	PDD-NOS
Repetitive or restricted behaviours	RRBs
Theory of mind	ToM
Typically developing	TD
Unusual sensory experiences	USEs
World Health Organisation	WHO

Chapter 1: Introduction to Autism and Sensory Processing

Clarification of Terms

There is no single, universally agreed way to describe autism and indeed, there have been disagreements about how autism should be described. A number of style guides, such as the Publication Manual of the American Psychological Association (2010, p.72) mandates writers to use *person-first language* (e.g., person with disability, person with autism) so that every person is treated the same (i.e., as a person first). Most recently though, it has been suggested that person-first language fails to do what is meant to do and that in fact, it is more frequently used to refer to people with disabilities than to refer to people without disabilities who have been described using *identity-first language* (e.g., typically developing [TD] children; Gernsbacher, 2017).

Most importantly, there has been growing evidence suggesting that people on the spectrum prefer identity-first language when referring to them (Kenny et al., 2015). Therefore, in this study identity-first language will be used throughout.

"Atypical" and "unusual" will be used to describe sensory processing and sensory experiences, respectively. Even though *atypical* and *unusual* are deemed synonyms, the word *unusual* will be used to characterise sensory experiences as it is more subjective in nature, just like the experiences per se. In contrast, the word *atypical* presupposes a comparison to something known as *typical* and will therefore be used to describe the commonly reported sensory processing characteristics or atypicalities in autism, such as hypersensitivity, hyposensitivity and strong seeking or avoidant preferences towards stimuli that are typically regarded as neutral (Cole, 2015; Crane et al., 2009; Elwin et al., 2013; Kern et al., 2006; Watling et al., 2001).

Hypersensitivity occurs when the sensory stimulus feels too intense (Robertson, 2012). For example, an individual might perceive lights as too bright, odours as too strong, or sounds as too loud. In contrast, hyposensitivity occurs when the individual under-reacts to a stimulus, and therefore sometimes becomes unresponsive to, or appears to “ignore” the stimulus (Robertson, 2012).

On the other hand, “unusual sensory experiences” (USEs) will be used when describing the “what it is like to live with sensory atypicalities” drawn from first-person accounts and therefore, is subjective to each individual. It is assumed that USEs can be perceived as both positive and negative by different individuals, as this has also been supported by literature (see Consequences of Unusual Sensory Experiences section).

Personal Interest in the Topic

Growing up in a small, loving, educated family where individuality and uniqueness were always endorsed, I learnt to look for, appreciate and respect those qualities in people around me. When I was 18 and during a summer volunteering placement at the Cyprus Autistic Association, I became fascinated by the uniqueness and great potential of each autistic person I met and worked with. This led me to read a lot about autism and pursue research in this area. I came to believe that if appropriate attention and help is given to autistic individuals early on—to learn how to cope with difficulties, as well as develop and enhance their innate special skills—they can do remarkable things and reach their full potential.

I also became particularly interested in the sensory processing of individuals on the spectrum. Sometimes, I was even able to relate to them as I experience sensory sensitivities myself. After conducting the literature review for the purposes of this study and after becoming aware that emotional states can also impact sensory experiences, I was able to reflect on my own personal experiences. For instance, I noticed that when stressed, I become more sensitive to touch: I become distressed, or even angry when someone hugs me. Also, my duvet suddenly becomes heavier. I attempted to bracket these experiences away while conducting this research to avoid biases, as discussed more in the reflexivity section in Chapter 3.

What is Autism?

Autism, also referred to as autism spectrum disorder (ASD), is a pervasive developmental disorder characterised by impairments in two primary domains: social communication and interaction, and repetitive or restricted behaviours (RRBs; APA, 2013). Autism comes from the Greek word *autos*, meaning *self*, and was conceptualised by the German psychiatrist Eugen Bleuler in 1910 as the "withdrawal of the patient to his fantasies, against which any influence from outside becomes an intolerable disturbance" (Bleuler, 1910, p.171; Kuhn & Cahn, 2004). The concept of autism was described in the 1940s by the American psychiatrist Leo Kanner and the Austrian paediatrician Hans Asperger (Asperger, 1944; Kanner, 1943).

Kanner (1943) observed the cases of 11 children who shared similarities in a few domains. Through his observations, Kanner identified four main domains of impairment: social disturbances, communication problems, language difficulties and insistence to sameness (i.e., rigid, ritualistic, routinised behaviours; Kanner, 1943). In later years, the so-called *triad of impairments* was formed (Wing, 1993), suggesting the three main domains of social interaction, social communication, and RRBs are the clinical and diagnostic features of autism, supporting Kanner's account of *classic* autism.

Asperger (1944) assessed the cases of children in his practice who lacked nonverbal communication skills and empathy and who showed RRBs. Until the fourth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; APA, 1994) and the latest version of the International Classification of Diseases (ICD-10; World Health Organisation [WHO], 1993), Asperger's syndrome (AS) was diagnosed when individuals met the same clinical features as autism, but had no significant delays in language and cognitive development.

Autism is frequently accompanied by comorbid disorders and associated problems, one of which is intellectual disability (ID; APA, 2013) which is characterised by limitations in intellectual functioning, that is, an IQ score below or equal to 70 ($IQ \leq 70$) and adaptive behaviours (APA, 2013; Luckasson et al., 2002). Relatively recent accounts acknowledge that autism can occur at all levels of intellectual functioning, and it is estimated that around 15 to 25% of autistic individuals have additional ID (Chakrabarti & Fombonne, 2001; Gillberg & Soderstrom, 2003; Wing, 1996). Individuals with AS achieve a normal or above average IQ score, just like individuals with high functioning autism (HFA), yet with no communicative abnormality or language delay (Baron-Cohen, 2000).

Diagnostic Criteria

The APA and the WHO edit the diagnostic criteria of autism every couple of years and provide an updated version of the DSM and ICD, respectively. The latest version of the APA's (2013) standard diagnostic criteria (i.e., DSM-5) proposed major revisions in the diagnostic criteria of autism. Autistic disorder and AS, along with pervasive developmental disorder not otherwise specified (PDD-NOS) that did not meet full criteria for either autistic disorder or AS, now come under the umbrella of ASD receiving a single diagnosis of autism or autism spectrum disorder on a severity scale (APA, 2013; WHO, 1993). Another major change includes the merging of the domains of social communication and social interaction to form a single domain of social communication and interaction, and the addition of sensory atypicalities as a subcategory to the RRBs (APA, 2013). For the purposes of this thesis, I will use the word autism to define any individual with an ASD, unless specified otherwise.

Diagnosis

For a diagnosis of autism to be made, an individual must have deficits in social communication and social interaction across multiple contexts (APA, 2013). The individual must also be characterised by RRBs in at least two of the following: motor movements, insistence on sameness, restricted and fixated interests, hypersensitivity or hyposensitivity to sensory input, and atypical sensory seeking behaviour (APA, 2013). The diagnosis is being received on a severity scale and symptoms must be apparent in the early developmental period of the infant's life and are not being explained by an ID. At last, the diagnosis needs to clarify whether autism is accompanied by any ID, language impairment or other comorbidities (APA, 2013).

Prevalence and Causes

The prevalence of autism is estimated to be 1 in 59 children (Baio et al., 2018), a rate that has increased over the years (Chakrabarti & Fombonne, 2001; Hansen et al., 2015; Hyman et al., 2001; Zablotsky et al., 2015). This increase could be due to the expansion of the diagnostic criteria and autism as a context, increased awareness, study methodologies, or a true increase in incidents (APA, 2013; Fombonne, 2009). Also, the male to female ratio for the condition is approximately 4:1, suggesting that autism occurs more frequently in males than in females (Fombonne, 2009; Zablotsky et al., 2015). Nevertheless, it has been suggested that subtler manifestation of social and communication difficulties in females may account for this big difference in ratio (Rivet & Matson, 2011).

It is suggested that autism is inherited given the high concordance rate in monozygotic twins: 60 to 90%, in contrast with 0 to 10% in dizygotic twins (Bailey et al., 1995; Muhle et al., 2004). Studies also showed that parents with one autistic child have a chance of 2 to 18% to have a second child on the spectrum (Ozonoff et al., 2011). Advanced parental age (mothers aged 35 or older and fathers aged 40 or older) was also found to be associated with greater autism risk (Durkin et al., 2008). Other environmental factors, such as low birth weight and exposure to valproate also seem to play a role in the development of autism (APA, 2013). Nevertheless, the aetiology of autism remains a challenge for medicine and psychology (Acquarone, 2007).

Sensory Processing in Autism

The odd response to sensory stimuli of individuals on the spectrum was always acknowledged as a feature and marker of autism (Frith, 1989); even since Kanner and Asperger’s accounts (Asperger, 1944; Kanner, 1943). In Asperger’s (1944) account, children displayed both hyposensitivities and hypersensitivities to sensory stimuli. For instance, some children displayed preference to very sour or strongly spiced foods. Other children displayed strong dislike for certain fabrics and a severe difficulty, as well as aversion to specific daily activities, such as nail trimming. Also, children displayed an extreme sound sensitivity, yet, at times, expressed a strong seeking preference to other sounds.

Yet, it was not until recently that they were given more emphasis and acknowledged as more than just an associated condition (APA, 2013). More specifically, DSM-5 (APA, 2013) included “hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)” as one of the diagnostic criteria of autism under the broader category of RRBs.

Sensory processing in autism is broadly referred to as atypical, affects almost all individuals on the autism spectrum, and persists through development (Billstedt et al., 2007; Crane et al., 2009; Klintwall et al., 2011; Lane et al., 2011; Lane et al., 2010). Sensory issues have been described in the tactile, auditory, visual, olfactory (smell) and gustatory (taste) systems (O'Neill & Jones, 1997), which have been termed according to the senses. The proprioceptive system, which describes the unconscious awareness of body position and body parts, as well as the vestibular system, which controls our sense of balance have also been described in studies (Lane et al., 2011).

As also described in the DSM-5, sensory processing issues in autism can take many forms, yet they are broadly divided into three main patterns: sensory hypersensitivity, sensory hyposensitivity and sensory seeking (Baranek et al., 2006).

Popular Theories in Autism

Given that the aetiology of autism is still a very complex concept and subject to difference, theories have attempted to explain the causes of the behavioural representations of autism. Theories provide possible explanations of how faulty mind mechanisms that underlie specific mental functions interfere with behaviour (Hill & Frith, 2003). Some of the theories also involve theoretical assumptions about the origins of sensory atypicalities in autism. Nevertheless, there is no theoretical model that fully explains them (Gerrard & Rugg, 2009; Rogers & Ozonoff, 2005).

Theory of Mind, or Extreme Male Brain Theory

Theory of mind (ToM; Baron-Cohen et al., 1985), which is one of the most influential theories in autism (Simmons et al., 2009), hypothesises that autistic individuals have difficulty inferring mental states (i.e., beliefs, intents, desires) to oneself and others (Premack & Woodruff, 1978). In fact, it is believed that 80 to 100% of autistic children lack a ToM (Baron-Cohen, 1995; Baron-Cohen et al., 1985) and that this possibly explains the range of their communication difficulties (Frith & Happé, 1994).

According to ToM, autistic individuals have an inability to interpret other people’s actions, which creates problems in their social and affective relatedness to other people (Hobson, 1993). A desire to share intentions, thoughts and emotions with others is an essential motivator to communication, which autistic individuals seem to lack, and has a profound impact on their communication abilities (Tager-Flusberg, 1996). It is believed that autistic individuals lack this desire, given they are not aware that other people may have different beliefs, thoughts, emotions and that language is a key means of discovering these differences (Baron-Cohen et al., 1994).

Baron-Cohen (2002) has more recently transformed the ToM hypothesis to the extreme male brain theory of autism, which argues that autistic individuals are good *systemisers* and poor *empathisers* (Baron-Cohen, 2002), just like males when compared to females (Baron-Cohen et al., 2002). Empathising is related to the concept of the ToM as it involves the ability to understand the emotional state of others and have an affective response to it, whereas systemising refers to the analysis and prediction of behaviours in a systemized way (Baron-Cohen, 2002).

One of the criticisms of both theories though, is that they fail to account for the sensory difficulties experienced by individuals on the spectrum (Robertson, 2012). Other criticisms include real-world *insignificance* (i.e., systemising skills were not evident in a real-world context; Pellicano et al., 2011), lack of *universality* (i.e., a group of participants managed to complete the task required, indicating no ToM deficit; Happé, 1994) and lack of *objective* evidence to support the extreme male brain theory (Falter et al., 2008). Milton (2012) also added:

> *When such "empathy" is applied toward an "autistic person" however, it is often wildly inaccurate in its measure. Such attempts are often felt as invasive, imposing and threatening by an "autistic person", especially when protestations to the contrary are ignored by the neuro-typical doing the "empathising". (p.2).*

Central Coherence Theory

Central coherence (CC) is defined as the cognitive ability to pull information together for higher-level meaning (Frith, 1989). CC theory (originally known as weak central coherence theory; Frith, 1989; Happé & Frith, 2006) proposes that autistic individuals have a weak CC, that is, detailed-focused processing style (Happé & Frith, 2006). This is in-line with Kanner's observation that autism is characterised by an "inability to experience wholes without full attention to the constituent parts" (Kanner, 1943, p.246). This was explained as the result of superior local processing in autism (Happé & Frith, 2006; Shah & Frith, 1983). An example is the classic study of Bartlett (1932), where autistic children were able to recall specific details from a story they had been told, but were not able to recall the actual meaning of the story.

CC theory can explain some auditory and visual patterns observed in autistic individuals, such as their ability to attend to extreme detail. The latter also explains their superior performance in visual tasks, such as the Block Design test (Kohs, 1923; Wechsler, 1974) that requires the reconstruction of an original block pattern from separate blocks. Some studies (e.g., Baron-Cohen et al., 2009) support that CC theory can also explain hypersensitivities in autism as a result of the individual's extreme attention to detail.

Executive Function Theory

Executive function is the ability to problem-solve and plan, resist urges, temptations, and impulses, as well as have flexibility of thought, and action (Ozonoff et al., 1991). Executive function theory (Ozonoff et al., 1991) has attempted to explain some of the cognitive difficulties autistic individuals have that reflect deficits in executive function. This theory is in-line with Kanner's initial observations of autistic individuals' obsessive desire to maintain sameness, as well as their characterised limitation in variety of spontaneous activity (Kanner, 1943).

Even though executive function theory does not explain sensory difficulties per se, it does address the RRBs of autistic individuals by assuming these could be the result of an inability to shift attention from a stimulus (Turner, 1999). Nevertheless, later studies (e.g., Rogers & Ozonoff, 2005) found no association between executive function and patterns of RRBs.

Enhanced Perceptual Functioning Theory

Enhanced perceptual functioning theory (Mottron & Burack, 2001; Mottron et al., 2006) explains autism as the result of superior low-level perception; It claims that early processing of information from various sensory modalities results to increased attention in lower-order, automatic cognitive processes (e.g., pattern recognition) at the expense of higher-order, conscious ones (e.g., construction of meaning and social interaction; Mottron & Burack, 2001; Mottron et al., 2006). This is similar to the CC theory's premise that autistic individuals exhibit superior local processing abilities (Shah & Frith, 1983, 1993).

An interesting update of the enhanced perceptual functioning theory which used to claim that autistic individuals were biased towards local processing (Mottron & Burack, 2001), suggests that their extraordinary local processing is a result of a mandatory global bias in TD individuals (Mottron et al., 2006); Higher-order processing is fixed in TD individuals even when it affects their performance in tasks requiring local processing, whereas it is optional in autistic individuals.

Enhanced perceptual functioning theory explains some of the sensory difficulties in autism, as well as their exceptional performance in perceptual tasks (e.g., the Block Design task). It also seeks to explain the hypersensitivities of autistic individuals as a possible result of some pathological mechanism, such as atypical neuronal growth, or atypical functional persistence (i.e., increased refinement of low-level processes at the expense of higher-order ones; Mottron et al., 2006).

Even though this theory is consistent enough with the literature so far (Robertson, 2012), it does not account for all sensory atypicalities reported in the autistic population (e.g., hyposensitivities).

Neural Noise Hypothesis

Neural noise hypothesis (Rubenstein & Merzenich, 2003; Simmons et al., 2007; Simmons et al., 2009) supports the existence of high levels of *endogenous* (i.e., intrinsic) *neural noise* (i.e., neural responses of indeterminate origin) in autism that cause “noisy” and unreliable neural signals. Simmons et al. (2009) argued that neural noise can either enhance or disrupt stimulus detection and, therefore, in contrast to the above theories, the noisy neural signals in autism can account for both the hypersensitivities, and hyposensitivities experienced by individuals.

To explain this, Simmons et al. (2009) used Bertone et al.’s (2005) study where autistic individuals exhibited hypersensitivity to *first-order stimuli* (i.e., luminance-defined) and hyposensitivity to *second-order stimuli* (i.e., contrast-defined) compared to TD individuals. Given that first-order stimuli are detected easily requiring little stimulus noise, the increased neural noise in autistic individuals could therefore result in increased sensitivity (Simmons et al., 2009). On the other hand, second-order stimuli presuppose a noisier process to start with. Therefore, any noise increase in autistic individuals would result in a decrease in the signal-to-noise ratio (i.e., more noise than signal), which means decreased sensitivity and hence, poorer performance due to detectability difficulty (Simmons et al., 2009). One main disadvantage of this theory is the lack of adequate empirical data to illustrate the neural noise levels of autistic individuals.

Overall, the role of these theories is to advance our understanding and provide explanations of the complex concept of autism and its causes, by linking mental functions to expressed behaviours. However, it seems they provide more *functionalist* and *cognitivist* explanations of autism and consider cognition, perception and behaviour, as separated domains (De Jaegher, 2013; Happé et al., 2006). De Jaegher (2013), quite interestingly noted “in a way, this is a kind of “weak coherence” view of mind. Or, in the words of Baron-Cohen (though he does not apply this term to autism theories), it is a systemising way of thinking" (p.4).

Nonetheless, autism does not have a single cause and we do not have to seek for a single theory to explain all characteristics and impairments of the condition. In fact, it has been suggested that "a single theory might be intractable" (Bolis & Schilbach, 2018, p.169). Thus, it is wise to be aware of how each theory explains what it aims to explain and consider all aspects so that we can apply them both to inform practice, as well as provide possible explanations to research findings.

Autism and Mental Health

In his original description of classic autism, Kanner (1943) referred to the substantial anxiety problems exhibited by the children he observed. Yet, the evaluation and treatment of mental health problems in this population received empirical attention only over the last few decades.

Epidemiological studies suggest that mental health problems are more common within the autistic, rather than the general population with a 54 to 70% prevalence rate (Croen et al., 2015; Romero et al., 2016; Simonoff et al., 2008). Table 2 shows prevalence rates of anxiety disorders, depression, attention deficit hyperactivity disorder, schizophrenia and bipolar disorder in the autistic versus the general population. It also includes prevalence rates of *alexithymia* (i.e., difficulty with emotional awareness, especially in identifying and describing own emotional states, as well as recognizing others'; Cameron et al., 2014), which seems to account for some of the emotional difficulties in autism as discussed below.

Anxiety disorders, such as social anxiety, are found to deteriorate with age (Bellini, 2006; Rutherford et al., 2002; Tantam, 2003) and persist through the lifespan of autistic individuals (Moss et al., 2015). Sometimes, anxiety in autism can be explained by autistic

Table 2

Prevalence rates of mental health conditions

Mental health condition	% in the autistic population	% in the general population
Anxiety disorders	11 to 42[a,b]	3 (children)[e], 15 (adults)[f]
Depression	7 (children)[c], 26 (adults)[a]	2 (children)[e], 7 (adults)[g]
Attention deficit hyperactivity disorder	30 to 61[b]	6 to 7[e]
Schizophrenia	4 to 35[d]	0.3 to 0.8[h]
Bipolar disorder	6 to 27[a]	4[i]
Alexithymia	55[j]	17 to 23[k]

[a]Croen et al. (2015). [b]Romero et al. (2016). [c]Greenlee et al., 2016. [d]Chisholm et al., 2015. [e]Perou et al. (2013. [f]Kessler et al., 2009. [g]National Institute of Mental Health (NIMH; 2017). [h]Moreno-Küstner, et al. 2018. [i]Kessler et al., 1994. [j]Milosavljevic et al., 2016. [k]Loas et al., 1995.

symptoms such as difficulties in social communication and interaction, as well as extreme sensory sensitivities to stimuli (Green & Ben-Sasson, 2010; Green et al., 2012).

Even though it is almost always assumed that autistic individuals prefer social isolation, many individuals reported that they are aware of their social disconnectedness and often wished that this was different (Attwood, 2000). Individuals with HFA are at greater risk for developing depression, anxiety and low self-esteem compared to autistic individuals with additional ID. This was said to be due to their awareness of their social interaction difficulties (Tse et al., 2007; White et al., 2009).

Also, in cases of autism and comorbid anxiety, anxiety can have a bidirectional effect with the social difficulties encountered in autism. For instance, social anxiety can lead to further social isolation, avoidance of social situations and awkward interactions with people (Myles et al., 2001).

On the other hand, others (e.g., Bird & Cook, 2013) argue that emotional difficulties in autism are associated to comorbid alexithymia and that are not caused by autism per se. Studies conducted on individuals with and without autism, and with varying degrees of alexithymia supported the above hypothesis. For instance, Cook et al. (2013) sought to find out whether alexithymia was responsible for face perception difficulties that were previously attributed to autism. In their study, autistic individuals and alexithymia-matched controls had no differences in their ability to recognise emotional expressions, suggesting that alexithymia, and not autism, is a predicting variable of expression attribution. Also, high-alexithymic individuals (autistic, or not) were able to describe physical differences present in morphed facial stimuli, yet were unable to interpret any emotional content (Cook et al., 2013), again suggesting that severe alexithymia, and not autism, is responsible for emotional awareness difficulties.

In another study by Bird et al. (2010), functional magnetic resonance imaging showed that there were no differences in the degree of empathy between autistic and control groups after accounting for alexithymia, supporting therefore their hypothesis that empathy deficits observed in autism could be attributed to the very often co-occurring condition of alexithymia, rather than representing a feature of social difficulties in autism.

In the recent study by Maisel et al. (2016), the association of emotional acceptance, alexithymia and intolerance of uncertainty with anxiety in autism was investigated. Questionnaires measuring core symptoms of autism, anxiety, emotional acceptance, alexithymia and intolerance of uncertainty were completed by adult autistic individuals and TD controls. The directional relationships between variables were tested and results suggested that increased levels of anxiety within autistic individuals are due to aversive reaction to emotional experiences and lack of ability to identify and understand emotions (Maisel et al., 2016).

Researchers support that autism, along with comorbid conditions, impairs functioning in autistic individuals and their families. Longitudinal studies showed that if left untreated, mental health problems of autistic individuals can have detrimental consequences in their lives, even for those with higher-functioning abilities and no additional intellectual, or language impairments. Such consequences include difficulties with meaningful and gainful employment, difficulties with autonomy and independent living, poor quality of life and adaptive functioning impairment (Farley et al., 2009; Gillberg et al., 2016; Howlin & Moss, 2012).

Access to Mental Health Care

In the 1970s and after the shift of mental health care from institutions to the community (i.e., *deinstitutionalisation*), access to high-quality mental health care has become a public concern (Gerrard & Rugg, 2009; Ziring et al., 1988). Yet - even nowadays - individuals with developmental disabilities experience great difficulty accessing the mental health care they need (Maddox & Gaus, 2019).

Maddox and Gaus (2019) outlined both the encouraging positive developments in community mental health care for autistic adults and the barriers autistic individuals face in accessing community mental health services. Positive developments included: more awareness and recognition of autism by clinicians, willingness and requests for further training in autism by clinicians and services, and recognition that mental health conditions, such as depression and anxiety, are distinct from autism and therefore, recognition of the benefits of psychological treatment for autistic individuals (Maddox & Gaus, 2019). Barriers faced by autistic adults included: lack of communication and integration between developmental disability related services, and mental health care services that results in individuals falling through the “cracks” and receive no, or inadequate care in each system, “punting” (i.e., when an autistic individual seeks support for anxiety or depression from mental health services and gets punted to developmental disability related services, and vice versa), unskilled or unconfident clinicians, and financial constraints of autistic individuals due to unemployment or underemployment which restricts choices about where they can access mental health services (Maddox & Gaus, 2019).

Chapter 2. Literature Review

The aim of this chapter is to review existing literature in regards to sensory processing in autistic individuals, including literature on atypical sensory processing and USEs, as well as their consequences on the lives of individuals. This chapter also explores the potential effect of emotional difficulties on sensory experience. At last, it includes the rationale and aim of this study and expands on its relevance to counselling psychology (CoP) and the role of counselling psychologists in supporting individuals on the spectrum.

Atypical Sensory Processing

Crane et al.’s (2009) quantitative study used self-reported questionnaires (i.e., Adolescent/Adult Sensory Profile [AASP]; Brown & Dunn, 2002) to assess the levels of sensory processing of adult autistic individuals and TD matched controls (aged 18 to 65). The results illustrated atypical levels of sensory processing in the everyday lives of autistic individuals compared to TD individuals across several sensory modalities, with a prevalence of 94.4% and a persistence throughout the lifespan. Autistic individuals showed extreme levels of sensory hyposensitivity, hypersensitivity, and sensation avoidance, but not sensation seeking. The results indicated within-group variability in the autistic group, suggesting different, yet equally severe sensory “atypicalities” within the autistic population.

Given that this study only recruited a small sample of participants (i.e., 18 autistic and 18 TD individuals), their results regarding the prevalence of sensory issues in the autistic population could be questioned about their generalisability. Nevertheless, the noted prevalence in their study is consistent with the prevalence rates found in other studies, such as the 95% prevalence of sensory atypicalities in 281 autistic children in Tomchek and Dunn’s (2007) study.

Cole’s (2015) study sought to replicate the research done by Crane et al. (2009), that is to assess the levels of sensory processing of autistic individuals and compare them with TD controls. Cole’s (2015) study recruited young adults (aged 18 to 24) with HFA and AS and compared their results to those found in Brown and Dunn’s (2002) standardisation study. Using the AASP, Cole (2015) found that young autistic adults exhibited sensory processing issues compared to TD individuals and more specifically, unresponsiveness, as well as avoidance to sensory stimuli, hence validating the findings by Crane et al. (2009).

Cole (2015) also found significant differences between mean scores of different sensory modalities (i.e., visual, touch, auditory, movement, and taste/smell and activity level modalities) within all four sensory quadrants (i.e., sensory sensitivity, sensation avoidance, sensation seeking and low registration or hyposensitivity quadrants). Participants reported greater sensitivity to auditory stimuli and less sensitivity to visual stimuli, less avoidance to visual stimuli and greater avoidance to auditory stimuli. The results of this study suggested modification of the AASP that only illustrates results on how sensory processing information is processed as a whole (i.e., across the four sensory quadrants) instead of how information is processed according to different sensory stimuli. The results also highlighted the complexity and variability of sensory issues within the autistic population.

These results, as well as Crane et al.’s (2009) findings, coincide with Dunn’s theory of sensory processing (1997). Even though not specific to autism, this theory suggests that low neurological *thresholds* (i.e., when people notice and respond to sensory stimuli more easily) interact with behavioural responses and thus, cause sensory sensitivity and sensory avoidance, whereas high neurological thresholds (i.e., when the neurological system of people require stronger stimuli to get activated) result in unresponsiveness and sensation seeking. This theory could potentially explain the outcomes and within-group variability found in both aforementioned studies. Therefore, I would have been very keen to read the author’s thoughts on this in their discussion.

Also, Cole’s (2015) study involved a very small sample size (i.e., 14 participants) and no control group. In addition, the normative data’s [i.e., the data from the standardisation study of Brown and Dunn (2002)] age distribution was much greater (i.e., individuals aged 18 to 64) than the ASD’s group in Cole’s (2015) study, hence compromising the validity of their results.

Even though data obtained directly from the participants of interest themselves is always most preferable, research in the autism population most often comes from second-hand account studies (Rogers et al., 2003), often derived from parent- or carer-reported questionnaires, with the Sensory Profile (Dunn, 1999) being one of the most popular ones.

Kern et al.’s (2006) study aimed to explore sensory processing of autistic individuals (aged 3 to 53) and TD matched individuals across different age stages, using the Sensory Profile. The questionnaire was either completed by parents, carers, or spouses, and in some instances by participants themselves (e.g., TD individuals aged 21 or over). Their results indicated significant between-group differences in all auditory, visual, touch, and oral sensory modalities, with the autistic group exhibiting atypical sensory processing compared to the TD group.

Interestingly, this study also found a change (i.e., improvement) in the sensory processing of autistic individuals with time, illustrating similarity in sensory processing between the two groups. The latter was not consistent with pre-existing literature though that supported the persistence of sensory atypicalities through the lifespan of autistic individuals.

Kern et al. (2006) omitted to expand on their finding that TD individuals’ sensory processing also changed with time. They found an increased responsiveness to sounds, as well as increased sensitivity to lights in older TD individuals compared to younger ones. Therefore, I would have been very keen to read a discussion or reflection in their paper regarding this finding, and also how they would link this to the sensory processing similarity found between the two groups with time. In addition, this study collected data from parents’ reports who may have underestimated their children’s sensory difficulties at an older age.

Indeed, several studies to date illustrate atypical sensory processing in autistic individuals compared to TD individuals (e.g., Kern et al., 2006; Kern et al., 2007; Leekam et al., 2007). Given that the results of these studies are not totally consistent in regards to specific sensory modalities, it is proposed that individuals on the autism spectrum are characterised by different sensory atypicalities (i.e., not specific to a single domain).

Nevertheless, a second-hand, quantitative study by Klintwall et al. (2011) performed structured interviews with the parents of 208 young autistic children (aged 20 to 54 months) to explore possible domain-specific sensory difficulties in autism. Parents’ reports suggested that the majority of children exhibit hypersensitivity to sound (44%) and hyposensitivity to pain (40%). In addition, 20 percent show hyposensitivity to cold and 7 percent to heat, 19 percent show hypersensitivity to touch and 5 percent to smell, and another 19 percent have an abnormal response to visual stimuli. The results of this study therefore suggested that sensory atypicalities in autism are exhibited more in the sensory domains of sound and pain.

Unusual Sensory Experiences

I have a natural interest in the subjective nature of experiences (see Reflexivity section); in this instance, I am interested in how it is like to live with atypical sensory processing. I am keen to explore research that involves qualitative methodologies that aim to understand meanings of experience, behaviour, actions, and events using interpretations of the participants, the researcher and cultures (Creswell, 2009). In addition, it allows for a deeper understanding of the lived experience of individuals.

This part of the literature review will focus on qualitative studies, as these are of a particular interest to Counselling Psychology (CoP), as well. Indeed, CoP is interested in the *person* and how one makes sense of their experience; this underpins CoP's philosophical base and ethical stance (Woolfe, 1990; Woolfe et al., 2009).

The first published first-hand account, qualitative study is the one by Jones et al. (2003). The aim of this study was to explore the sensory experiences of adult autistic individuals, using self-published online accounts of five individuals who self-identified with HFA. Data was analysed using the qualitative methodology of Grounded Theory (GT; Strauss & Corbin, 1990) and four categories emerged: turbulent sensory experiences, coping mechanisms, enjoyable sensory experiences and awareness of being different. These results suggested that individuals on the autism spectrum experience both distress and enjoyment as a result of their atypical sensory processing. In addition, they suggested that autistic individuals with USEs tend to develop coping mechanisms that enable them to deal with the distress caused by those experiences and even, in some instances, to derive some enjoyment out of them. The development of coping mechanisms could also explain Kern et al.'s (2006) finding that sensory difficulties of autistic individuals improve with time. Nevertheless, their sample presupposes good cognitive function (i.e., individuals who are able to express their experiences in writing and with good awareness of their experiences) and therefore, the developed theory may not be applicable to all autistic individuals.

A small number of studies have also looked at sensory experiences of autistic children. For instance, Robertson (2012) employed small, interactive group interviews with autistic children (aged 9 to 14 years), as well as a focus group with nine adult caregivers of autistic children (not related to the children participating in the study) to explore the living sensory experiences of autistic children, the effects of USEs on their lives, as well as the coping mechanisms developed. This study used General Inductive Approach (Thomas, 2006) to analyse their data and results indicated both enjoyable and upsetting reactions to sensory experiences. In general, hypersensitivity was suggested to lead to discomfort and hyposensitivity to sensation seeking. Even though children experienced negative reactions to a variety of stimuli across all sensory modalities, auditory stimuli caused them the most difficulty. Stimuli characteristics (e.g., certain textures) and control over stimuli played an important role in children's perception of sensory stimuli - a result also found in adult studies (e.g., Robertson and Simmons, 2015). The effect of USEs on children, as expressed by both children and caregivers is outlined in the *Consequences of unusual sensory experiences* section below.

The above study recruited verbal autistic children, without having any inclusion or exclusion criteria in regards to their cognitive functioning. Indeed, the author noted that some children in her study exhibited lower language abilities and had difficulty staying focused on tasks compared to the rest of the children. The author also noted that richer and higher in volume data was produced by higher functioning children. Nevertheless, similar concepts emerged from all children suggesting that sensory experiences are similar despite their difference in communication ability. This study also showed how children are able to take part in qualitative studies and indeed, provide fruitful information about their experiences.

Kirby et al. (2015) conducted a phenomenological study to explore the perspectives of autistic children on their sensory experiences. They recruited 12 autistic children aged 4 to 13 years of age and interviewed them at their homes using face-to-face semi-structured interviews. Flexible, non-prescriptive coding elicited three main themes in relation to how children share their sensory experiences: by normalising, storytelling, and describing their responses to their sensory experiences. More specifically, children perceived their experiences as “normal”, felt that they were “as other people" and termed them as "likes and dislikes". Children felt motivated to change in order to expand their daily activities and as part of growing up. Storytelling methods used by children involved anecdote, internal dialogues, demonstration and simile. Last but not least, children described their reactions to sensory experiences, which included coping strategies, uncontrollable physical reactions and fear (Kirby et al., 2015).

The study implemented some very useful and thorough techniques to ensure rich data collection. Interviews were video-recorded, which was proven very effective, as it allowed reference to the children's body language and body mannerisms. The interviewers also used salient clips of the children's recorded experiences (i.e., home-videos) to facilitate discussion during interviews. They also personalised interview procedures to meet the individual needs of children (e.g., in some instances, children preferred to respond to questions with a pen and paper). All the above, enhanced feasibility of interviews and the study concluded that children can successfully participate in such studies.

In their study, Smith and Sharp (2013) employed a modified version of GT (Charmaz, 2006) to explore how USEs affect the lives of nine adult individuals with AS, and how they cope with them. Online interviews were carried using an instant messaging platform. Overall, individuals reported avoidance of overwhelming situations, which often results in further social difficulties. For instance, solely the interaction with people can cause them sensory stress (e.g., others being noisy). Therefore, individuals tend to avoid or escape such situations, or even attack the source of sensory stress (e.g., "If someone touches me when I am rocking, I will thrust towards them"; Smith & Sharp, 2013, p. 898). Some coping strategies reported are utilising *moderating factors* (i.e., factors that make sensory events better or worse). For instance, individuals tend to avoid eye contact in order to block out multiple inputs that make sensory events unbearable.

Interestingly, *emotional dysregulation*, which is a central theme in autism (Chamak et al., 2008) occurred as an important factor in the emerged theory in Smith and Sharp’s (2013) study. More specifically, it occurred that negative experience of sensory stimuli results in great distress, and also high levels of stress result in increased sensitivities, which then cause greater distress, and so on. The authors named this vicious cycle *sensory avalanche*.

As the authors already noted, it would have been helpful if the study involved a more standardised tool to elicit information in regards to sensory experiences, such as the Sensory Profile (Dunn, 1999), to complement the interview process. This would potentially elicit more information in relation to hyposensitivities that were underrepresented in the study.

Another key, qualitative and more recent study is the one by Robertson and Simmons (2015) that employed Thematic Analysis (Holton, 1975; Merton, 1975) to gain an insight into the sensory experiences of six adult individuals with HFA. This is the first *published* study that employed focus groups as a means for data collection. Thematic Analysis showed USEs (both positive and negative) in all individuals, which often result in physical, as well as emotional reactions. It was suggested that when participants have control over the stimuli (e.g., being the “stronger” person in a hug) and when specific aspects of stimuli (e.g., texture) are bearable, then individuals perceive stimuli as enjoyable, which in turn has a positive effect, and physical reaction on them, and vice versa.

Their results also suggested that negative emotional states can both alter sensory perception, as well as be a consequence of interaction with “negative” sensory stimuli. For instance, a participant reported that her anxiety could affect whether she was able to enter a busy environment. This finding is consistent with Smith and Sharp’s (2013) stress avalanche theme.

Consequences of Unusual Sensory Experiences

Literature suggested that USEs and atypical sensory processing, in general, impact on the lives of autistic individuals. This section will therefore focus on the physical, social and emotional consequences of USEs.

Physical

Evidence suggests that hypersensitivity to stimuli can cause individuals pain and discomfort. For instance, individuals reported feeling pain after exposure to unnatural (e.g., fluorescent) lights, loud noises, light touch (even light hugs), and certain scents (Robertson, 2012; Robertson & Simmons, 2015). Autobiographical accounts also reported pain resulting from exposure to bright, flashing and strobe lights (e.g., McKean, 1994), and unexpected sounds (e.g., Grandin & Scariano, 2005). Headaches, migraines, nausea, sickness (Robertson, 2012; Robertson & Simmons, 2015), food selectivity issues and restricted diets (Carrington & Graham, 2001; Cermak et al., 2010; Cornish, 1998) were also reported as some of the negative physical consequences of exposure to sensory stimuli. On the other hand, hyposensitivity was reported to cause stimulation seeking behaviours, which sometimes lead to self-injuries, or self-stimulation behaviours (Bogdashina, 2003).

Evidence also suggests that sensory perceptual difficulties can result in exhibition of RRBs, which often have calming properties (e.g., by seeking deep pressure) and provide pleasure (e.g., fascinating smells, movements and patterns; Chamak et al., 2008).

Literature also reported positive physical consequences of USEs. For instance, Smith and Sharp (2013) reported calming and pleasurable aspects of USEs (e.g., an “obsession” with music which improves a participant’s mood), as well as remarkable skills or abilities gained due to USEs (e.g., remarkable hearing abilities, such as hearing the trains from five miles away).

Social

USEs often result in exhibition of challenging behaviour in autistic individuals as outlined below. It was suggested that one of the consequences of challenging behaviour is isolation and restriction, especially in relation to social events (Robertson, 2012). Caregivers reported being put in uncomfortable positions due to the challenging behaviour of their child and therefore, avoid places that cause their child distress. They also reported that others (e.g., friends and relatives) sometimes avoid engaging with them because of the challenging behaviour of their child (Robertson, 2012).

Social consequences of USEs also involve avoidance of other people, given that speech and body language can overload the autistic individual (Smith & Sharp, 2013) and damage social interactions with other people (e.g., not focusing on the other person) due to distraction and fixation to odd sensory stimuli (Smith & Sharp, 2013).

However, some positive social consequences were also reported by individuals as a result of their remarkable skills and abilities gained due to their USEs. For instance, a few participants in Smith and Sharp’s (2013) study reported positive interactions and admiration from others due to their remarkable skills (e.g., hearing the train from five miles away), which in turn helped in self-acceptance.

Emotional

Evidence suggests that hypersensitivity to sensory stimuli can cause distress, discomfort (Bogdashina, 2003) and anxiety (Green & Ben-Sasson, 2010; Green et al., 2012). Smith and Sharp (2013) reported that one major long-term effect of USEs is depression due to social isolation and loneliness resulting from USEs. Fear (Robertson, 2012; Smith & Sharp, 2013), anger, urge to attack, escape, or avoid sensory stimuli (Smith & Sharp, 2013), as well as challenging behaviour (Bogdashina, 2003; Robertson, 2012) have also been reported as some of the emotional consequences of USEs. Sensory-related anxiety has been included as a subscale in the recently-developed anxiety scale for autistic children by Rodgers et al. (2016), suggesting that sensory concerns are very critical and prevalent in autism. Indeed, studies (e.g., Uljarević et al., 2016) found that the more severe the sensory dysfunction in autism, the more severe the anxiety of individuals is.

The psychophysiological study by Corbett et al. (2016) investigated physiological stress response during peer interaction, as well as the role of sensory sensitivity in autistic children and TD controls. Salivary cortisol (i.e., the “stress hormone”) measures were taken before, during and after peer interaction to measure stress levels. These were also compared to parent reports of child stress and sensory sensitivity. Statistical analyses showed increased cortisol levels in response to peer interaction in autistic children compared to TD children. Higher cortisol levels were also associated with greater sensory sensitivity and increased stress, in general and was unique to the ASD group suggesting that sensory dysfunction in autism may lead to increased physiological stress (Corbett et al., 2016).

In another psychophysiological study by Green et al. (2015), the aim was to explore brain activity and habituation to mildly aversive sensory stimuli in autism by comparing functional magnetic resonance imaging of high-functioning autistic children with, and without hypersensitivity to sensory stimuli and TD matched controls. They also aimed to explore whether hypersensitivity was related to regulation of emotional response to sensory stimuli or to abnormalities in sensory processing. Their findings showed more activation in primary sensory areas, as well as the insula, amygdala and orbitofrontal cortex in the autistic children compared to TD children, suggesting increased anxiety during emotional processing of sensory stimuli. This activation was found to be positively correlated with sensory hypersensitivity, especially when multiple sensory modalities (i.e., auditory and tactile) presented simultaneously, suggesting that autistic children with hypersensitivity have difficulty regulating their emotional response to aversive sensory stimuli. Their findings suggested that this was due to failure to habituate in autistic children with sensory hypersensitivity compared to autistic children without sensory hypersensitivity and TD children (Green et al., 2015).

Interestingly, it was suggested that sometimes anxiety can further affect sensation. Smith and Sharp (2013) themed sensory avalanche to explain the vicious cycle being created when sensory stimuli cause stress, and then stress causes more sensitivity to sensory stimuli, and so on. Therefore, it seems that not only USEs cause stress, but stress in general can worsen the negative impact of USEs on individuals. Similarly, Robertson and Simmons's (2015) emerged themes suggested that negative emotional states can both be a consequence of interaction with negative sensory stimuli, as well as affect sensory perception.

The following section focuses on how known emotional difficulties in autism may affect the sensory experiences of individuals.

Emotional Difficulties in Autism and Sensory Experiences

Green and Ben-Sasson (2010) proposed a theory that seeks to explain how anxiety contributes to sensory hypersensitivity in autism. Their theory suggested that hyperarousal and hypervigilance in anxiety focuses attention on one specific type of sensory stimulus. Therefore, when an autistic child is hypervigilant and continuously scans the environment for threats, they are very likely to notice and react to sensory stimuli and less likely to regulate their emotional and physiological reaction to those stimuli. This reaction can also worsen through classical and interoceptive conditioning (i.e., the association of an aversive event with a previously-neutral stimulus and the association of a stimulus with a physiological reaction, respectively). Green and Ben-Sasson (2010) explained that this in an oversimplified model though that does not account for possible genetic or environmental influences to the aetiology and course of anxiety and sensory hypersensitivity (Green & Ben-Sasson, 2010).

Milosavljevic et al.'s (2016) study explored the prevalence of alexithymia in autistic adolescents and its relationship to sensory sensitivities, emotional, and behavioural symptoms and cognitive performance. This was the first study to explore the relationship between co-occurring alexithymia and sensory sensitivities in autism. Cognitive, as well as self- and parent-measures were used to assess 56 verbal autistic adolescents and 32 adolescents without autism. Their findings showed increased anxiety, emotional difficulties, sensory processing difficulties (i.e., hyposensitivity) and difficulty with emotion recognition (i.e., anger) in autistic individuals with co-occurring alexithymia (Milosavljevic et al., 2016).

Neil et al. (2016) investigated the relationship between anxiety, intolerance of uncertainty and sensory sensitivities in 64 autistic children and 85 TD children. Parents' reports illustrated greater levels of anxiety, sensory sensitivities and intolerance of uncertainty in autistic children compared to TD children. Statistical analyses illustrated that intolerance of uncertainty predicted sensory sensitivities in both groups of children, yet the predictive power of intolerance of uncertainty was greater in autistic children. This was partially mediated by anxiety levels (Neil et al., 2016), illustrating that the greater the anxiety and intolerance of uncertainty, the greater sensory sensitivities are.

In addition, *emotional dysregulation*, which is a central theme in autism (Chamak et al., 2008; Mazefsky et al., 2013) was found to be a significant predictor of intolerance of uncertainty (when controlling for anxiety) by Lindstone el al. (2014), suggesting that autistic individuals with emotional dysregulation may find uncertain situations and events as very distressing and hence, develop strategies to avoid uncertainty, as well as fear conditioned responses to uncertain situations (Lidstone et al., 2014).

Zantinge et al. (2017) suggested that individuals with emotional dysregulation may experience heightened physiological arousal which may then compromise development of more adaptive strategies to regulate emotions and sensations and hence, result in dysregulated reactions like self-injury, aggression and tantrums (Mazefsky et al., 2013; Zantinge et al., 2017).

Rationale

After the recent change in the diagnostic criteria of autism (APA, 2013), sensory issues have been acknowledged as more than just an associated symptom of the condition and more researchers got involved in relevant research studies.

Whilst reviewing the literature, it has become apparent that negative emotional states, difficulty recognising and regulating emotions, as well as intolerance of uncertainty can affect sensory perception in autism and as a result compromise the quality of life of individuals on the spectrum. Overall, research primarily focused on the impact of USEs on the lives of individuals, providing evidence for the physical, emotional and social consequences of USEs. Even though literature suggests that the opposite is sometimes the case (i.e., emotional difficulties affect sensory experiences), there is a general lack of research on how emotions and emotional difficulties affect sensory experiences within the autistic population.

Additionally, qualitative studies demonstrated that fruitful and significant information can be elicited from first-hand accounts and provide valuable recommendations for further research and implications for practice.

It should be noted that a critical literature review, over a systematic review, was done for the purposes of this study. Nonetheless, attempts were made to ensure that most, if not all existing literature on the topic was considered but no set method was followed. More specifically, databases such as PubMed and Science Direct were used to find existing literature on the sensory processing of autistic individuals, as well as literature on their sensory experiences, preferably including qualitative data. The current Chapter was concerned about reviewing and evaluating literature and placing the current research within the existing body of knowledge (e.g., by identifying potential gaps in the literature), instead of finding all existing evidence to answer a specific research question. This study's aim and research question stemmed from the critical literature review as it was suggested by studies to be an interesting, yet under-researched area of study.

Research Question and Aims of Study

The research question proposed is "How do autistic individuals experience and understand the potential impact of emotions on their sensory experiences and what the process of describing this part of their sensory world is like for them?"

Aims. This study will attempt to understand the emotional and sensory experiences of autistic individuals, particularly whether and how emotional experiences affect and shape their sensory experiences. This will potentially add to existing knowledge and provide practitioners, especially psychologists, with guidance and ideas on how to work therapeutically with these individuals and assist them on how to cope and manage a broad set of difficulties that usually come with autism, like emotional and sensory difficulties.

Relevance to Counselling Psychology

CoP is particularly interested in exploring barriers to quality of life, as well as in developing, advancing and adopting techniques and interventions to improve quality of life.

There is substantial evidence to support that certain emotional difficulties (e.g., emotional dysregulation, alexithymia, anxiety, intolerance of uncertainty) co-occur with autism instead of being caused by it, yet they tend to worsen autism symptomatology (e.g., sensory sensitivities, RRBs, social isolation and withdrawal). Unfortunately, autistic individuals even though more prevalent than others to mental health issues, they tend to fall through the cracks of the mental health system and their needs get neglected.

This study may potentially provide more insight about the emotional needs of autistic individuals, as well as inform practice and provide useful recommendations (even for continuing professional development training) on working therapeutically with autistic individuals. Adopting therapeutic models to the needs of autistic individuals is vital for better outcomes in practice, which in turn reflects the person-centred ethos of CoP (Woolfe et al., 2009).

The role of counselling psychologists in supporting autistic individuals with unusual sensory experiences. The role of counselling psychologists in the lives of autistic individuals often involves working alongside with caregivers and family members in a systematic way to enhance therapy and family relationships. Indeed, literature (e.g., Robertson, 2012) supports the role of caregivers in enhancing the positive sensory experiences of the autistic individuals, as well as helping the individuals make adaptations (e.g., develop compensatory strategies) so that they can interact with sensory stimuli in the social context. Very often, atypical sensory processing, exhibiting as USEs, causes lots of stress on both the individual and the people around them. Stress and mood problems though, seem to worsen the USEs.

Counselling psychologists can therefore intervene to assist the individual in managing and regulating emotions, including intolerance of uncertainty, as well as in improving mood and coping with USEs. They can also intervene to help caregivers support and enhance the positive experiences of autistic individuals. Therefore, understanding more about the sensory experiences of autistic individuals could prove to be highly informative and helpful for caregivers and relevant professionals.

Chapter 3. Methodology

Research Design

The sensory world of autistic individuals was investigated using qualitative methods. Data was collected from three autistic individuals via a semi-structured interview and Skype and was analysed using Interpretative Phenomenological Analysis (IPA; e.g., Smith et al., 2009).

Rationale for IPA

The aim of this study was to gain an understanding on how autistic individuals experience and make sense of the impact of emotions on their sensory world and what is the process of describing this part of their sensory world like for them. In-depth personal accounts were sought in order to explore that. A qualitative method was pursued as it has been described as the most suited to eliciting and analysing such information (Willig, 2013). Given the limited existing information in literature, no quantitative methods were considered for the purposes of this research.

IPA was chosen as the most appropriate methodology as it engages with people's reflections of their unique lived experiences, explores how people make sense of them (Larkin & Thompson, 2012; Smith et al., 2009) and is therefore consistent with the research aims of this study. IPA has also been suggested when exploring sensory perceptions, in general (Pietkiewicz & Smith, 2012).

Alternative qualitative methodologies considered for this study were Grounded Theory (Strauss & Corbin, 1990) and Constructing Grounded Theory (Charmaz, 2014). The latter is closer to my epistemology as a researcher as it brings relativity and subjectivity into the process. Although similar to IPA in its genuine interest to explore meaning of a phenomenon using participants' accounts, both approaches to GT also aim for the development of a theory that can be generalised to a more general population. They achieve that through hypothesis testing and theoretical saturation (Dallos &

Vetere, 2005). The reason IPA was chosen over GT approaches is because this research is more concerned in using emerging themes to inform literature and practice rather than developing an explanatory theory. In addition, given the limited existing knowledge about the phenomenon under investigation, essential exploratory research is more essential prior to attempting to develop a theory.

Introduction to IPA

IPA is a qualitative method of data analysis which is designed to explore how people make sense of their unique lived experiences (Larkin & Thompson, 2012; Smith et al., 2009; Smith & Osborn, 2008), by providing an *idiographic* (i.e., focused on the particular, as opposed to the general), yet in-depth analysis of people's subjective and conscious experiences. It is committed to detail and depth of analysis (Smith et al., 2009) and interested in how the particular, such as a subjective experience, is understood from the perspective of particular people, in a particular context (Smith et al., 2009).

IPA provides a *phenomenological* approach that is "exploring experience in its own terms" (Smith et al., 2009, p. 1) to the interpretation of the participants' accounts (Larkin & Thompson, 2012; Larkin et al., 2006; Smith et al., 2009). As Larkin et al. (2006) specifically described, IPA is *giving voice* to the concerns of the participants and *making sense* of these accounts by seeking to interpret their meaning.

IPA aims to "get close to the participant's personal world" (Smith & Osborn, 2008, p. 53), and then interpret it in order to understand the participant's particular experience (Smith et al., 2009; Smith & Osborn, 2008). In other words, the researcher engages in a *hermeneutic* process of "making sense of the participant trying to make sense of what is happening to them" (Smith et al., 2009, p. 3). This process is referred to as the *double hermeneutic* process which acknowledges the impact of the researcher's subjectivity (i.e., experiences, feelings, understanding of the world) on the interpretation of data. IPA stresses the importance of the awareness of our own material as researchers, as well as the importance of our commitment to grounding our interpretations in our participants' views and encourages reflexion upon our role (Larkin & Thompson, 2012).

It is important to highlight that the findings of IPA studies cannot be generalised to the wider population of interest. Yet, IPA never sought to do so in the first place given that is more interested in in-depth analyses of particular phenomena (Larking & Thompson, 2012; Pietkiewicz & Smith, 2012).

Philosophical Stance of IPA

Ontological and epistemological positions, i.e., philosophical stance, inform methodological choices in research, including data collection, analysis and interpretation of data (Hesse-Biber & Leavy, 2010; Smith et al., 2009). *Ontology* is the study of existence, whereas *epistemology* is the study of knowledge (Burr, 2015). Ontology is concerned with what is out there to know and epistemology is concerned with what and how we can know (Burr, 2015).

IPA's philosophical stance is influenced by phenomenology, idiography and hermeneutics. The German philosopher and founder of phenomenology Edmund Husserl (Sawicki, n. d.) believed that in order to examine someone's subjective experience, one should "bracket" the *natural attitude,* and seek to describe it as it appears in the world, i.e. *ontological realism* (Henton, 2015; Maxwell, 2012), without any speculations (Shinebourne, 2011; Smith et al., 2009). Nevertheless, as Heidegger argued, the person is embodied and embedded in the world, in a particular historical, social, and cultural context and that inevitably, a phenomenological description needs to be interpreted in order to convey meaning (Shinebourne, 2011). Therefore, our understanding of this world is a construction from our own perspectives, i.e. *epistemological constructivism and relativism* (Henton, 2015; Maxwell, 2012), which also reflects the humanistic values of counselling psychology (Orlans & Van Scoyoc, 2008; Woolfe et al., 2009). *Critical realism* is a sequence of both the positions above and suggests that different perspectives of the world are equally possible (Bhaskar, 1975; Guba & Lincoln, 1994). Critical realism is also the theoretical stance of IPA (Henton, 2015), which in turn reflects my own epistemological position as a researcher and practitioner. Indeed, counselling psychology stresses individual complexity and the uniqueness of subjective experience and encourages researchers to reflect upon their own position or subjectivity as it acknowledges that it is impossible for us to position ourselves "outside" the process of our work, both in regards to research and practice (Orlans & Van Scoyoc, 2008; Woolfe et al., 2009).

Reflexivity

The role of the researcher is not totally objective. Personal and professional experiences play a role in the development of the theoretical standpoint of the researcher. It is therefore vital for the researcher to acknowledge the possible influences so that they can understand how these impact on their conceptualization of the world and the participants' experiences (Etherington, 2004).

Reflexivity means "bending back upon oneself" (Finlay & Gough, 2008, p. ix), that is, to be self-aware, thoughtful and aware of the dynamics in the researcher-participant relationship. Reflexivity is said to be essential in qualitative research as it can provide an opportunity to the researcher to "justify" his, or her interpretation of the participants' material and construction of research findings (Finlay & Gough, 2008).

This section provides my personal reflections, as well as my epistemological and ontological orientation as a researcher.

Epistemology

Autism, as a *spectrum*, implies a continuum, that is, a condition that is not limited to a specific presentation and is constructed differently according to the specific and unique presentation of each individual.

Overall, I like to believe that all human beings are unique and that we should not overgeneralise someone's experience. In regards to autism for example, I always like to think that "If you have met one person with autism, you have met one person with autism" (first quoted by Dr Stephen Shore who was autistic himself). This means that each individual on the spectrum is so unique that is impossible to meet another one with the exact same presentation or experiences.

I believe that autism, as a concept, is a matter of change and expansion. This is apparent with the change and update of the diagnostic criteria of autism through the years (Volkmar & McPartland, 2014). For example, in the early years, autism was considered the result of parental psychopathology (Bettelheim, 1972), as well as an early manifestation of childhood schizophrenia (Volkmar & McPartland, 2014). Therefore, solely the recognition that autism exists and stands on its own, as well as the later development of multiaxial approaches to diagnosis that specified the level of functioning of the individuals diagnosed, were major advancements (Volkmar & McPartland, 2014). A most recent example, is the recognition of sensory difficulties as one of the diagnostic criteria of the condition and not just as an associated condition.

Also, I believe that better understanding of the subjective experiences of the population of interest definitely affects this expansion and shapes our understanding of it, as it "gives voice" to individuals, silenced by how knowledge has been mainly produced so far (i.e., through quantitative studies). Hence, the outcomes of my study in relation to the impact of emotional states on the sensory experiences of autistic individuals may influence the conceptualisation of what being autistic and experiencing a range of emotions and sensations is like.

Personal Reflexivity

I engaged myself in deep reflections to uncover any unconscious driving forces that may have influenced the research process. I came to realise that my research question, as well as third question of the interview schedule (see Appendix A), imply an effect of emotions on sensations. This was due to my own personal experience with USEs, as well as beliefs, which were reinforced after finding indications for this impact in the literature (e.g., Robertson and Simmons, 2015).

My own USEs also led me to believe in the following hypothesis: Negative emotions negatively affect sensations and positive emotions positively affect sensations. This hypothesis is not only limiting, but it also implies a very simple and straight-forward relationship between sensations and emotions. After reviewing the literature, I realised that this relationship is not as simple and that emotional experiences and difficulties, can vary and therefore, their impact on sensations, if any, can vary too.

I also came to realise that during the first two interviews, I tried hard to “bring” participants back to my questions, rather than allow them to talk about what was important to them. Upon reflection, I realised that the reason for that was that during my training and whilst working therapeutically with a number of autistic individuals, they tended to wander off topic very often and I had to, then, bring them back to the topic as we only had a limited number of sessions for our work. In addition, given that finding participants for this study was quite hard, I was afraid I would not have enough data to analyse and therefore tried, through my questions, to elicit as much relevant information as possible.

Indeed, I remember that during the first two interviews, often wondering “How does that answer the question?” After engaging with the data though, I realised that the data collected was very fruitful and interesting. After recruiting the third participant, I felt great relief, as I had the recommended amount of participants for such a study.

Therefore, during the interview, I allowed her more time to talk about whatever she felt was important.

Participants

IPA methodology requires *purposive* sampling of participants through inclusion and exclusion criteria in order to achieve a *specific* and fairly *homogenous* sample. The reason is that the phenomenon under investigation will be of particular significance for the group of participants and that findings will be product of *theoretical generalisability* (i.e., possible to draw links between study findings, own experience and claims in literature). The above will also allow exploration of psychological variability within the group of participants, or in other words exploration of the similarities and differences between the participants (Pietkiewicz & Smith, 2012; Smith & Osborn, 2008; Smith et al., 2009).

The idiographic nature of IPA encourages a small sample size to ensure an in-depth analysis of the phenomenon under investigation. Smith and Osborn argue that researchers should sacrifice “breadth for depth” (p. 56). More specifically, they recommend a sample size of three participants for students doing IPA for the first time (Smith & Osborn, 2008).

Inclusion and Exclusion Criteria

To increase specificity and homogeneity of the sample, the following inclusion and exclusion criteria were set:

- The participants hold a clinical diagnosis of HFA or AS (APA, 1994), or a diagnosis of autism with no additional ID or language impairment (APA, 2013). High-functioning adults were recruited to ensure effective communication of experience and emotions (Ozonoff et al., 1991). It seems that research in this area, in general, is benefiting more when recruitment of participants involves those in the higher-functioning side of the spectrum, given they are more able to provide fruitful information, especially in qualitative research (Robertson, 2012).

- The participants are adults (aged 18 to 65 years of age).

  Even though literature supports that children are also able to draw on their own experiences and communicate these effectively (Robertson, 2012), this study recruited adult autistic individuals given that literature suggested that with time, autistic individuals learn how to deal with their difficulties more effectively (i.e. *emotional maturation*, Robertson, 2012; Smith & Sharp, 2013). Hence, it was assumed that adult participants are better able to make sense of their experiences, as well as draw possible links between their emotions and sensory experiences.
- The participants are English-speaking.

  Native, English-speaking participants were recruited to ensure effective communication and avoid any translation biases.
- The participants believe they experience unusual sensory symptoms, such as hypersensitivity and hyposensitivity to sensory stimuli, sensory avoidance and sensory seeking behaviours. The above have been suggested as the sensory atypicalities experienced by many individuals on the autism spectrum by literature (e.g., Crane et al., 2009; Kern et al., 2006), as well as the diagnostic criteria of autism (i.e., APA, 2013). These were also the phenomenon under investigation in this study.
- The participants have no moderate to severe anxiety, nor depression. This, is to minimise the possibility of distress during data collection (see Recruitment and Ethical Considerations sections).

It is important to note that both male and female individuals were chosen to be recruited as, according to literature (e.g. Robertson, 2012), no significant sensory differences exist between the two groups.

Participant Information

The group of participants consisted of three native English-speaking, adult, verbal autistic individuals with a clinical diagnosis of autism and no moderate to severe anxiety, nor depression. More detailed information, including depression and anxiety scores, diagnosis information, and data collection method for each participant is provided in Table 3.

Table 3

Participant information

Pseudonym	**Age**	**Diagnosis**	**Age of diagnosis**	**Interview method**	**Depression (PHQ-9 score)**	**Anxiety (GAD-7 score)**
Mary	32	AS	31	Face-to-face	Mild (6)	Mild (10)
Zoe	36	HFA	35	Skype	Minimal (1)	Minimal (1)
Paul	20	HFA	5 to 7	Skype	Minimal (3)	Minimal (4)

Procedure

Recruitment

The study gained full ethical approval from the London Metropolitan University Ethics Committee prior to recruitment. The recruitment strategy involved contacting organisations, such as the National Autistic Association, Research Autism and Scottish Autism for help in advertising my study through their websites and circulating my advertising sheet (see Appendix B) with their contacts and potential participants. It also involved posting the advertising sheet online on Facebook groups, such as the Autism Friendly UK group.

To ensure genuine interest of participation, autistic individuals were asked to email me expressing their interest in participating. They then received an information sheet (see Appendix C) that outlined the purpose and aim of the study, as well as their right to withdraw. They also received anxiety and depression scales (i.e., PHQ-9; Kroenke et al., 2001) and GAD-7; Spitzer et al., 2006); see Appendix D and Ethical considerations sections) to complete and return. Participants were also asked to verbally confirm their clinical diagnosis and year of diagnosis. If participants met all inclusion criteria, an interview date was arranged.

I was happy to make arrangements to meet participants anywhere in the UK at local universities or libraries for the purposes of the interview prior to me leaving the UK in August 2018. Skype was later offered as the only means to interview and was granted ethical approval before any arrangements could be made. The duration of the interview was approximately one hour for each participant and were conducted between June 2018 and February 2019. Participants were given a £10 Amazon gift voucher as a benefit for participating in this study, which was self-funded.

Recruitment was more difficult than I initially anticipated and only three participants were recruited. This was both a strength and a limitation of the study as further discussed in Chapter 5. It has been suggested that a good sample size for IPA is between three and six participants (Smith et al., 2009; Thomson, Smith & Larkin, 2011). Indeed, during the first International IPA Conference, held in Glasgow in 2017 (Smith, Larkin & Flowers, 2017), it was quoted that three participants is a very good sample size for a Doctoral Thesis.

Data Collection

Audio-recorded, semi-structured interviews in person and via Skype were used for the purposes of this study. One participant was interviewed in person at her local library and the rest of the participants were interviewed via Skype. Participants were encouraged to be interviewed alone, in a quiet room with a good internet connection to avoid any interruption to the interview (Smith & Osborne, 2008).

Semi-structured Interviews

Semi-structured interviews is a flexible data collection method that allows the researcher to modify questions to fit the participant's responses so that significant and interesting material is elicited. Usually, the researcher creates an interview schedule (see Appendix A for the interview schedule used in this study) with a set of questions based on their idea of the area of interest and the questions they want to pursue. Semi-structured interviews are only "guided" by the interview schedule and not "dictated" by it (Smith & Osborn, 2008) as participants are encouraged for further elaboration or clarification and to discuss what is important to them so that richer data is produced.

Skype Interviews. Skype is a software that allows free communication over the internet and a means to audio or video interviewing. Skype has the advantages of overcoming time and financial constraints, as well as geographical dispersion (Janghorban et al., 2014).

Observing nonverbal communication is encouraged in interviews to monitor the effect of the interview or specific questions on the participant (Smith & Osborn, 2008). This can be compromised in Skype interviews; even with the use of video camera, the view of the participant's body language is limited (Bayles, 2012).

Establishing rapport did not seem to have been compromised in this case as participants expressed themselves freely and appreciated the option to be interviewed in the comfort of their homes.

Transcription

Audio-recorded interviews were transcribed verbatim. Smith et al.'s (2009) transcribing and APA's formatting guidelines were followed for transcribing collected data. More specifically, ellipses were used at the end of a participant' statement to indicate a “tailing off” of speaking or at the beginning of a sentence to indicate that the participant was continuing from a previous thought. Nonverbal communication such as significant pauses, laughs, and sighs were noted in square brackets. Long pauses (i.e., longer than 5 seconds) in speech were also noted, whereas slight pauses were indicated by commas. Inaudible words were identified in parentheses and emphasised words were italicised. Any identifiable information was altered or removed. False starts, such as when a participant does not finish a word or changes their thought part way through a sentence, were indicated by a long dash.

Data Analysis

IPA has not a prescribed single method for analysing data (Smith et al., 2009). Smith et al. (2009) and Larking and Thomson (2012) suggested analytic steps to be used as guidance by researchers rather than a prescription and encouraged researchers to be “innovative”. As a novice qualitative researcher and given that this was my first “serious” attempt with IPA, I followed Larking and Thomson’s (2012) suggested analytic steps while also keeping Smith et al.’s (2009) suggestions in mind and adapting them in a way that made more sense to me. More specifically, the following steps were followed:

1. The transcripts were read several times and my emotional responses, initial ideas about potential themes, assumptions, psychological concepts, and interesting sayings were noticed. This helped in the identification of my own preconceptions so I could then bracket them away during coding, and stay close to the participants words.
2. A close, line-by-line analysis of the experiential claims, concerns, and understandings of the participant, i.e. *phenomenological coding* (Larkin & Thompson, 2012) was noted on the right margin of the transcript, along with some possible interpretations in brackets.

3. The third stage involved the identification and development of themes. The left margin of the transcript was used to give flexible, yet descriptive titles.
4. Once the phenomenological core of the data was mapped out, the right margin of each transcript was used again, to note, in a different colour, my interpretative ideas, i.e. *interpretative coding* (Larkin & Thompson, 2012) about what it might mean for my participants to have such concerns, as well as some thoughts that were due to be analysed further in the written narrative.
5. Once both phenomenological and interpretative coding (see Appendix E for a sample of an annotated transcript illustrating analytic steps 2 to 4) was completed, the salient and most interesting aspects of the participant's account were noted on a Word document (see Appendix F).
6. The above steps were then repeated for each subsequent transcript. It was aimed and attempted that each transcript was treated on its own terms in order to secure the idiographic nature of IPA.
7. The final stage involved looking for patterns across cases (see Appendix G) and the construction of a table of master themes and subthemes (see Table 4) where the emerging themes from all transcripts were brought together. This stage took time, effort and reflection. I shared my ideas about potential labels to themes with colleagues and classmates before I decided on the final theme labels.

Improving Quality of Findings

Researchers should demonstrate quality, commitment, transparency and rigour in their methodological process so that their findings can be trustworthy and valuable

(South & Rodgers, 2017). Certain steps were taken in order to improve the quality of findings.

To begin with, published IPA studies and guidance by Larking and Thompson (2012) and Smith et al. (2009) were used to learn about and familiarise myself with IPA. Also, I attended the International IPA conference of 2017, where I had the chance to learn more, ask questions and advice from the founders of IPA themselves (e.g., Professor Jonathan Smith).

In terms of commitment, significant time was taken for the analysis of data (i.e., approximately one month for each case). When writing the findings of this study, excerpts from the participants' transcripts were used to allow the reader to judge whether the interpretation of the participants' concerns are plausible. In addition, the transcripts were read by the research supervisor who also closely observed the process of developing the themes. Peers and colleagues were also consulted during the process of developing the themes. Last but not least, reflexive statements were included in the narrative to inform the reader of any biases, as well as the thinking process in order to increase transparency.

Ethical considerations

A full ethical approval was sought and gained from the London Metropolitan University Ethics Committee. This study also followed the Code of Human Research Ethics of the British Psychological Society (BPS, 2014) and the following principles were applied:

Consent

Prior to the interview date, participants were sent information sheets (see Appendix C) that outlined the purpose, and aim of the study and their right to withdraw (i.e., up to four weeks after the interview day), as well as informed consent forms (see Appendix H). Participants were allowed ample time to consider their participation in the study to avoid undue pressure to consent (Willner, 2003). Once participants agreed to continue with participating in the study, they were required to complete, sign and return the consent forms by email, indicating their voluntary participation.

Confidentiality

The face-to-face interview was conducted in a pre-booked room at the council library of the participant's hometown. Prior to conducting any Skype interviews, I read Skype's user agreement to ensure confidentiality of contents. During Skype interviews, I ensured I was alone in a quiet room and asked participants to do the same. Interviews were recorded in a password-protected device. Data was pseudo-anonymised and all identifiable information was excluded from the transcripts and narrative. Data was stored in password-protected devices that only I had access to and will be disposed once I will be awarded with the Doctorate.

Managing Distress

Even though the nature of the study was unlikely to cause any distress per se, I did acknowledge that solely, social contact with me could cause that. In order to prevent that to the highest degree possible, participants with moderate or worse scores on either, or both the PHQ-9 depression scale and the GAD-7 anxiety scale (see Appendix D) were excluded from participation. It is easy to assume that talking about emotions and experiences can potentially cause some distress or produce uncomfortable feelings to any individual. This was taken into consideration whilst deciding on the target population and inclusion, and exclusion criteria of the study (i.e., emotionally "mature" individuals; see Inclusion and Exclusion Criteria section). Last but not least, participants were given the time they required during the interview process and were allowed to take regular breaks, if they wished to.

Thankfully, none of the participants reported experiencing any kind of distress during the interview. Nevertheless the following plan would have taken place if any distress did occur. I would have initially used my clinical skills to try and manage the situation. If further support was required, the interview process would have terminated and participants would have been advised to contact the services provided in the list (see Appendix I for the service list) for emotional and psychological support.

Debriefing

The contact details of the researcher and the research supervisor were included in the debrief sheets (see Appendix J) provided after the interviews, in case participants wished to raise any concerns and complaints, or ask further questions after the interview. At last, participants were asked whether they wished to receive a final report with the outcomes of the study once it is completed.

Chapter 4. Findings

Reflections on the Analysis

During the interpretative stage of the analysis, I caught myself struggling. Upon reflection, I realised that I was afraid to interpret and risk to lose any truthfulness, or misinterpret the reality of the participants. Therefore, I ensured that my interpretations are reflected in various points in the transcripts. I also attempted to provide a number of possible interpretations where possible.

I also remember feeling thrown, but at the same time amazed by how differently each participant experienced the effect of emotions on their sensory world. My initial assumptions and hypothesis on this relationship (see Personal Reflexivity section) were proven very simple to account for the experiences of all the participants.

Deciding on theme names was again, a tough process. I engaged in worrisome and self-doubting thinking processes. Talking to classmates and family helped to ease those thoughts, as well as receive feedback on the analysis.

Themes

Four main themes, often referred to as master themes, emerged from the analysis. Findings are displayed as main themes with their constituent subthemes in a table (Table 4) and a narrative format. The table provides an overview of the themes and subthemes along with indicative quotes from the transcripts of the participants' interviews. The narrative analysis describes these and also offers my interpretations.

The indicative quotes underwent some minor changes to become more readable; utterances such as “um”, have been removed and added words (for clarification purposes) were displayed within brackets. Three dotted lines in parentheses indicate that segments of the quote have not been included as they were not giving any significant information. Participants' direct quotes are italicised to differentiate them from any interpretations and emphasised words were double-italicised (i.e., standard type).

Table 4

Table of themes and subthemes with sample quotes

Master themes	Subthemes	Indicative quotes (participant: line number)
1. Experiencing sensations and emotions	a. Reactions to sensory stimuli: Physical and emotional	“When they were strobe lights (…) it would just give me headaches and make me feel uncomfortable.” (Paul: 95-97)
	b. Receiving “too much” information	“Too much information and it's just loud, *loud* all the time and you can’t really hear people speaking (…) you just hear noise - an overwhelming noise.” (Mary: 272-275)
	c. The impact of emotions	“I don't mind people hugging me or touching me (when happy).” (Mary: 359-360)
2. Coping with the consequences	a. Developing strategies	“I always pretty much wear headphones whenever I'm outside, just to play music and stuff, just to kind of draw it (noise) out” (Paul: 12-14)
	b. Compromising (for the sake of social life)	“The thing that's going to happen from now on is we're probably gonna take two cars (…) we've got a plan for me to leave if I need to…” (Zoe: 367-373)
	c. Withdrawing: Mental or physical escape	“I just used to like switch *off* and basically kind of not be there and removed myself sort of mentally…” (Zoe: 195-197)
3. “The base part of what I have to do in my everyday life”: Making sense	a. Sense of self: Labelling and ability to cope	“As I’ve got older, I've realised that I don't feel normal and I don't come across as normal.” (Mary: 66-67)
	b. A conscious process	“I kind of got this barrier that it stops things through, making sure that it makes sense before it gets in my head.”
	c. Normalising: A protective process	“Some neurotypical people feel like that as well.” (Mary: 332)
4. The process of describing	a. Talking about it	“I can throw a bunch of words and say it is *like* this and I can give you a general idea.” (Paul: 604-605)
	b. The experience of talking about	“It's *very* hard to describe what it *exactly* feels like.” (Paul: 414-415)

Theme 1. Experiencing Sensations and Emotions

Participants' reactions to various situations seem to shape their experience. This theme explores participants' emotional and physical adverse reactions to sensory stimuli. A key concern for all participants was that they receive "too much" sensory information from the environment. This theme also explores how the sensory experience of the participants is shaped by other factors, such as emotions, suggesting a bidirectional relationship between the two.

1a. Reactions to sensory stimuli: Physical and emotional. All three participants shared their emotional reactions to situations and stimuli. They could easily recall how it felt like to be in a situation or perceive certain sensory stimuli from the environment.

All three participants reported feeling overwhelmed as a result of their sensory experiences. For instance, Paul said *"the sounds were too loud and it was all quite overwhelming"* (9-10) during a restaurant visit, suggesting that the intensity of the stimulus is a problematic feature.

Participants also reported feeling stressed as a result of their sensory experiences. Paul explained that a situation with sounds and noises can be a *"stressful"* and *"difficult"* one, so bad it can cause him *"full-blown…panic attacks"* (20-22). Mary reported having intense emotional reactions, such as nervousness, and feeling awful and horrible because of birds. She stressed how negative she feels towards birds by repeating how much she hates them and how they are the *"worst thing ever"* (211,222). The feature of birds that is problematic for Mary, may be unpredictability of birds, as when prompted to clarify what quality of birds causes such strong reactions, she said *"it's just in case they hit me when they fly"* (210).

Zoe said that she finds flickering lights, as well as loud noises, like the school bell, *"annoying"* (44), suggesting that the quality of visual stimuli, as well as the intensity of auditory stimuli affects her perception of them. She said she can also *"get angry about it as well and quite stressed" (44-45)*. Zoe also talked about her reaction to visual stimuli and said she does not want to look at *"a lot"* of information as it would *"stress"*, *"annoy"*, and *"irritate"* her *(348-350)*. Prior to receiving her autism diagnosis, Zoe made sense of her sensory experiences by noticing her emotional reactions to them. She was not aware enough to know she had certain sensitivities to sensory stimuli and could only recall how she felt in a given situation, suggesting this may be the first step towards experiencing and making sense of a sensory experience.

> *…outside my classroom I've got lockers (…) I found I was just getting a bit annoyed and I didn't know why I was getting annoyed and then since diagnosis I've read quite a lot and I realised that I'm getting annoyed because there's banging going on. (Zoe: 22-27)*

Sometimes, participants' emotional reactions to sensory stimuli were the end-result of the physical, adverse reactions they had to those. Zoe said *"the noises annoy me. I get quite angry about like, if I'm walking down the road and then you get loud motorcycles and, or sirens (...) because it hurts, it's just painful"* (597-600). I assume, that the unpredictability of these particular stimuli (i.e., you cannot predict when a motorcycle or siren will be heard) is what infuriates Zoe, as she feels out of control, unable to prevent it.

Even though Paul briefly mentioned experiencing sensitivity to visual stimuli (i.e., lights) at the beginning of the interview, he only talked more about it once prompted.

> *I think it's a simpler relationship. I noticed very early in age, at kids' parties and stuff, when they were strobe lights or something like that, it would just give me headaches and make me feel uncomfortable when it was all happening. (94-97)*

Paul explained that strobe lights have caused him headaches, since he was a young boy, suggesting a sensitivity to a specific quality of visual stimuli. His understanding of this relationship, which he characterised as *"simpler"* compared to sounds', was possibly influenced by the fact that he experienced a very precise and "tangible" consequence (i.e., headaches). In contrast, his reaction to sounds was to feel overloaded with information (see Theme 1b) which he had to grow old-enough to be able to attribute meaning to. This also reinforces my assumption that participants may have not talked about experiences that are less significant (see Discussion of Findings section for more).

Paul also talked about his reaction to olfactory stimuli.

> *…if there was a food and I smelled it and it was* overpowering*, not necessarily smelled bad, but overpowering, it would just repulse me and I wouldn't want to go anywhere near it. And it was almost to the point where, it would put me off it for like,* years*. (116-120)*

Paul explained that it is not necessarily the nature of a smell that bothers him, but rather its intensity, suggesting that he can either, or both, cope well and not be bothered by certain stimuli, as long as he does not receive "too much" of it. This could also explain some other reactions of Paul and potentially some of the difficulties exhibited in autism (see Discussion of Findings section for more). Paul also emphasised his intense reaction by explaining that he would avoid the specific stimulus for a number of years, illustrating a strong sensory avoidant behaviour.

Mary also shared her physical reactions to sensory stimuli.

> *It's like, what you call that, "trypophobia" (?) or something* - *where you're scared of things with holes on them (…) it makes me feel physically sick! It's like somebody's hands there with lots of holes in them*

> *and it's not nice. So, even some pictures can make me feel a bit sick. (307-313)*

As with her experience with birds, Mary's experience of holes could also be attributed to a phobia. Nevertheless, Mary made sense of her reactions to be a result of sensory sensitivities. Retrospectively, I wished I had explored both experiences of her further to elicit more information.

Zoe reported that physical pain caused by an adverse reaction to certain sensory stimuli, ends up distracting her and disrupting her concentration. More specifically, she said she gets *"physical pain if it is like a whistle noise or, like a banging noise"* (16-17), attributing the pain to particular features of stimuli. She also used the school bell example and said that it is *"really really loud and quite painful. So there's that kind of physical pain and not being able to think, not being able to function properly"* (33-35). It seems that Zoe's attention, suddenly and uncontrollably, shifts to the stimuli and therefore, she loses concentration. During the skype interview, Zoe's children were watching TV in another room. When her dog pulled the door open, Zoe was able to hear the TV and immediately lost concentration. Zoe became aware that she lost concentration and attributed this to her difficulty to *"multitask"* and a shift of attention to the noise, which resulted in a loss of her *"train of thought"*, thus confirming my assumption.

> *…that was an example there like the kids' TV was on and I* couldn't *think any more about what was going on because I could hear the Star Wars and it was like—not able to do more than one thing at once - multitask. So it's that. It's being kind of the—your train of thought has to stop. (Zoe: 587-591)*

This reminded me of Paul's reasoning behind his difficulty to focus on different things, which is that his brain tries to concentrate on all things and Paul ends up with an overloading of information (see Paul's statement in Theme 1b). It could also be that Zoe's loss of concentration is an uncontrollable reaction to feeling overwhelmed, which leads to a mental escape or withdrawal (see Theme 2c for more), as she said *"if it (exposure to sounds and lights) goes on for too long I tend to I shut down"* (43-46).

Zoe also talked about an uncontrollable and almost automatic reaction she had in a specific situation, where the stimulus occurred suddenly and unexpectedly.

> *This child came into my room and shouted as he came (...) my reaction was to hit him. I didn't—I obviously didn't hit him, but—is that kind of getting something away from you quick because if you don't like it—I suppose if you touch something and it's hot, you're gonna pull your hand away faster. It's more of a reaction really, than you're really thinking about it. (564-570)*

Zoe stressed how painful auditory stimuli can sometimes be by using the analogy of "touching something hot" where one's immediate reaction is to pull their hand away fast. Zoe also used this analogy to illustrate her adverse reaction to that kid's shouting, which was to attack the source of information.

1b. Receiving "too much" information. Apart from the intensity of a stimulus, which seems to affect how negatively participants react to it, as explored in Theme 1a, all participants talked about receiving "too much" information from the environment, including sensory information, at most times. They talked about social, emotional, and sensory overloading as the end result of that, depending on the context.

For instance, Mary talked about an occasion when she went for a trip to a city she has never been to before. When she talked about her perceived experience of sounds while strolling around the city, she said *"too much information and it's just loud,* loud *all the time and you can't really hear people speaking, if that makes sense, you just hear noise - an overwhelming noise - that's it. I just got to go home"* (272-275). Even though

Mary described a situation that most people can sometimes relate to, she needed to escape from that and go home, illustrating an unbearable experience. Mary noted that it was her first time in that city and *“didn't know where everything was”* (263), suggesting an anxiety to a new, unknown situation and assuming an enormous amount of information needing to be processed; Whilst having to figure out where to go, Mary also had to deal with the unpredictability and uncertainty of this new situation, as well as process sensory stimuli from the environment, all, at the same time.

Paul also talked about receiving multiple auditory stimuli from the environment simultaneously. He said:

> *I think also, it has a lot to do with the amount like, all the sounds, where they are coming from. When you're in a street, you've got the sound of the cars, you’ve got the sound of the people talking, you've got the sound of like, you know, animals. You've got* lots *and* lots *of sounds coming from lots of places and it almost feels like, in my head (...) a lot of the time I'm hyper-focused on things and when I'm in that situation, and there's so many things happening, and I can't focus on* all *of them, but my brain is still trying automatically to do it, I feel that's when it becomes overloaded. (82-92)*

Paul talked about how his capacity to focus on extreme detail is a limitation when it comes to his perception of sounds from the environment, even on a regular walk down the street. Paul exaggerated (e.g., *“the sound of animals”*) to demonstrate the intensity of his experience and his attention to details. Also, Paul’s argument as to why such experience can result in an overloading, seemed very reasonable and well-contemplated, suggesting that Paul has previously thought about all these and attempted to make sense of his experiences (see Theme 3b for more).

Paul described social overloading, which is the result of processing too much sensory information in a social context.

> *I find that if I go out with friends and you know, we're going to places that is going to be loud (...) the next day, I almost [laugh] hide for the day in my room cause it's like been so much, so much interaction and socially overloaded. (Paul: 71-72)*

Paul, who highlighted the importance of making sense in his account (see Theme 3b for more), very interestingly stated that the only times he feels processing is not vital, is when he knows what to expect.

> *The only times that I would say that is limited (making sense), I feel like, I almost have safe spaces, or people that if I'm with them, or if I'm in this place, I feel the most content I can be. For example, one of my safe spaces for me would be my bedroom because if I'm in here, it's all the way that I wanted it to be, I'm used to it, I know what it is, not many things could happen in my bedroom that could really set me off. (Paul: 397-403)*

Therefore, in a social context, where a number of things are uncertain and cannot be predicted, the amount of information can be enormous for Paul.

Participants used different words to describe the end result of receiving too much information that is hard to process. For instance, Paul talked about experiencing *"attacks"*, where *"the filter just completely* gives away *and everything just comes in and it feels like a washing machine going off in my head" (230-231).* Paul claimed receiving *"everything"* from the environment and used the analogy of "a washing machine spinning" inside his head to emphasise the intensity of his racing thoughts while making sense. Paul's analogy of a "filter" that stops "strained" unwanted information, emphasises the value of this process. It seems that making sense, can both improve (see Theme 3b for more), as well as be a consequence of the experience of receiving too much information.

Zoe described her experience of a sensory built-up she was unable to escape from, as a *"meltdown"*. She said:

> *I had like a meltdown before where—I didn't know it was a meltdown 'till years later—where it was just too much and there was nowhere to go and I felt trapped (...) it was a thought that I couldn't escape, but I felt like there was no answer and logically trying to like, think of like "Why is this happening?" and trying to make sense of it. (722-729)*

Following my previous interpretation, making sense can help individuals understand their experience, others and the world (see Theme 3b for more). Therefore, individuals "learn" that this is a helpful process and their brains automatically perform this process at all times, as Paul described. However, as Paul again said, *"things don't always make sense"* (226), which can result in a built-up of information and a feeling of being overloaded.

In the excerpt above, Zoe described a vicious cycle: being somewhere with too much information and unable to physically escape, engaging in a rationalisation process to understand her perceived experience which could not be explained with logic, leading to racing thoughts and her wanting to "escape" her thinking process.

1c. The impact of emotions. All participants recalled situations where they noticed a difference in their sensory sensitivities. More specifically, they reported experiencing less or more sensitivity to stimuli, depending on their emotional state. Zoe, said that when overwhelmed *"you hear things louder and things annoy you more*" (719-720). Mary also said:

> *...and then, I would get anxious because I'm tired. I would feel more nervous, if that makes sense, and then start to feel a bit sick - especially if*

> *I haven't eaten - and then, I go really pale and then, everything sounds different - noises sound different; the sound's not as loud as if I went somewhere I haven't been before, but I've noticed that noise sounds louder when I'm tired. (292-298)*

The direction of the relationship between the variables mentioned in the excerpt above, is not very clear. It seems though, that Mary notices the physical symptoms of emotions in her body (e.g., feeling sick), as well as any difference in symptoms when she is tired, nervous, or stressed. Mary said she is more sensitive to sounds and implied that anxiety has a bigger effect on her sensitivity compared to tiredness. Indeed, Mary previously talked about how she *"always get anxious about places that I have never been before"* (259-260), which reinforces the above interpretation and suggests that the higher her anxiety, the more sensitive she becomes to sounds.

Mary also noticed a difference in how she feels sensory-wise when she experiences positive emotions. She said *"If I'm happy then, I just feel normal - like a normal person: The noises that were loud previously aren't loud anymore and things that normally bothered me and itched me, don't"* (349-351). After asking her a clarifying question, Mary said: *"I don't mind people hugging me or touching me (when happy)"* (359-360), which I found was a very powerful statement to make; Not only Mary did clarify that her emotional experiences affect her perception of sensory stimuli to a great extent, but also that her USEs make her feel "abnormal", which could explain Mary's tendency to normalise (see Theme 3c for more). Overall, it seems that Mary's sensory and emotional experiences are positively correlated.

Paul shared his experience with "extreme" positive emotions, which was different from Mary's.

> *…even if I'm happy and I am enjoying myself, that can still work the same as if I wasn't enjoying myself and the senses increased and it becomes*

> *too much; there's too much "I'm feeling good, feeling happy", and I need to step back and kind of mellow myself. I suppose, whether I'm getting too agitated with negative emotions, or being too happy with positive emotions, the result is the same, but on a different axis, you know; If I'm either extremely happy, or extremely sad, my body would react in the same way of kind of—I would feel quite hot, I would forget about other things, the filter (making sense) disappears and you know, I still reach the same place just in a different way (...) the happiness overload it hasn't happened in a long time, but it has definitely happened when I was a kid (...) being overloaded of happiness when I was a kid, and just being too much (...) I was in that almost "spell of happy" and I couldn't stop myself moving and I was blind to it; the filter disappeared and I was taking in everything and I was on—it's like boarding control; my filter isn't checking any of the things that are coming in. So, if anything is coming in and also everything is coming out… (538-565)*

Paul explained that extreme emotions, regardless of whether they are positive or negative, have an adverse effect on his experience of sensations, suggesting, once again, that the intensity of emotions (as with sensations), massively affects his perception and experience of it. Paul shared his interpretation on this; he explained that he usually has a *"filter"*, which job's is to make sense of information (see Theme 3d for more). He also explained that when he is overwhelmed with feelings, positive or negative, this filter disappears and information builds up and becomes hard to process. Paul previously referred to sensory stimuli as information (i.e., *"even like lights and sounds, I think of them as added information"* [391-392]). He explained that when he is busy processing other information then *"the filter is quite weaken"* (389) and information cannot be processed as effectively. Therefore, when Paul is overwhelmed with feelings, he finds it difficult to process sensory information from the environment, i.e., to understand and prioritise the information he needs to focus on. This is in line with Paul's previous interpretation (see excerpt in Theme 1b) about his brain that tries to focus on all information simultaneously.

I found Paul's analogy of the "boarding control" quite interesting. It seems that Paul feels powerless and out of control, unable to monitor and process the information he receives from the environment. I can only imagine how hard it is to be monitoring this process on a regular basis and be aware of it. It seems that for most people, this is a *"blind"* or an unconscious process. It is not surprising that Paul ends up with a sensory overload he needs to *"escape"* (54) from, otherwise he ends up experiencing a panic attack.

Paul's perception of sensory stimuli as *"added"*, or "additional" information, assumes that his experience of sensations becomes difficult in various instances in which he is not totally comfortable with. Paul explained that when he is *"out and about"*, or *"hungry"* (406), or *"tired"* (389) then *"filtering those sensations - the light, the sound, the noises, all that -becomes a lot more challenging"* (407-408) and affect him even *"further"* (412). Paul referred to filtering various times throughout the interview, emphasising the importance of making sense and "tidying up" information. This, I assume, reduces the amount of information piled up and results in a more positive experience overall.

Zoe's approach to the impact of emotions on her experience of sensory information is very similar to Paul's. Zoe talked about a situation at work where she was already overwhelmed because of a series of things going on and ended up becoming very sensitive to sensory stimuli she would otherwise ignore.

> *I had a bit too much going on with like the lesson I just had, like nothing bad, just a lot of interaction and just feeling drained, just kind of quite*

> *tired and then I noticed about three or four things I wouldn't normally notice. So someone came in and then somebody else like, [sigh] (inaudible) down, but quite loudly and somebody had to do the microwaves and the other was just talking and the bell went. And I was just like "Oh my gosh", like this. And I don't think I'd always pick up on all of those things, but I think because I was already feeling a bit like—a bit overwhelmed. Yeah! So, I think there's some things that it wouldn't matter how I was feeling in a way, I would always notice them. But I think it probably is worse when I'm already like, full. I suppose I used the term "full" when you're just full of... [laugh] yeah, with everything you already had to process. (638-651)*

Zoe described a situation where she attended to, and was affected by a number of sensory stimuli she would otherwise possibly ignore, given she was already *"full"* with other information that was piled up and processing. The term "full" presupposes a situation where the maximum quantity of something is being contained and there is no empty space for anything else. It also presupposes that if the tiniest of something is being added, then an overflow or explosion will take place. This is my interpretation on what Zoe described in the excerpt above, which is similar to Paul's perception of sensory stimuli as additional information to a processing system that is already busy with a lot of other information. Her experience could also be interpreted with Paul's theory of a filter that is weaken due to tiredness.

Theme 2. Coping with the Consequences

This theme aims to capture participants' experience with coping by exploring their strategies and compromises. It also explores participants' attempts to physically or mentally remove themselves away from the source of distress.

2a. Developing Strategies. Participants shared some strategies they have developed that help them cope on a daily basis. Paul said *"I mainly—I always pretty much wear headphones whenever I'm outside, just to play music and stuff, just to kind of draw it out"* (12-14). He corrected himself and stressed the importance of *"always"* carrying and using his headphones *"whenever"* he is outside, illustrating their necessity in protecting him from auditory stimuli. Similarly, Zoe tried wearing *"earplugs"* that she said are working only *"a* bit*"* (399) and explained the difficulty she is experiencing with them (e.g., while eating or talking). In order to minimise the intensity of auditory stimuli at work, Zoe developed the following strategy:

> *I've put sellotape over the fire alarm [laugh] which is also—and I haven't like covered—it sounds awful. I haven't like—the fire alarm is also the bell - it's like the same bell - and it was like a tiny little room with a really loud speaker and I haven't covered it all cause I know it's against health and safety, but I put like a strip of sellotape along it just so it's not so loud and overbearing and no one notices the difference anyway. I just made it slightly less loud than normal, but I'm not like covering up the fire alarm. I'm not doing anything horrendous. I'm just fine that [laughs] I'm just covering up the school bell so it's not too, too loud. (431-441)*

Even though Zoe seems to worry whether other people will find out and perceive her action to cover the bell as *"awful"*, *"horrendous"* and *"against health and safety"*, she still covered it. In addition, even though the advantage of her action was minimal (i.e., *"slightly less loud than normal"*), it outweighed the risk of being "caught", illustrating Zoe's desperate need to find a way to cope with the negative experience. Zoe noted how different her experience is from other people by stating that *"no one notices the difference"*, yet the difference in experience is significant for her.

Participants also stressed the importance of taking their time and dealing with a situation at their own pace.

> *I find that if I go out with friends and you know, we're going to places that is going to be loud, or something like that, I might just have to say to them you know, "I'm just going to go outside for a bit and relax", because I need that time… (Paul: 66-69)*
>
> *I'm at that stage where let's say, there's too many people talking to me at once, I have to go inside, or I have to say "Just leave me for a minute" because it's just too much (...) I just need that time you know, try and catch up [laugh] with what everyone is saying (...) It's like when you're—when you're in school and the work can be bit too much sometimes and then you go out for break time, like a brain break (Mary: 55-76)*

In both excerpts above, participants needed some time - a break - from their social interactions. Mary needed the time to process the information that has piled up during her interaction with others and Paul stated that he needs the time to relax, away from the stimuli. Mary's analogy of the "school work" illustrate her struggle and the hard job her brain and she are doing in a typical social situation.

Zoe emphasised the value of predictability in coping.

> *Kids' parties, they are short-term and they're predictable and it's fine. I can be sociable for an hour. I know it's going to be noisy, but it's—it's fine because it's an hour or two hours and you know—you know the structure; you're gonna turn up, have something to eat, and have some chances where you can chat to maybe three or four people. It's all fine. So things like that don't really bother me. It's just when it goes on for too long. And it's—I don't know when it's going to end and yeah. Like queuing. I hate queuing. It sounds ridiculous but I don't like it. Cause I*

> *don't know when it's going to—this queue's going to ever end and I get very like annoyed being in queues. (518-529)*

Zoe stressed the importance of knowing and predictability by twice emphasising the word “know” in her speech. She explained that, in a given situation where most factors are expected (e.g., the duration of the situation and the sensory stimuli present) and there is also a structure to follow, she finds it easy to cope, suggesting a value of predictability and reducing uncertainty in shaping more positive experiences (including sensory experiences). In contrast, when the duration of a situation is unknown and she does not know *“exactly”* (698) what is going to happen, even for *“stupid things, like how we all are going to sit around the table”* (699-700), she gets annoyed.

Zoe stated that even though she wants to *“know what's going to happen”* (702), she understands that sometimes it is *“pointless trying to predict”* (701) a situation. Mary on the other hand, is actively trying to minimise uncertainty to the extent that it is possible, in any given situation and developed strategies in order to do so.

> *I want to know what they (people) look like especially if I have never seen them before because if I go somewhere and I've never met a person before, I'll Google them online, or I will Google the place to see if they come up on that, but yeah that helps - if I know what they look like. So, I think that's the worst: is anxiety of not knowing. (139-144)*

Paul also shared how he came up with the strategy to cook for himself, which partly helps him understand the ingredients better, but also to know what to expect.

2b. Compromising for the sake of social life. Indeed, all participants seemed to worry about their social lives and expressed their wish not to miss out. Therefore, they developed some strategies that are characterised by negotiations and compromises.

> *…but it's not something that I, you know, I try to let hold me back, say to say. I constantly try to push myself with it, but I find that at least for me,*

> *one of the most important things, is being making compromises with myself. As I said, trying to push myself, trying to go out more… (59-64)*

Paul makes a conscious attempt to keep up with his social life. He stressed the hard job he is doing whilst socialising, by pointing out that he needs to withdraw and *"hide"* from others in his room the following day (see excerpt in Theme 1b).

Mary also talked about how, in order to go out and leave the house often, her family and she thought *"not to go out with too many of us [laugh] and just keep it you know, as a small family" (18-19).* Similarly, Zoe and her family decided *"no more family holidays with lots of people. So we're better off in our family unit going somewhere on our own" (396-397).* Both Mary and Zoe do not want to, due to their difficulties, deprive themselves from spending time with their families and therefore, came up with the above compromises and negotiations. It could also be that they do not want to deprive their children and partners from going out and socialising, or a combination of both.

> *I don't want to make everyone leave early for me. The thing what's going to happen from now on is we're probably gonna take two cars and when I get to the point where I had enough all—if my husband's with me, he can just stay with the kids or I can take the kids if it's getting too late. And then we've got a bit of a—a reason—not reason—we've got a plan for me to leave if I need to, rather than having to stay, if he wants to stay longer with his family so… (367-374)*

Zoe's sincere commitment to her husband and children, to enjoy social situations without being affected by her difficulties, is illustrated in the above excerpt. Zoe highlighted that she would only leave a situation if she had *"enough"* and that she would leave with a second car so that her husband and children can get to stay longer.

2c. Withdrawing: Mental and physical escape. Sometimes, when participants find it hard to cope in a given situation, they escape in order to distance themselves from the stimuli or the information that overwhelms them. Zoe explained that when overwhelmed *"you might move away from that, whatever it is, that's annoying you to try and reduce it"* (720-721), suggesting a physical escape from "negative" stimuli. She also implied that sometimes, she needs to mentally escape a situation if a physical escape is not viable as she said *"in the past I've had to have alcohol to deal with that…that helps to an extent because you feel like you can escape, even if you can't escape"* (712-714). During her description of a meltdown (see Zoe's excerpt in Theme 1b), Zoe, again implied the need to mentally escape a situation through reasoning and understanding, again emphasising the value of making sense in coping. She added that when she is overwhelmed, she withdraws to herself and shuts down.

> *I can be a bit cold in family situations again, when it just gets a bit much. And I just sort of stop talking and get a bit switched off (...) That was my kind of escape. Just getting a bit quiet and switching off a bit. (Zoe: 199-204)*

Paul said *"I would much prefer to have my headphones and when I'm in a stressful situation and feel overloaded, in general, having an escape"* (52-54), suggesting that certain strategies, such as the use of headphones, help him "escape" situations he physically cannot. Mary also explained how she withdraws to herself in order to cope. Sometimes, Paul and Mary physically escape by taking a break (see excerpts in Theme 2a). Mary also talked about wanting to escape her city-break and return home as she felt overloaded (see Mary's excerpt in Theme 1b).

Theme 3. Making Sense: "The Base Part of What I Have to Do in My Everyday Life"

Participants seem to engage in sense-making processes in order to understand their experiences and the world. This theme illustrates participants' views about themselves, including how they think they come across to others and their ability to cope. It also illustrates their conscious, almost constant, attempt to understand their environment and experiences, as well as their tendency to normalise as a means to protect themselves, sometimes, from their own understandings.

3a. Sense of self: Labelling and ability to cope. Participants described themselves mainly in relation to their autism characteristics, emphasising the impact of their diagnosis and lived experience on their identity development. Paul said *"people would always describe me as quite high-functioning"* (152-153) and *"*no one *really knows that I am autistic unless I tell them"* (154-155). Paul seems like he has a very set idea on how others think about him. This is apparent in his absolutist language (e.g., *"always"*, *"no one"*, *"anyone"*).

Mary said *"as I've got older, I've realised that I don't feel normal and I don't come across as normal"* (66-67). Mary used the word "normal" various times during the interview. She referred to her experiences as "normal" (see Theme 3c for more), but defined herself as "not normal", emphasising how common her experiences are within her autistic family (she has three autistic children) and how different she feels compared to other, non-autistic people, respectively. She also characterised herself as an *"anxious person"* (125-126) and emphasised how she has *"always"* (126) been like that.

Zoe shared her husband's view that she is not *"autistic-enough"* (896) as she is very considerate of others at the expense of her own needs (see Zoe's excerpt below). On a positive note, Zoe feels she is *"clever and articulate"* (97-98), *"successful"* (135), able to *"really"* focus (134), as well as *"write essays really easily and do loads of research constantly"* (136-137). She attributed the above qualities to autism which and said *"you can kind of offset the issues with the sensory stuff, with the other things that I'm sort of* better *out really"* (139-140). Last but not least, Zoe stated *"I can be sociable when I want to be, and when I'm in my frame, that's fine, but I can't do* too *much of* *that"* (420-422), implying and emphasising how receiving too much of something is disabling an otherwise-good ability.

All participants also stressed their capacity and ability to cope with their difficulties, with minimal to no support from others. Paul explained that when he was younger, he benefited from his mother's support who was *"trained to be able to deal with people"* (444-445) like him. He elaborated and said that she helped him calm down during difficult times. On the other hand, he explained that when it came to learning about, acknowledging and understanding his experiences, he *"had to teach"* himself (451). He also compared his "grown-up" self to his younger self and said that he is now better able to deal with his long-standing difficulties (e.g., sensory sensitivities, adherence to schedule), to the extent that he experiences minor discomfort and annoyance, whereas in the past he had *"full-blown attacks"* (22).

> *...I do quite like to schedule myself. And when that doesn't happen, I can deal with it - I used to struggle with it a lot more - but it just slightly makes me uncomfortable and it feels like—just annoys me… (Paul: 182-185)*

Even though the development of coping strategies seem to have helped Paul having better experiences overall, he also felt the need to "prove" he is able to deal with his difficulties just as well, without his coping strategies. At the beginning of the interview, Paul stressed the necessity to *"always"* carry and use his headphones (see Paul's excerpt in Theme 2a) *"whenever"* he is outside his house. On a different instance, he said that carrying his headphones *"is not necessary"* (55) but at the same time emphasised how much it *"really helps"* (55). This contradicting and inconsistent statement suggests a possible conflict deriving from acknowledging his need for support to cope (i.e., from the headphones), whilst also proving himself he is able to cope and hence, feel better about himself. Paul's need for support was also illustrated in his decision to join the autism support group during a difficult period of adjustment in his life.

When Mary talked about her experience with sensations, she said *"sometimes it can be very overwhelming, other times I can cope really well with it"* (27-28). Mary went through a lot of difficult situations (unrelated to autism) since she was diagnosed. When describing everything, she twice said that she has coped *"quite well"* (87), with a smile. My initial though in that moment, was that Mary realised for the first time how well she has coped given the difficulties and possibly felt proud of herself for doing so. Sometimes though, she explained that she feels unable to cope and therefore, withdraws to herself; other times she talks to her mother, close family and friends to seek for their support and understanding.

Zoe also claimed a good ability to cope with difficulties. She said *"I can't really think of anything else that gets me particularly anxious (…) because I can deal with everything else"* (516-518), and gave a specific example of managing a kid's party (see Zoe's excerpt in Theme 2a). Generally, it seems that Zoe is able to cope in situations that cause her minimal anxiety, especially if certain factors are in place (e.g., predictability of a situation). This supports the value of these factors in coping. It also seems that Zoe feels proud of herself, and possibly privileged, for managing so well. She compared herself to other autistic people who would *"definitely struggle"* (539) being at a kid's party *"a lot"* (538), whereas she emphasised that she does not.

Zoe also explained that when she becomes overwhelmed, she *"just"* knows the signs and how to *"manage"* and *"deal with it when it's happening"* (740-741). She said *"I'm very good at knowing…how my body reacts and because of the biology, and I'm a (job role) and I kind of know like, this means that..."* (852-854). Zoe feels confident noticing her bodily reactions to stimuli and situations which in turn, help her develop strategies in order to manage situations and cope with difficulties, emphasising the importance of the former in shaping better sensory experiences.

At the same time though, Zoe does not hesitate to seek support and understanding from others. Various times during the interview, she talked about how she attempts to explain herself and struggles to others and provide them with instructions on how to help her.

> *...she (daughter) was just jumping around the room doing like gymnastic-type of stuff and I was like "Can you just go in the hall and do that? Cause I can't focus if you're moving around?" So she's fine. They (children) understand and they go out and like, you know, they know when I find something tricky. And I'll say that just like, "I'm just really struggling with this. Could you please do that?" (446-452)*

3b. A conscious process. All participants talked about how they need to process a lot of information on a daily basis (see Theme 1b) and their conscious attempt to make sense of it. This happens to (a) understand the experience and therefore, develop appropriate strategies to cope, and (b) place themselves in a more “reasonable” and predictable world (see Discussion of Findings section for more).

Participants highlighted the value of making sense and rationalising in their perception of stimuli and experiences, in general.

> *...in arguments with partners and stuff, it's not always logical [laugh]; sometimes you're just arguing. And when we got in those situations, my brain would always try to rationalize it and I would always be trying to find a solution, even if my partner didn't necessarily want to find a solution (...) I would get to the point where I would be so stressed out because the answer was so difficult to find and she wasn't helping me (...) the way that I feel it: everything gets very loud in my head, all the*

> *thoughts are kind of jumbled in there and it just gets incredibly loud and I have almost an attack (...) it feels like I have always had filter that filters things through (...) cause let's say I'm over-*sensitised *to experiencing things so, I kind of got this barrier that it stops things through, making sure that it makes sense before it gets in my head. Of course things don't always make sense to me (...) And when I'm having those attacks so to say, I feel like the filter just completely gives away and everything just comes in and it feels like a washing machine going off in my head. (Paul: 205-231)*

Paul referred to his filter various times throughout the interview and explained that it helps him control the enormous amount of information he acquires from the environment and through his senses by making sense of it. Paul explained that when he is overwhelmed with emotions, his thoughts race, information is not being controlled or processed and as a result he gets even more overwhelmed. Paul highlighted the necessity of the filter by repeatedly emphasising how his brain *"always"* tries to rationalise information.

Paul talked about how his ex-girlfriend was not helping him make sense of their arguments. I felt that Paul compared his essential "need" to rationalise and find a solution with his ex-girlfriend's "non-obligatory" wish to find a solution to their argument, which also illustrates the necessity of making sense for Paul. Indeed, Paul stated that filtering is *"the base part of what I have to do in my everyday life" (395-396).*

I also felt that his mother has possibly held that role for him prior to him moving to another country to stay with his ex-girlfriend. This is illustrated in the following excerpt:

> *...I went over to another country to be with this girl, for like six months, and this kind of living with another family—because my mum is incredibly well—incredibly used to dealing with me you know, and she's so good in doing it that I kind of stopped realising that—is not that I was a problem to deal with, but there were certain things that people who don't have an autistic child wouldn't be used to and the people who are around autistic people would be used to. (159-166)*

His mother’s role must have been significant in containing and making sense of his emotions. As long as his mother held that role, Paul potentially did not acknowledge the extent of his difficulties (e.g., communication and emotional difficulties). I wonder whether Paul actually wanted to say that he did not realise how “problematic” he was, given that his mother dealt with his difficulties to the extent they were not problematic anymore. This reminded me of the notion that sometimes and as long as the circumstances are helpful (e.g., accessibility) and non-limiting, a disability is not a “disability” anymore.

Zoe’s need to understand and rationalise, as well as the value of that in coping, was illustrated in her description of a meltdown (see Zoe’s excerpt in Theme 1b), where she explained she tries to reason and find logical answers to her experiences.

Zoe and Mary, who were diagnosed in their early 30s, illustrated the importance of understanding, by seeking to increase their awareness about autism. Zoe said that she *“read a few books”* and *“joined a few like things on Facebook”* (787-789). Similarly, Mary said she has *“done University courses on autism”* (417). Increasing their awareness, helped them understand their difficulties and make sense of their experiences. Zoe, who never read about autism prior to being diagnosed, stated that she *“kind of fit it (sensory experiences) into place after”*. This is also illustrated in the following excerpt:

> *I found I was just getting a bit annoyed and I didn't know why I was getting annoyed and then since diagnosis I've read quite a lot and I realised that I'm getting annoyed because there's banging going on. (Zoe: 24-27)*

Paul said that *"one of the reasons"* he joined the *"autistic support group"* (157-158) was because he went abroad to live with his ex-girlfriend and experienced difficulties he could not make sense of. He also said that his mother who is *"incredibly used to dealing with me"* (162) was not there, confirming his mother's role in making sense for him. Paul, who highlighted the importance of making sense in his account, very interestingly stated that there are times he feels making sense is not necessary (i.e., *"only"* when he knows what to expect), suggesting: (a) the value of making sense in coping, (b) the negative impact of uncertainty on emotional states and the positive impact of certainty on feeling "safe" and "content", and (c) the negative impact of uncertainty in increasing the information needing to be processed.

> *The only times that I would say that is limited (filtering/making sense), I feel like, I almost have safe spaces, or people that if I'm with them, or if I'm in this place, I feel the most content I can be. For example, my safe space—one of my safe spaces for me would be my bedroom because if I'm in here, it's all the way that I wanted it to be, I'm used to it, I know what it is, not many things could happen in my bedroom that could really set me off. (Paul: 397-403)*

Paul also suggests that people, like his mother, who know his idiosyncrasy and how to deal with him, either, or both help him make sense of the world and avoid engaging with him in a way that would "set him off".

3c. Normalising. All participants seem to engage in processes that tend to normalise their experiences. My understanding is that these processes seek to protect them from feeling excluded, alienated, and unusual and help them feel “normal”. My interpretation is reinforced by participants’ ideas and preoccupations with what autism is and how that shaped their sense of self.

Even though participants value their diagnosis, they still felt that autism is *“different from normal”*. Paul said *“I never really felt alienated for it (not wanting to go to clubs), but I was aware it was different from norm—it was different for ‘neurotypical’ people, but quite common in the autistic community”* (36-38). On a different instance he said *“normal people, well, neurotypical people”* (50-51), again correcting himself from using the word “normal” to describe neurotypical or TD people. That would potentially imply that autistic people are “abnormal” and hence, he is too. The fact that in both occasions, Paul’s natural response was to define neurotypical people as “normal” and also be clear that he differentiates himself and experiences from them, may indicate that deep down, Paul *does* feel abnormal. This would also explain his tendency and need to normalise a lot of his experiences, as a way to protect himself from his own beliefs.

Mary, openly talked about not feeling normal various times throughout the interview.

> *I just don't feel normal. But as I’ve got older, I've realised that I don't feel normal and I don't come across as normal. That is why I sought the diagnosis in the first place (65-68)*

The repetition of the word “normal” indicates the significance of her feeling this way. It seems that Mary had an expectation that a diagnosis would potentially lead to her feeling differently or maybe normal, in a “special” way. Indeed, she said that her autistic children and she *“just say it's just the autism and we just feel normal. It’s just normal”* (491-492). By receiving the diagnosis she has longed for, Mary is now able to normalise her feelings and experiences, as not only they now make sense to her, but also they are all characteristics of autism. Hence, they are normal in autism.

Mary's longing for the diagnosis, as well as her irritation with that being delayed, were evident in her statement: *"I should have been diagnosed when I was 7, but school just completely dismissed* everything *about me (inaudible). So, it's school's fault really (68-70).* Mary previously stated that she does not *"come across as normal"* to others, yet school dismissed *"everything"* about her. Her irritation with the school could be attributed to a speculation that school left her feeling different from normal, whereas a diagnosis would have potentially left her feeling normal, just in a different way.

Indeed, Mary's "normal" felt different from Paul's; for Paul, it meant "neurotypical", whereas the only time Mary felt normal was after she received her autism diagnosis. I believe that this difference in attribution of meaning to the same word was significantly influenced by the age of their diagnosis. Mary received her diagnosis as an adult and therefore, has been treated as a neurotypical, or "normal" her whole life, which did not feel right, as she felt she was different from her peers. In contrast, Paul received his diagnosis early in childhood. Hence, he has been treated as an autistic his whole life who can only assume what it feels like not to be autistic.

Participants acknowledged that their experiences are different from others, yet they explained that this has always been their reality or "normality", as they never knew any other way. For example, when Paul talked about not wanting to, in contrast to his friends, go to nightclubs due to the loud noise and flickering lights, he said that *"everyone is different"* (33) and that it was *"normal"* (32) for him. In other words, rather than "blaming" his sensory sensitivities for his struggle to be in nightclubs, he attributed that to the fact that people are different and have different likes and dislikes. My sense, is that Paul engaged in a normalising process in order to feel less different from others. It could also be that, given his young age at the time (i.e., when he was in college), he could not make sense of his experiences in any other way. Indeed, Paul mentioned how *"oblivious"* (675) he was to his sensitivities and difficulties when younger and that his awareness and ability to makes sense developed in time.

When talking about his emotions, Paul also said *"I don't think by any means that I don't have emotions because you know, I think everyone has emotions, I just think it's expressed differently"* (133-135). Similarly, when Mary talked about her experience with emotions and sensations, she explained how she *"just"* gets on with it, as it is *"just normal"* (196) for her, while also acknowledging this is not the case *"for everyone else"* (196). Mary attributed this to the fact that she has *"been feeling like that a long time"* (197) and that it is *"just the autism"* (490-491).

In a different stage during the interview, Mary also said that her feelings are *"just normal. All these are just normal to me. My feelings are just normal"* (378-379). I felt that Mary, repeatedly characterised her experiences as "just normal", to emphasise the duration of time she has been feeling and experiencing the world the opposite way. Indeed, she said *"this way I've been all my life. I've been* all *my life, all my life"* (137-138). Her way of talking, which included repeating specific statements three times in a row, suggests a significant meaning for Mary. My interpretation is that Mary "had" to accept that this is her life with all its difficulties. My interpretation is further reinforced by her description of her anxiety world where she said:

> *(It's) horrible [whispering] cause that's, I think—that overrules lot of things: so, rather than me feeling happy, I'm feeling anxious and sad. (...) But I'm now used to it. I just get on with it. (146-150)*

The above excerpt illustrates that Mary has been defeated by her emotional difficulties and that she almost "surrendered" to this *"horrible"* reality of been *"anxious and sad"* for *"all"* her life. This in turn, further reinforces my interpretation that normalising acts as a protective process for Mary.

Participants also talked about their sensory sensitivities as preferences or dislikes, underemphasising or minimising their impact. Paul said he *"prefer(s) to be in a room where there isn't any strobe lights"* (102-103), despite the fact that they would give him *"headaches"* (96) and make him feel *"uncomfortable"* (97) if he was. In addition, he said *"I certainly do feel that I'm not really a fan of going to like, nightclubs or bars, in general, anything where there is lots of sounds, lights and I can't really escape"* (24-26). I found Paul's wording in this excerpt quite interesting, yet conflicting. Paul claims that he *"certainly"* is *"not a fan"* of going to places he needs an *"escape"* from. In both examples above, "not being a fan" and his "preference" to avoid certain stimuli, seem understatements. In addition, they imply that he sometimes does go to nightclubs and bars at the cost of feeling *"stressed"* and finding the experience *"difficult"*. It is therefore easy to assume that Paul pays the cost in order to gain something. It may be that he compromises for the sake of social life or that this reinforces his perception of his ability to cope that in turn, shapes his sense of self.

When asked about her sensory experiences, Mary referred to them as dislikes:

> *I don't like too many people. I don't like certain noises. Eye contact as well, I'm not really good at (...) Certain feels of clothes, like wool - thick wool - I don't like that on my skin. If anyone touches me sometimes, it can feel a bit, I don't know, I just don't like it (...) I don't like spinning around, I don't like feeling dizzy. (4-11)*

Zoe also does the same; she explained that when describing her sensory experiences to others, she keeps it *"really simple"* (879-880).

> *He just knows that I don't like loud noises or when he's got the dog, he shouldn't be whistling for the dog in front of me and make sure that I'm not stood behind him. Otherwise I'm—don't like it. (Zoe: 869-872)*

Zoe emphasised how her husband *"shouldn't"* whistle in front of her. In addition, various times throughout the interview Zoe mentioned how she experiences *"physical pain if it is like a whistle noise"* (16) and how it *"will always annoy"* (559-560) her. Therefore, when she simply says she does not *"like"* it, it seems like an understatement, minimising the extent it actually bothers or affects her.

One interpretation could be that Zoe attempts to normalise her experience in order to protect herself from feeling the "problematic" one who struggles. Another interpretation could be that Zoe finds it difficult to express her sensory sensitivities in a way that others could really understand her and therefore, she keeps it simple in hope that others will simply avoid causing her difficulties.

Another way that participants attempted to normalise their experiences, was through comparing them to others and finding similarities.

> *... when obviously I was on the autism support group and talked to more autistic people, I found it was quite a common trait. So I never really felt alienated for it, but I was aware that it was (...) different for 'neurotypical' people, but quite common in the autistic community. (Paul: 32-38)*

Paul explained that his experiences can be regarded as normal, as long as he compares them to autistic people and not *"neurotypical people"*. His statements were also flexible and adaptive depending on the circumstances. More specifically, when he was younger and less aware of autism characteristics and difficulties, he made sense of his experiences by regarding them as normal: (a) for him and (b) because *"everyone is different"*. Whereas now, he perceives his experiences as a normal and common trait shared by autistic people. Indeed, Paul referred to a *"community"* of autistic people that shares particular characteristics or traits in common. This may suggest that now (i.e., since joining the autism support group), he feels like he belongs somewhere, where if compared to others, he is normal. In either case, Paul's normalising process acts as a protective and a coping method to ensure he does not feel *"alienated"*.

Mary also compared herself to her autistic daughter and said *"I can relate to my daughter because I was just like her at school. I was exactly like her. So, she presents like I did when I was her age"* (392-394). She emphasised, with a positive tone, how she was *"exactly"* like her daughter when she was younger, suggesting a positive outcome from this comparison. In addition to her statement *"we (her children and she) just say it's just the autism and we just feel normal"* (49-491), it seems that Mary's normalising tendency is soothing and comforting. In other words, in a family of five, where four are autistic, comparing experiences with each other may act as a protective normalising process resulting in mutual understanding and a sense of normality.

Zoe on the other hand, attempted to normalise her experience to "protect" herself, but in a different way.

> *I think I put them (own children) into the nursery quite a lot when they were younger. I think I struggled with them when they were babies and toddlers (...) so when (son) was a baby, I was doing my (degree), for (course) (...) So he (son) went to nursery and I just cracked on it (degree), like doing my research and stuff for that, so that was quite good (...) It was more because that was easier, like not having him. Cause babies are really loud aren't they? And quite obviously… Yeah. So, not all the time and they didn't go in every day but I think like, only one or two days a week. (453-464)*

Zoe was explicit that her son went into nursery when he was still a *"baby"*. She also said that she *"put"* her children into nursery and felt like explaining the number of days she did. I assume that Zoe is potentially feeling guilty for sending her children to nursery in order to focus on her studies. I felt that, in order to alleviate her guilt for *"struggling"* with her children and sending them to day care, Zoe attempted to normalise and justify her behaviour by comparing her children to other children who are all *"really loud"* when they are babies.

Theme 4. The Process of Describing

This theme captures how participants experience the attempt to talk about and describe their sensory world and emotions.

4a. Talking about it. Participants utilised a variety of ways to describe their sensory and emotional experiences. For instance, Mary, conveyed her views in an interesting and very intriguing way. Sometimes it felt like she was parroting the Autism-Spectrum Quotient (AQ; MacLeod, 2019) screening test. When asked about her sensory experiences, Mary said *"I'd rather come to the library than go to a party"* (37-38), which is exactly one of the responses in the AQ, suggesting a preconceived idea.

I also remember feeling surprised with her choice of the word *"idiosyncratic"* (411) to describe her daughter's unusual play, as well as her use of the word *"vestibular"* (386). Both words could be considered as "technical" autism terminology often used by researchers, which are not, as far as I am concerned, words commonly used in the lay English language. At times, I was under the impression that Mary was "box-ticking", ensuring she lists all the criteria. At the very beginning, when prompted to talk about her general sensory experiences, Mary was quick to account for most sensory modalities (see excerpt in Theme 3c). Zoe also started the interview with a similar statement:

> *…I'm kind of aware of all the different areas that autistic people find challenging. For me it's basically flickering lights, loud noises is the worst and movement (…) Taste has never been an issue, texture is not an issue. Clothing is not a problem. (6-13)*

Paul's preconception was apparent in his answer to the same, very first question of the interview, where he said that he has *"the usual: very sensitive to sounds, very sensitive to lights" (5-6)*, implying that these are they typical sensory characteristics in autism.

It is not uncommon for autistic individuals to be able to easily recall information, such as difficult, technical words or lists. My view is that receiving the autism diagnosis was almost like a "catharsis" for all participants, as it literally provided them with the words to describe their emotional and sensory experiences that were otherwise very difficult to articulate (see Theme 4b) and helped them make sense of them.

They used *simile* to compare their experience to something known, in order to make their descriptions more clear. For instance, Paul said that his racing thoughts feel *"like a washing machine going off"* (231) in his head. Mary described the itching caused by a cut label on a jumper, as *"a cactus on the back of your neck"* (333). Zoe also used simile when she described her "automatic" response to sudden noise; she compared her reaction to the reaction people usually get when they *"touch something and it's hot"* and they pull their hand *"away faster"* (568-569).

Paul also referred to a common action movie scene in his attempt to describe his helplessness when he is overwhelmed with sensations:

> *…in movies when an explosion happens and there is that scene with the character lying there on the floor and everything is kind of just like— everything is almost slowed down in a way, and like everything is kind of*

> *almost happening in slow motion and they're kind of a passenger on that; they are not involved in it, they're kind of feeling it. (651-656)*

Paul compared the overwhelming-ness with an explosion, and his helpless self with a passenger, who is laying there, just *"feeling"* the situation, unable to influence it.

Similarly, Mary referred to a common YouTube video in her attempt to describe an increase in sound sensitivity during a stressful situation:

> *If you have ever watched one of the autism videos on YouTube: too much information and it's just loud, loud all the time and you can't really hear people speaking, if that makes sense, you just hear noise - an overwhelming noise - that's it. (271-275)*

Participants also used *anecdotes* to narrate incidents and experiences from their past. For example, Mary said *"I've had some labels that can be quite sharp and then I've cut them off, which made them even sharper"* (325-327).

They also used *scenarios* to postulate a sequence or development of a common experience. For example, Paul talked about his sensitivity to food and smell and how it is not as bad when he feels safe and content. He said *"If I am in my house, if there are not many people there, so let's say if it's just my mum and goes 'Here, try this' then, that will be a lot easier for me to try"* (311-313).

Participants also used *inner dialogues* to describe their experiences, especially when they wanted to illustrate their thinking processes during that time.

> *My brain is thinking—my brain can at least associate it with "Okay, I'm in a good situation now, let's eat this food". (Paul: 513-518)*
>
> *I think it made me worse the fact that I was on my own. I thought "What if I got lost?" as well. "What the hell am I gonna do if I get lost?" (Mary: 278-281)*

Mary also explained she utilises *"anything visual"* with her autistic children, such as *"visual timetables"* and *"comic strips"* (507) in order to encourage them to talk about their feelings and experiences.

4b. The experience of talking about it. All participants were asked about their experience of describing this part of their sensory world (i.e., their sensory experiences, any changes in sensitivities, factors contributing in changes, etc.).

> *...it is quite challenging because it's quite odd to put it into words. Like, "How you feel when you're overwhelmed?" and "What senses are you particularly feeling?" (...) but in terms of like "How you feel?" is very hard to articulate it (...) Like, I'll use the word "stressed" when I know it's quite a basic word and I can't think of another one, that's a bit more kind of descriptive. So yeah, I think it's quite hard to find a variety of words to describe how you're feeling. (Zoe: 849-861)*

It seems that Zoe's struggle with describing her sensory experiences per se, is due to her difficulty describing something that is felt in the body using words, which she said she finds *"quite odd"*. In addition, when attempting to describe her emotional experiences, Zoe finds it difficult to find words that can describe the particulars of each experience and rather, finds *"quite basic"* words.

Similarly, Paul said that even though he *"enjoys"* talking about it (582) in the context of an interview in order to *"help they psychological field in terms of understanding autistic people better"*, he generally finds it "very *hard to describe it"* (585-586). He expanded by saying:

> *I am quite good with my words so, I don't necessarily know if it's that. [Sigh] When you describe something, in my opinion, you're rationalizing it to something that you understand. Even your use of words—so, you're using words that would be associated with something similar that you*

> *have already understood (...) When I'm having those attacks, or I'm overly-sensitised (...) I really don't have anything to describe it all cause there's not really anything that I feel that is like it. So, I don't necessarily think that the words is an issue because I can throw a bunch of words and say it is like this and I can give you a general idea—at least for me, I am not speaking for every autistic person, but for me—I can give you a general idea what it's like because if I'm giving you a specific kind of look into it, is very difficult (...) When trying to describe it to another person, it's like you're almost speaking in a different language (...) sometimes I wish I could be like, "here, this is what I feel" for a couple of seconds [laugh]. (Paul: 588-620)*

Paul explained that even though there are ways to describe similar sensations or experiences, he is never satisfied with his descriptions, as he feels he cannot convey the particulars of the experience to others, but only the *"general idea"*. He also explained that sometimes the difficulty lies in the struggle to understand and rationalise certain experiences, which makes the process of describing them to another person, almost like speaking a *"different language"*. Paul emphasised that this is how he experiences the process of describing and acknowledged that other autistic people may experience something different. Paul said that he had, in the past, heard other autistic people describing their sensory world:

> *I have heard of other autistic people describing. It can help, but then again it comes to a problem that it's still not the same thing. Me and another—I have had this before when I talked to other autistic people and they have said "I do feel it as well" and "this is almost how I feel it" and they can give me some words, or a scenario, or something like that and I can say "yeah, that is definitely like how I feel but it's not exactly how I*

> *feel". But it does give—it's better than not knowing at all. That gives me some ground to kind of be like, "okay, it's kind of like this". (624-632)*

Paul, once again, emphasised his dissatisfaction with descriptions that only seek to explain a similar experience but not the *"exact"* experience. On the other hand, he acknowledged the value of those general descriptions and said that they can provide him with ideas on how to talk about his own experiences.

Some participants though, felt that having the *"right"* or exact words to describe their experiences is not that important as they said, it is not something they get to talk about often. For instance, Zoe said *"I don't know if it would—it would help a lot of people if they have the right words for it, because I don't think it comes up in general conversation"* (872-874). She even said *"it's not the kind of conversation I'm having with my husband"* (865-868) to emphasise how seldom she talks about these experiences. This may indicate a lack of awareness of their own experiences, a lack of understanding from others, a perception of normality and therefore, a lack of need to talk about it, or a combination of the above. Paul said *"I don't naturally think about it that much because it's just something that I deal with every day"* (669-671). Similarly, Mary explained how her autistic children and she say *"it's just the autism"* and they *"just feel normal"* (491-492).

Mary found it *"weird"* talking about her sensory experiences during the interview:

> *It's strange to talk about how I feel cause, it's normally people coming to me and telling me how they feel, rather than the other way around. And sometimes I don't like to talk about it. So this is really, really strange. (454-457)*

Mary emphasised that talking about *her* feelings and experiences, does not happen often. I felt, that Mary implied that she sometimes does want to talk to others, but she does not as other people seek for her help *"rather than the other way around"*, suggesting a lack of understanding from others. Mary may feel quite disappointed, or even bitter that this is the case and in order to normalise her disappointment, she said that *"sometimes"* she does *not* want to talk about her experiences in her daily life. Mary was very eager to participate in this study, which suggests a need to open up and process her feelings and experiences.

Zoe also felt that others do not understand the *"extent"* of her sensitivities and experiences, which in turn affects how she seeks to talk about it.

> *I just say I don't like—I don't like it. So, just keep it really simple. But I don't like it when—I think it's challenging for my mother-in-law because essentially I'm telling her that I don't like it when her grandson makes noises that are too loud or turns the light switches on and off (...) I know she finds it challenging as well. And it's that whole like—she—she does appreciate that it's annoying, like when he does that, but I don't think she appreciates that to the extent that I can't function properly when he's doing that. (879-890)*

Zoe explained that her mother-in-law only understands her to the extent of her own experience, but not to the extent of Zoe's experience. Therefore, Zoe does not attempt to explain herself and instead, keeps it *"really simple"*.

On a more positive note, Paul felt like sharing a reassuring message to other autistic people. He explained that no matter how well or bad they can currently describe their experiences, with time this can *"definitely"* improve, which also emphasises the importance of being able to talk about it.

> *I think that other autistic people, whether they are at a stage that they can describe it very well, or if they completely are oblivious to it—like I*

> *was when I was a child and I didn't realise it was something that was more abnormal—with time it can definitely get better. (673-677)*

Chapter 5. Discussion

This chapter explores the findings of this study in the context of existing, relevant literature and theories. It also discusses implications for practice and provides an evaluation of the study. The overall conclusions, as well as recommendations for future research are provided towards the end of the chapter, before closing with my autobiographical reflections on the whole process of conducting and writing up this study.

Discussion of Findings

The aim of this study was to gain an understanding on how autistic individuals experience and make sense of the impact of emotions on their sensory world. It also aimed to gain an insight on the process of describing this part of their sensory world. In-depth personal accounts were sought in order to explore that and four main themes emerged from the analysis.

Theme 1. Experiencing Sensations and Emotions

Participants experience negative reactions to sensory stimuli (i.e., *hyper-reactivity*). These consist of emotional responses (e.g., feeling overwhelmed, stressed, angry) and uncontrollable physical reactions (e.g. headaches, physical pain, sickness, and loss of concentration) to sensory stimuli. Similar emotional and physical reactions were also reported in previous studies (e.g., Bogdashina, 2003; Smith & Sharp, 2013 and Kirby et al., 2015; Robertson, 2012; Robertson & Simmons, 2015, respectively), indicating that these may be the usual reactions to sensory stimuli exhibited by autistic individuals. Some features of the stimuli, such as certain qualities (e.g., “itchy” texture of a jumper), as well as high intensity, prolonged exposure and unpredictability, affect participants’ perception and experience, thus mirroring the results by Robertson (2012), Robertson and Simmons (2015), and Smith and Sharp (2013).

In contrast to some previous research, participants in this study did not report pleasurable, positive responses to sensory stimuli, indicating that: (a) they do not find pleasure in any sensory stimuli, (b) they assumed they had to talk about negative experiences only, or (c) negative sensory experiences are more significant (i.e., impact their lives more) to them. In addition, no participant reported *hypo-reactivity* to stimuli, which again contradicts many previous studies, but mirrors the findings by Smith and Sharp (2013) whose participants exhibited hypersensitivities only.

Participants' reported reactions accounted for most sensory modalities, whereas difficulties with auditory and visual stimuli were the most frequently reported ones among all three participants. This is consistent with previous children studies (e.g., Robertson, 2012; Klintwall et al., 2011), as well as adult studies (e.g., Cole, 2015), suggesting that hyper-reactivity to auditory stimuli may be the most common sensory experience in autism. Touch was very significant for one participant; Movement and taste/smell were briefly reported by two individuals.

A main concern for all participants, is the amount of information they feel they receive from the environment and through their senses, as well as during social interactions. They all described feeling overloaded as a result, emphasising their need to escape - physically or mentally - from the source of information. They described "meltdowns" and "panic-attacks" as the end-result, when unable to escape.

The urge to escape was described in other studies (e.g., Smith & Sharp, 2013), as a response to sensory stimuli, where participants reported escaping the source of sensory stress. In the current study, participants emphasised that their reactions are proportional to the amount and duration of stimulation and that their ability to cope depends on this amount (e.g., "I know it's going to be noisy, but it's fine because it's an hour or two hours…It's just when it goes on for too long…").

Sensory overloading was also described in the study by Jones et al. (2003), where participants added that they find it difficult to process information from multiple senses at the same time. This was not reflected in the current study though.

Another main concern for all participants, is the impact of emotions on their sensory experiences. All participants, shared similar experiences in relation to how *negative* emotional states affect their experience of sensory stimuli. Two participants shared similar experiences in relation to how *positive* emotional states affect sensory experience, whereas one participant had a slightly different approach to that. What was equally interesting though, was how participants attributed meaning to, and understood the impact of emotions on their sensory world.

More specifically, all participants agreed that negative emotional states, particularly anxiety, makes them more sensitive, or more reactive to sensory stimuli (e.g., “[when overwhelmed] you hear things louder and things annoy you more”). Mary and Zoe suggested that positive emotions make them less sensitive to sensory stimuli. Mary, who emphasised her adverse reactivity to touch, claimed that when in a positive emotional state, she does not mind people hugging her. She continued explaining that when happy, she feels like a “normal person”, suggesting that sensory experiences may influence how autistic individuals view and feel about themselves. Zoe, explained that when in a negative emotional state, she is more attentive to stimuli compared to when feeling “good” and rested.

Paul explained that when overwhelmed with *“extreme”* emotions, regardless of whether they are positive or negative, then his reaction to sensory stimuli will be adverse. The way he makes sense of this is that, when feeling overwhelmed, his thinking process and ability to make sense become negatively affected. Then, information builds up and any additional information from the environment (e.g., through the senses) becomes intolerable and results in, what he described as, a "panic-attack".

Even though previous studies suggested a relationship between sensory experiences and emotions (i.e., mainly how USEs affect emotional experience), Smith and Sharp (2013) was the first study, to my knowledge, to suggest an impact of emotional dysregulation to the sensory experiences of autistic individuals. They stated: "Emotional dysregulation occurred within an important part in a vicious cycle (sensory avalanche) of stress and sensitivity, as high levels of stress increased sensitivities, which caused higher levels of stress and so on" (p. 905). Even though, in the current study, emotional dysregulation did not arise as concern, high levels of stress did impact on, and increased sensory sensitivities. This explanation is taken into consideration though, as extreme levels of emotions, including positive emotions, seem to affect sensory experience, implying a possible difficulty in regulating extreme emotions.

Similarly, participants in Robertson and Simmons's study (2015) reported an impact of negative emotional states (e.g., anxiety and distress) on the perception of sensory stimuli. Their participants explained that negative emotional states either decrease their tolerance for sensory stimuli, or diminish their ability to perceive pain. In their data, there was no evidence of positive emotional states affecting sensory perception. A decrease in tolerance for sensory stimuli when anxious, could explain participants' experiences in the current study. However, the current study did not echo the remainder of their findings in relation to the impact of emotions on sensation.

Given the above, it could be assumed that positive emotional states increase tolerance to sensory stimuli for Zoe and Mary. Another hypothesis, is that when participants are in a positive emotional state, they tolerate and have no significant reactions to sensory stimuli. In addition, when experiencing an overloading of extreme emotions, whether positive or negative, then either their tolerance decreases, or they become more hypervigilant and attentive to sensory stimuli in the environment. The latter has been proposed by Green and Ben-Sasson (2010) who suggested that hyperarousal and hypervigilance caused by anxiety, increases attention of sensory stimuli through “scanning” for threats in the environment, which resonates with Zoe’s descriptions.

In the current study, all participants are concerned with the unpredictability and uncertainty of various situations and stimuli, as well as the anxiety that results from those. Their accounts reflect strategies aiming at reducing uncertainty and hence, anxiety. Zoe highlighted the importance of predictability by explaining that when sensory stimuli are expected, she can tolerate them better, indicating that these factors may affect autistic individuals’ sensory experience. This is consistent with the study by Neil et al., (2016) who found that intolerance of uncertainty, together with anxiety, predicted sensory sensitivities in autistic individuals. It is also consistent with other reports in the literature, such as the ones by Temple Grandin (e.g., “I'm sensitive to sounds. Loud sounds. Sudden sounds. Worse yet, loud and sudden sounds I don't expect.” [Grandin & Panek, 2014]).

These findings can be also explained by psychophysical, imaging studies (e.g., Cascio et al., 2012; Cascio et al., 2008). These studies investigated autistic individuals’ reactions to tactile stimulation by studying their brain activity. Their results found no difference in responses in the sensory cortex of autistic and TD individuals, suggesting no difference in sensitivities between the two groups. Rather, they found increased activity in the limbic system (i.e., the “emotional” brain) of autistic individuals, compared to TD individuals, suggesting that autistic individuals’ responses to sensory stimuli could be shaped by their emotional reactions to those.

Theme 2. Coping with the Consequences

Participants' experience of emotions on their sensory world also involves their attempts to cope with the consequences of their sensory experiences. All participants shared some strategies they developed in order to cope. Such strategies involve attempts to eliminate the intensity of the stimulus (e.g., using headphones) and taking a short break away from the stimulus. Similar coping strategies were reported by participants in the study by Smith and Sharp (2013).

Coping strategies in the current study also involve attempts to reduce uncertainty and increase predictability of stimuli and situations, a finding consistent with previous studies (e.g., Robertson & Simmons, 2015; Smith & Sharp, 2013). For instance, participants in Robertson and Simmons's (2015) study, shared a few strategies aiming at taking control over stimuli and increasing predictability (e.g., adapting their work environment).

Interestingly, all participants in the current study, do not want allow their experiences to negatively impact on their social lives. Therefore, some of their coping strategies are characterised by negotiations and compromises, as well as conscious attempts not to "miss out".

Sometimes, when participants' experience becomes unbearable, for instance when they receive too much information from the environment, they escape the situation, either by physically, or mentally withdrawing from it. Zoe talked about this process that takes place almost involuntary when she feels overwhelmed; she withdraws to herself, shuts down and does not allow any information from the environment enter her body or brain. This reminded me of Eugen Bleuler's concept of autism (see quote in What is Autism? section).

Also, this seems like a defence mechanism that is, mildly dissociating and mentally separating oneself from one body or the environment. The following definition of *dissociation* resonates with participants' descriptions:

> *Dissociation is a state of disconnection from the here and now. When people are dissociating, they are less aware (or unaware) of their surroundings or inner sensations. Reduced awareness is one way to cope with triggers in the environment or from memories that would otherwise reawaken a sense of immediate danger. (Brickel, R., 2020)*

Even though, in mild cases this can successfully act as a coping mechanism, it can also have some consequences. Indeed, Zoe explained that when withdrawing she cannot engage in a conversation and comes across as *"rude"* and *"cold"*.

Theme 3. Making Sense: "The Base Part of What I Have to Do in My Everyday Life"

Participants' autism diagnosis and associated experiences, shape their sense of self. Participants label themselves according to autism characteristics. This is consistent with a number of qualitative studies in the literature, which suggested that autism diagnosis affected individuals' identity development and helped them cope. For instance, in Smith and Sharp's (2013) study, participants emphasised the impact of their autism diagnosis in helping them and their significant others cope with difficult situations, as well as feel less negative about themselves and their USEs. Also, Huws and Jones (2008) emphasised the impact of diagnosis in participants' perceptions of what being autistic is like.

A major concern for participants in this study, is their awareness of being different from others and their need to feel normal, a finding consistent with previous studies (e.g., Jones et al., 2013). Participants engage in processes, such as normalising, in an attempt to protect themselves from their own beliefs and feelings of being excluded, different and "abnormal". Normalising was also reported by autistic children, in the study by Kirby et al. (2015), which was characterised by an awareness of being different and an approach to describing sensory experiences as likes and dislikes, similar to the participants in the current study.

Personal capacity and ability to cope also shapes participants' sense of self which then affects their perception and reaction to sensory stimuli. Participants emphasised how they had to learn how to figure their sensory landscape by themselves regardless of whether they had support from others, illustrating that making sense, since a young age, affects and shapes present and future experiences of the world.

A key concern, for all participants, that has not been highlighted as much in the existing literature, is therefore their conscious attempt to understand and process information, which Paul described as "the base part" of what he has to do in his everyday life. In addition to helping individuals develop appropriate strategies, making sense also helps them understand, learn and predict the world around them, which from their descriptions, seems to be unpredictable and complex.

Making sense seems to be highly related to individuals' perception of receiving too much information, as discussed earlier. This relationship seems to be a bidirectional one (i.e., the more they attempt to make sense, the more attentive they become to information and the more information they attend to, the more they need to make sense of it). The predictability of a situation seems to lessen the need to make sense, suggesting that the process of making sense may be a conscious attempt to predict outcomes.

The latter, is in line with recent evidence suggesting that autistic brains have difficulties adapting their predictions about the sensory environment based on context (Sapey-Triomphe, Leiros Costa, & Wagemans, 2019), which suggests that sensory hyper-reactivity in autism mostly depends on issues with contextual predictions.

This is also in line with Professor Peter Vermeulen's conceptualisation of autism (Vermeulen, 2012). He proposed that difficulties with social interaction, communication, and the sensory world are the consequences of autism and not the "problems" in autism. He argues that the main problem in autism is uncertainty, where the “absolute” thinking of individuals does not allow them to correctly guess or predict situations based on context. Therefore, the relative world we live in can be a very confusing and overwhelming place to live in for autistic individuals.

Theme 4. The Process of Describing It

Participants utilise a variety of methods to talk about their sensory world and emotional experiences; they use simile, anecdotes, scenarios, inner dialogues and visual supports. This indicates that autistic adults describe their sensory world in a very similar way to autistic children (see Kirby et al., 2015).

Sometimes, in their descriptions, participants cite and claim to experience well-established autism characteristics. Their way of talking about it, which is often characterised by “box-ticking” or reference to technical terms, could be misinterpreted as “non-genuine”. On the other hand, participants find talking about their experiences very challenging. Their diagnosis provides them with opportunities to learn more about autism and therefore, my view is that the greatest their awareness on autism and its characteristics, the better the participants are able to make sense of their own experiences and also, describe them. Therefore, referencing technical terms and this box-ticking method helps participants give name to their experiences.

Theoretical perspectives

Popular theories in autism (see Popular Theories in Autism section) explain the findings of the current study with varying success. ToM (Baron-Cohen et al., 1985) and extreme male brain theory (Baron-Cohen, 2002) do not offer any explanations for sensory sensitivities in autism. In the current study though, participants referred to their awareness, as well as experience of being “different” and having different experience from others. They talked about their affective responses to the emotional states of their people. Last but not least, they were able to share their thoughts, emotions and experiences with me during the interview process, contradicting the ToM and extreme male brain theory.

Executive function theory (Ozonoff et al., 1991) also does not explain sensory sensitivities per se. Turner (1999) proposed though, that the RRBs exhibited by autistic individuals could be the result of an inability to shift attention from a stimulus. Zoe’s description of her difficulty to maintain concentration once stimulated, is consistent with Turner’s (1999) proposal. However, more recent studies (e.g., Rogers & Ozonoff, 2005) found no association between executive function and patterns of RRBs, making this theory difficult to explain findings in this study.

CC theory (Frith, 1989; Happé & Frith, 2006) explains some auditory and visual patterns, as well as hypersensitivities in autism, as the result of extreme attention to detail (Baron-Cohen et al., 2009). In the current study, all participants talked about their tendency to attend to details (mainly auditory details) in their environment, as well as their hypersensitivities to sensory stimuli, which are consistent with CC theory. CC theory’s limitation to account for the hyposensitivities in autism, is not limiting explanations for the findings in this study, as no hyposensitivities were reported by the participants. The same findings could be also explained by the enhanced perceptual functioning theory (Mottron & Burack, 2001; Mottron et al., 2006), yet participants’ descriptions did not provide evidence to suggest that their attention to detail happens at the expense of global percept.

Neural noise hypothesis’s (Simmons et al., 2009) argument that noisy neural signals can enhance or disrupt stimulus detection could also explain the sensory hypersensitivities reported by participants in this study.

Strengths and Limitations

The study achieved its aim in eliciting information about autistic individuals’ experience and understanding of emotions on their sensory world, as well as their experience of talking about it. It provides an insight of lived experience that seems to lack from the majority of autism research (MacLeod, 2019), adding to the current understandings of autism. Claims of generalisability and replicability were not made, acknowledging that the experiences discussed in this study are unique to the participants. This does not ignore the similarities in experience reported by autistic individuals in other studies or the potential that these may be true for other people on the spectrum.

Another strength of this study was that interviews took place and were analysed a long-time apart from each other. This helped in protecting the idiography of each set of data. The use of Skype as a means to interviewing autistic participants was also an advantage. The two participants interviewed via Skype expressed positive feedback and, from my point of view, it provided them with the opportunity to “attend” the interview from the safety of their own bedrooms, helping them feel as comfortable as possible. Again, from my point of view, this offsets the cost of losing some non-verbal communication in interviewing autistic individuals via Skype.

The small sample size of three participants was both a strength and a limitation of the study. It allowed for an in-depth analysis to occur as suggested by Smith and Osborn (2008) and protected the idiographic nature of IPA. Nevertheless, it would be interesting to see whether additional participants would affect the dominant themes that resulted from the analysis, as the themes chosen represented all three participants, whereas potential themes that represented the minority of the participants were not included in the final themes. It would also be interesting to look for patterns across more cases, which could potentially provide more explanations for the findings.

The participants’ age at diagnosis has not been considered in relation to its potential impact on how well participants are able to make sense of their lived experiences. Even though fruitful information was gathered from all three participants, one of the two participants who was diagnosed only a year prior to the interviews, did not seem to engage in as many sense-making processes compared to the other two. Further research may be needed to explore this.

Another possible limitation was that all participants were highly able individuals with no reported moderate or extreme levels of mental health concerns. There is a possibility that sensory experiences, and more specifically, experiences of the impact of emotions on the sensory world, may be different for autistic individuals with further challenges and struggles. Nevertheless, Kern et al. (2007) did not find such differences in adolescents and adults.

Last but not least, given that participants did not report any hyposensitivities, it might have been useful if a “standardised” measure (e.g., the Sensory Profile; Dunn, 1999) was used to inform the interview schedule, or during the interviews, to initiate discussion about both hypo- and hyper-sensitivities.

Conclusion

This study sought to understand how autistic individuals experience and make sense of the impact of emotions on their sensory world, a much under researched topic, as well as their experience of describing this part of their sensory world. Literature on atypical sensory processing in autism was reviewed, in addition to literature concerning reported unusual sensory experiences. Literature on the consequences of the above, as well as literature concerning the emotional difficulties in autism was also reviewed.

The research was concerned with generating in-depth understanding of personal experience, understanding and feelings and therefore, IPA (Larkin & Thompson, 2012; Smith et al., 2009) was identified as an appropriate methodology. Four main themes emerged from the analysis, entitled Experiencing sensations and emotions; Coping with consequences; Making sense: “the base part of what I have to do in my everyday life”; The process of describing.

The study found that autistic individuals’ sensory experiences are shaped by their physical and emotional reactions to sensory stimuli. When it comes to how their emotional states shape their overall sensory experiences in particular, it was found that negative and extreme positive emotions make them more sensitive and more reactive, whereas milder positive emotions make them less sensitive reactive to sensory stimuli. It was also found that the intensity and unpredictability of situations and stimuli affect how individuals react, that is the more intense and unpredictable a situation or a stimulus is, the more sensitive and reactive they are.

In addition, autistic individuals’ experience is shaped by their attempts to cope with the difficulties, which then affect their perception of sensory stimuli (i.e., the better they cope the less they react to sensory stimuli). Some of their coping strategies, involve exerting control over stimuli (e.g., eliminating intensity) and reducing uncertainty, again highlighting the significance of this factor.

Another key finding is participants’ conscious and constant sense-making of the information they receive from the environment. This process helps individuals cope by helping them understand, develop a sense of self and normalise their perceived “abnormalities”, but also burdens them by accumulating more information from the environment – including sensory information, thus making their experiences more difficult. Participants emphasised that this is a process they “had to” learn how to do by themselves, indicating their capacity to figure out the world, including their sensory landscape.

This study illustrated that autistic individuals are equally capable of participating in qualitative research and use a variety of methods to describe their experiences. Nevertheless, their perceived experience of describing their sensory world is a difficult one, as they feel that they cannot convey the particulars of their experiences to the maximum.

Participants in this study described unwanted sensory experiences, as well as experiencing uncertainty in their everyday lives, all of these while dealing with life’s complexities (e.g., in relationships) and a constant attempt to make sense. Nevertheless, when able to control, predict and understand situations and stimuli, participants are able to cope well, socialise, spend time with their significant others, travel, etc.

I therefore propose that, it is not that autistic individuals are not able to process information or deal with uncertainty, ambiguity and distressing sensory experiences per se; they struggle because they receive “too much” of these – too much uncertainty, too much ambiguity and too much information to make sense of; no wonder they sometimes slow down developmentally. On the other hand, making sense and figuring out the world all by themselves since a very young age, in my opinion, suggests a tremendous capacity, rather than a deficit, of autistic individuals.

Recommendations for research and practice

The variability of experience within participants in this study, as well as between participants of other studies, emphasises the spectrum of difficulties and experience in autism, thus illustrating the necessity to provide individualised support rather than develop “one size fits all” interventions. Mental health professionals would therefore benefit from specialised training in working therapeutically with autistic individuals and in particular, how to adapt interventions to suit the particular needs of each individual.

The findings of this study suggest that mental health interventions should focus on educating autistic individuals in evaluating their developed coping strategies, as it seems that they sometimes work at the expense of other factors, such as social life. They should also focus on helping individuals develop helpful coping strategies. Mental health interventions should also focus on helping individuals learn how to deal with, and regulate intense emotions. They should also focus on providing them with techniques aiming to shift or direct attention and focus, so that autistic individuals can learn how to take more control over their sensory experiences. Last but not least, mental health professionals should aim on increasing awareness about the sensory landscape of autistic individuals and its particulars, such as the factors contributing in increased sensitivity and reactivity.

Future research is recommended to explore the particulars of the relationships between unpredictability, intensity of situations or stimuli, anxiety, and sensory sensitivity (e.g., whether there is a moderating effect of unpredictability and intensity on the relationship between anxiety and sensory sensitivity), as well as the impact of the age of diagnosis on these.

Further qualitative research on emotional dysregulation and alexithymia (even though the latter did not seem to be a concern for participants in this study), and their impact on sensory experiences in autism is recommended.

Last but not least, research on the effect of mental health interventions, including psychoeducation, on the sensory and emotional experiences of autistic individuals is recommended. Research should focus on the development of a flexible and adaptive plan that mental health professionals can use with autistic individuals in their practise.

Autobiographical Reflections

As soon as I finished all the taught modules of this doctorate, as well as my placements, a sudden health “adventure” began. I felt the need to reflect on this and how it affected this study and my development as a researcher.

After a surgical complication I had to be transferred in a hospital in Israel, where I fought for my life for three months. The doctors’ only hope was that my body and I, would be strong enough to survive, as there was nothing they could do other than dealing with the complications. After multiple surgeries and my return back to my home-country, I thought I was able to “simply” go back to this project as if nothing had happened. The process was toughest than I imagined and the psychological pressure was enormous. I felt angry and confused; angry because my estimated time for completion of the project was not viable and realistic, and confused because I had mixed feelings for a project I previously felt very passionate about.

One year after, I only managed to recruit and interview my second participant and make some corrections to the first two chapters. This project felt like a burden and I constantly beat myself up for not progressing fast enough, as well as not finding the motivation to. The realisation that life goes on though - whether I decide to follow and make the best out of it, or not - really shocked me.

I started working on it and it started reminding me of my wishes, goals, dreams, and aspirations in life and almost took me out of the dark place I was. As soon as I had all my data collected and analysed, I realised that I may have found important information, which was a huge driving force; it was a need of mine to make a difference in the lives of these people and a need to feel alive again, with all the struggles and beauties that come with life.

Whilst writing the discussion section of this study, suddenly, a lot (i.e., my emotional reactions to this project) made sense. What I was going through at the time (i.e., coming to the realisation that I could have died whilst having to complete the research project, start court procedures against the doctor whose negligence almost cost my life, deal with pain on a daily basis, accept my body with scars and deformities and deal with the effects of all these on my relationships) was simply “too much” to be able to “function” without great difficulty.

Yet, my health adventure and the process of this research made me realise how strong and resilient I am. They also taught me that nothing is impossible unless you give up on it. They helped me get one step closer to the world of autistic people, who have to, on a daily basis, deal with so much information.

For my future work, research and life, I will carry the lessons learnt, remind myself that it is okay to slow down sometimes as long as I do not give up, as well as remind myself of my dreams and goals whenever I feel “lost”.

References

Acquarone, S. (2007). *Signs of autism in infants: Recognition and early intervention.* Karnac Books Ltd.

American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Author.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5 ed.). Author.

Asperger, H. (1944). Autistic psychopathy in childhood. In U. Frith (Ed.), *Autism and Asperger syndrome.* Cambridge University Press.

Attwood, T. (2000). Strategies for improving the social integration of children with Asperger syndrome. *Autism, 4*(1), 85-100. https://doi.org/10.1177/1362361300004001006

Bailey, A., Le Couteur, A., Gottesman, I., Bolton, P., Simonoff, E., Yuzda, E., & Rutter, M. (1995). Autism as a strongly genetic disorder: Evidence from a British twin study. *Psychological Medicine, 25*(01), 63-77. https://doi.org/10.1017/s0033291700028099

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., Kurzius-Spencer, M., Zahorodny, W., Rosenberg, C. R., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L., Harrington, R., Lopez, M., Fitzgerald, R. T., Hewitt, A., . . . Dowling, N. F. (2018). *Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2014.* Centers for Disease Control and Prevention. http://doi.org/10.15585/mmwr.ss6706a1

Baron-Cohen, S. (1995). *Mindblindness: An essay on autism and theory of mind.* MIT press.

Baron-Cohen, S. (2000). Is Asperger syndrome/high-functioning autism necessarily a disability? *Development and Psychopathology, 12*(03), 489-500. https://doi.org/10.1017/s0954579400003126

Baron-Cohen, S. (2002). The extreme male brain theory of autism. *Trends in Cognitive Sciences, 6*(6), 248-254. https://doi.org/10.1016/s1364-6613(02)01904-6

Baron-Cohen, S., Ashwin, E., Ashwin, C., Tavassoli, T., & Chakrabarti, B. (2009). Talent in autism: Hyper-systemizing, hyper-attention to detail and sensory hypersensitivity. *Philosophical Transactions of the Royal Society of London B: Biological Sciences, 364*(1522), 1377-1383. https://doi.org/10.1098/rstb.2008.0337

Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a "theory of mind?" *Cognition, 21*(1), 37-46. https://doi.org/10.1016/0010-0277(85)90022-8

Baron-Cohen, S., Tager-Flusberg, H., & Cohen, D. J. (1994). *Understanding other minds: Perspectives from autism.* Oxford University Press.

Baron-Cohen, S., Wheelwright, S., Lawson, J., Griffin, R., & Hill, J. (2002). The exact mind: empathising and systemising in autism spectrum conditions. In U. Goswami (Ed.), *Handbook of cognitive development* (pp. 491–508). Blackwell Publishers.

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31*(1), 5-17. https://doi.org/10.1023/A:1005653411471

Bartlett, F. C. (1932). *Remembering: A study in experimental and social psychology.* Cambridge University Press.

Bayles, M. (2012). Is physical proximity essential to the psychoanalytic process? An exploration through the lens of Skype? *Psychoanalytic Dialogues*, *22*(5), 569-585. https://doi.org/10.1080/10481885.2012.717043

Bellini, S. (2006). The development of social anxiety in adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 21*(3), 138-145. https://doi.org/10.1177/10883576060210030201

Bettelheim, B. (1972). *The* e*mpty fortress*. Simon & Schuster Inc.

Bhaskar, R. (1975). Feyerabend and Bachelard: Two philosophies of science. *New Left Review, 94*(3), 31-55.

Billstedt, E., Gillberg, C., & Gillberg, C. (2007). Autism in adults: Symptom patterns and early childhood predictors. Use of the DISCO in a community sample followed from childhood. *Journal of Child Psychology and Psychiatry, 48*(11), 1102-1110. https://doi.org/10.1111/j.1469-7610.2007.01774.x

Bird, G., & Cook, R. (2013). Mixed emotions: The contribution of alexithymia to the emotional symptoms of autism. Translational Psychiatry, 3(7), 285. http://dx.doi.org/10.1038/tp.2013.61

Bird, G., Silani, G., Brindley, R., White, S., Frith, U., & Singer, T. (2010). Empathic brain responses in insula are modulated by levels of alexithymia but not autism. Brain, 133(5), 1515-1525. https://doi.org/10.1093/brain/awq060

Bleuler, E. (1910). The theory of negativism (Zur theorie des schizophrenen negativismus). *The British Journal of Psychiatry, 237,* 381-383.

Bogdashina, O. (2003). *Sensory perceptual issues in autism and Asperger syndrome.* Jessica Kingsley Publishers.

Bolis, D., & Schilbach, L. (2018). Observing and participating in social interactions: Action perception and action control across the autistic spectrum.

Developmental Cognitive Neuroscience, 29, 168-175. https://doi.org/10.1016/j.dcn.2017.01.009

Brickel, R. (2020). *Coping with trauma through dissociation.* Psych Central. https://pro.psychcentral.com/coping-with-trauma-through-dissociation/

Brown, C. & Dunn, W. (2002). Adolescent/Adult Sensory Profile [Measurement instrument]. Pearson.

Burr, V. (2015). *Social constructionism*. Routledge.

Cameron, K., Ogrodniczuk, J., & Hadjipavlou, G. (2014). Changes in alexithymia following psychological intervention: A review. Harvard Review of Psychiatry, 22(3), 162-178. https://doi.org/10.1097/hrp.0000000000000036

Carrington, S., & Graham, L. (2001). Perceptions of school by two teenage boys with Asperger syndrome and their mothers: A qualitative study. *Autism, 5*(1), 37-48. https://doi.org/10.1177/1362361301005001004

Cascio, C., McGlone, F., Folger, S., Tannan, V., Baranek, G., Pelphrey, K. A., & Essick, G. (2007). Tactile perception in adults with autism: A multidimensional psychophysical study. *Journal of Autism and Developmental Disorders*, *38*(1), 127–137. http://doi.org/10.1007/s10803-007-0370-8

Cascio, C. J., Moana-Filho, E. J., Guest, S., Nebel, M. B., Weisner, J., Baranek, G. T., & Essick, G. K. (2012). Perceptual and neural response to affective tactile texture stimulation in adults with autism spectrum disorders. *Autism Research, 5*(4), 231–244. https://doi.org/10.1002/aur.1224

Cermak, S. A., Curtin, C., & Bandini, L. G. (2010). Food selectivity and sensory sensitivity in autistic children spectrum disorders. *Journal of the American Dietetic Association*, *110*(2), 238-246. https://doi.org/10.1016/j.jada.2009.10.032

Chakrabarti, S., & Fombonne, E. (2001). Pervasive developmental disorders in preschool children. *The Journal of the American Medical Association, 285*(24), 3093-3099. https://doi.org/10.1001/jama.285.24.3093

Chamak, B., Bonniau, B., Jaunay, E., & Cohen, D. (2008). What can we learn about autism from autistic persons? *Psychotherapy and Psychosomatics, 77*(5), 271-279. https://doi.org/10.1159/000140086

Charmaz, K. (2014). *Constructing grounded theory*. Sage Publications, Inc.

Chisholm, K., Lin, A., Abu-Akel, A., & Wood, S. J. (2015). The association between autism and schizophrenia spectrum disorders: A review of eight alternate models of co-occurrence. *Neuroscience & Biobehavioral Reviews, 55*, 173-183. https://doi.org/10.1016/j.neubiorev.2015.04.012

Cole, K. L. (2015). Sensory Sensitivities of Young Adults with High-Functioning Autism Spectrum Disorders. *Explorations, x*, 80-90.

Cook, R., Brewer, R., Shah, P., & Bird, G. (2013). Alexithymia, not autism, predicts poor recognition of emotional facial expressions. Psychological Science, 24(5), 723-732. http://doi.org/10.1177/0956797612463582

Corbett, B. A., Muscatello, R. A., & Blain, S. D. (2016). Impact of sensory sensitivity on physiological stress response and novel peer interaction in children with and without autism spectrum disorder. *Frontiers in Neuroscience, 10*, 278. https://doi.org/10.3389/fnins.2016.00278

Cornish, E. (1998). A balanced approach towards healthy eating in autism. *Journal of Human Nutrition and Dietetics, 11*(6), 501-509. https://doi.org/10.1046/j.1365-277x.1998.00132.x

Crane, L., Goddard, L., & Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. *Autism, 13*(3), 215-228. https://doi.org/10.1177/1362361309103794

Creswell, J. W. (2009). Research design: Qualitative, quantitative, and mixed methods approaches. Sage Publications, Inc.

Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism, 19*(7), 814-823. https://doi.org/10.1177/1362361315577517

De Jaegher, H. (2013). Embodiment and sense-making in autism. *Frontiers in Integrative Neuroscience, 7*, 15. https://doi.org/10.3389/fnint.2013.00015

Dunn, W. (1997). The impact of sensory processing abilities on the daily lives of young children and their families: A conceptual model. *Infants and Young Children, 9*(4), 23-35. https://doi.org/10.1097/00001163-199704000-00005

Dunn, W. (1999). *Sensory Profile*. Psychological Corporation.

Durkin, M. S., Maenner, M. J., Newschaffer, C. J., Lee, L.-C., Cunniff, C. M., Daniels, J. L., Kirby, R. S., Leavitt, L., Miller, L., Zahorodny, W., & Schieve, L. A. (2008). Advanced parental age and the risk of autism spectrum disorder. *American Journal of Epidemiology, 168*(11), 1268-1276. https://doi.org/10.1093/aje/kwn250

Elwin, M., Ek, L., Kjellin, L., & Schröder, A. (2013). Too much or too little: Hyper-and hypo-reactivity in high-functioning autism spectrum conditions. *Journal of Intellectual and Developmental Disability, 38*(3), 232-241. https://doi.org/10.3109/13668250.2013.815694

Etherington, K. (2004). *Becoming a reflexive researcher: Using ourselves in research*. Jessica Kingsley Publishers.

Falter, C. M., Plaisted, K. C., & Davis, G. (2008). Visuo-spatial processing in autism: Testing the predictions of extreme male brain theory. *Journal of Autism and Developmental Disorders, 38*(3), 507-515. https://doi.org/10.1007/s10803-007-0419-8

Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., Block, H., Pingree, C. B., Ritvo, E. R., Ritvo, R. A., & Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research, 2*(2), 109-118. https://doi.org/10.1002/aur.69

Finlay, L., & Gough, B. (2008). *Reflexivity: A practical guide for researchers in health and social sciences.* Blackwell.

Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Paediatric Research, 65*(6), 591-598. https://doi.org/10.1203/PDR.0b013e31819e7203

Frith, U. (1989). *Autism: Explaining the enigma*. Blackwell Publishing.

Frith, U., & Happé, F. (1994). Language and communication in autistic disorders. *Philosophical Transactions of the Royal Society of London B: Biological Sciences, 346*(1315), 97-104.

Gernsbacher, M. A. (2017). Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry, 58*(7), 859-861. https://doi.org/10.1111/jcpp.12706

Gerrard, S., & Rugg, G. (2009). Sensory impairments and autism: A re-examination of causal modelling. *Journal of Autism and Developmental Disorders, 39*(10), 1449-1463. https://doi.org/10.1007/s10803-009-0773-9

Gillberg, C., & Soderstrom, H. (2003). Learning disability. *The Lancet, 362*(9386), 811-821.

Gillberg, I. C., Helles, A., Billstedt, E., & Gillberg, C. (2016). Boys with Asperger syndrome grow up: Psychiatric and neurodevelopmental disorders 20 years after initial diagnosis. *Journal of Autism and Developmental Disorders*, *46*(1), 74-82. https://doi.org/10.1007/s10803-015-2544-0

Grandin, T., & Panek, R. (2014). *The autistic brain: Exploring the strength of a different kind of mind.* Ebury Publishing

Grandin, T., & Scariano, M. M. (2005). *Emergence: Labelled Autistic* (2nd ed.). Grand Central Publishing.

Green, S. A., & Ben-Sasson, A. (2010). Anxiety disorders and sensory over-responsivity in autistic children spectrum disorders: is there a causal relationship? *Journal of Autism and Developmental Disorders, 40*(12), 1495-1504. https://doi.org/10.1007/s10803-010-1007-x

Green, S. A., Ben-Sasson, A., Soto, T. W., & Carter, A. S. (2012). Anxiety and sensory over-responsivity in toddlers with autism spectrum disorders: Bidirectional effects across time. *Journal of Autism and Developmental Disorders, 42*(6), 1112-1119. https://doi.org/10.1007/s10803-011-1361-3

Green, S. A., Hernandez, L., Tottenham, N., Krasileva, K., Bookheimer, S. Y., & Dapretto, M. (2015). Neurobiology of sensory over-responsivity in youth with autism spectrum disorders. *JAMA psychiatry, 72*(8), 778-786. https://doi.org/10.1001/jamapsychiatry.2015.0737

Greenlee, J. L., Mosley, A. S., Shui, A. M., Veenstra-VanderWeele, J., & Gotham, K. O. (2016). Medical and behavioral correlates of depression history in children and adolescents with autism spectrum disorder. *Pediatrics, 137*(Supplement 2), S105-S114. https://doi.org/10.1542/peds.2015-2851I

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of Qualitative Research, 2*(163-194), 105-117.

Hansen, S. N., Schendel, D. E., & Parner, E. T. (2015). Explaining the increase in the prevalence of autism spectrum disorders: the proportion attributable to changes in reporting practices. *JAMA Pediatrics, 169*(1), 56-62. https://doi.org/10.1001/jamapediatrics.2014.1893

Happé, F. (1994). Wechsler IQ profile and theory of mind in autism: A research note. *Journal of Child Psychology and Psychiatry, 35*(8), 1461-1471. https://doi.org/10.1111/j.1469-7610.1994.tb01287.x

Happé, F., & Frith, U. (2006). The weak coherence account: Detail-focused cognitive style in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 36*(1), 5-25. https://doi.org/10.1007/s10803-005-0039-0

Happé, F., Ronald, A., & Plomin, R. (2006). Time to give up on a single explanation for autism. *Nature Neuroscience, 9*(10), 1218-1220. https://doi.org/10.1038/nn1770

Hesse-Biber, S. N., & Leavy, P. (2010). *The practice of qualitative research.* Sage Publications, Inc.

Hill, E. L., & Frith, U. (2003). Understanding autism: Insights from mind and brain. *Philosophical Transactions of the Royal Society of London B: Biological Sciences, 358*(1430), 281-289.

Hobson, P. (1993). Understanding persons: The role of affect. In S. Baron-Cohen, H. Tager-Flusberg & Cohen D. J. (Eds.), *Understanding other minds: Perspectives from autism* (pp. 204-227). Oxford University Press.

Holton, G. (1975). On the role of themata in scientific thought. *Science, 188*(4186), 328-334. https://doi.org/10.1126/science.188.4186.328

Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *The Canadian Journal of Psychiatry, 57*(5), 275-283. https://doi.org/10.1177/070674371205700502

Huws J. C., & Jones, R. S. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual & Developmental Disability, 33*(2), 99-107. https://doi.org/10.1080/13668250802010394

Hyman, S. L., Rodier, P. M., & Davidson, P. (2001). Pervasive developmental disorders in young children. *The Journal of the American Medical Association, 285*(24), 3141-3142. https://doi.org/10.1001/jama.285.24.3141

Janghorban, R., Roudsari, R. L., & Taghipour, A. (2014). Skype interviewing: The new generation of online synchronous interview in qualitative research. *International Journal of Qualitative Studies on Health and Well-Being*, *9*(1), 24152. https://doi.org/10.3402/qhw.v9.24152

Jones, R. S., Huws, J. C., & Beck, G. (2013). 'I'm not the only person out there': Insider and outsider understandings of autism. *International Journal of Developmental Disabilities*, *59*(2), 134-144. https://doi.org/10.1179/2047387712Y.0000000007

Jones, R. S., Quigney, C., & Huws, J. C. (2003). First-hand accounts of sensory perceptual experiences in autism: A qualitative analysis. *Journal of Intellectual and Developmental Disability, 28*(2), 112-121. https://doi.org/10.1080/1366825031000147058

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, *2*(3), 217-250.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442-462. https://doi.org/10.1177/1362361315588200

Kern, J. K., Trivedi, M. H., Garver, C. R., Grannemann, B. D., Andrews, A. A., Savla, J. S., Johnson, D. G., Mehta, J. A., & Schroeder, J. L. (2006). The pattern of sensory processing abnormalities in autism. *Autism, 10*(5), 480-494. https://doi.org/10.1177/1362361306066564

Kern, J. K., Trivedi, M. H., Grannemann, B. D., Garver, C. R., Johnson, D. G., Andrews, A. A., Savla, J. S., Mehta, J. A., & Schroeder, J. L. (2007). Sensory correlations in autism. *Autism, 11*(2), 123-134. http://doi.org/10.1177/1362361307075702

Kessler, R. C., Aguilar-Gaxiola, S., Alonso, J., Chatterji, S., Lee, S., Ormel, J., Üstün, B., & Wang, P. S. (2009). The global burden of mental disorders: An update from the WHO World Mental Health (WMH) surveys. *Epidemiology and Psychiatric Sciences, 18*(1), 23-33. https://doi.org/10.1017/s1121189x00001421

Kessler, R. C., McGonagle, K. A., Zhao, S., Nelson, C. B., Hughes, M., Eshleman, S., Wittchen, H. U., & Kendler, K. S. (1994). Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States: results from the National Comorbidity Survey. *Archives of General Psychiatry, 51*(1), 8-19. https://doi.org/10.1001/archpsyc.1994.03950010008002

Kirby, A. V., Dickie, V. A., & Baranek, G. T. (2015). Sensory experiences of children with autism spectrum disorder: In their own words. Autism, 19(3), 316-326. https://doi.org/10.1177/1362361314520756

Klintwall, L., Holm, A., Eriksson, M., Carlsson, L. H., Olsson, M. B., Hedvall, Å., Gillberg, C., & Fernell, E. (2011). Sensory abnormalities in autism: A brief report. *Research in Developmental Disabilities, 32*(2), 795-800. https://doi.org/10.1016/j.ridd.2010.10.021

Kohs, S. C. (1923). *Intelligence measurement*. Macmillan Company.

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9. *Journal of General Internal Medicine, 16*(9), 606–613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

Kuhn, R., & Cahn, C. H. (2004). Eugen Bleuler's concepts of psychopathology. *History of Psychiatry, 15*(3), 361-366. https://doi.org/10.1177/0957154x04044603

Lane, A. E., Dennis, S. J., & Geraghty, M. E. (2011). Brief report: Further evidence of sensory subtypes in autism. *Journal of Autism and Developmental Disorders, 41*(6), 826-831. https://doi.org/10.1007/s10803-010-1103-y

Lane, A. E., Young, R. L., Baker, A. E., & Angley, M. T. (2010). Sensory processing subtypes in autism: Association with adaptive behavior. *Journal of Autism and Developmental Disorders, 40*(1), 112-122. https://doi.org/10.1007/s10803-009-0840-2

Larkin, M & Thompson, A. (2012). 'Interpretative phenomenological analysis'. In A. Thompson & D. Harper (Ed.), Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners (pp. 99-116). John Wiley & Sons, Ltd. http://doi.org/10.1002/9781119973249

Lidstone, J., Uljarević, M., Sullivan, J., Rodgers, J., McConachie, H., Freeston, M., Couteur, A. L., Prior, M, & Leekam, S. (2014). Relations among restricted and repetitive behaviors, anxiety and sensory features in children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 8*(2), 82-92. https://doi.org/10.1016/j.rasd.2013.10.001

Loas, G., Fremaux, D., Otmani, O., & Verrier, A. (1995). Prevalence of alexithymia in a general population. Study in 183 "normal" subjects and in 263 students. *Annales Médico-Psychologiques, 153*(5), 355-357.

Luckasson, R., Borthwick-Duffy, S., Buntinx, W. H., Coulter, D. L., Craig, E. M. P., Reeve, A., Schalock, R. L., Snell, M. E., Spitalnik, D. M., Spreat. S., & Tassé, M. J. (2002). *Mental retardation: Definition, classification, and systems of supports*. American Association on Mental Retardation.

MacLeod, A. (2019). Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review. *Research in Autism Spectrum Disorders, 64*, 49-62. https://doi.org/10.1016/j.rasd.2019.04.005

Maddox, B. B., & Gaus, V. L. (2019). Community mental health services for autistic adults: Good news and bad news. *Autism in Adulthood, 1*(1), 15-19. https://doi.org/10.1089/aut.2018.0006

Maisel, M. E., Stephenson, K. G., South, M., Rodgers, J., Freeston, M. H., & Gaigg, S. B. (2016). Modelling the cognitive mechanisms linking autism symptoms and anxiety in adults. Journal of Abnormal Psychology, 125(5), 692. https://doi.org/10.1037/abn0000168

Mazefsky, C. A., Herrington, J., Siegel, M., Scarpa, A., Maddox, B. B., Scahill, L., & White, S. W. (2013). The role of emotion regulation in autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(7), 679-688. https://doi.org/10.1016/j.jaac.2013.05.006

McKean, T. A. (1994). *Soon will come the light: A view from inside the autism puzzle.* Future Horizons.

Merton, R. K. (1975). Thematic analysis in science: Notes on Holton's concept. *Science, 188*(4186), 335-338. https://doi.org/10.1126/science.188.4186.335

Milosavljevic, B., Leno, V. C., Simonoff, E., Baird, G., Pickles, A., Jones, C. R., Erskine, C., Charman, T., & Happé, F. (2016). Alexithymia in adolescents with autism spectrum disorder: its relationship to internalising difficulties, sensory modulation and social cognition. *Journal of Autism and Developmental Disorders*, *46*(4), 1354-1367. https://doi.org/10.1007/s10803-015-2670-8

Milton, D. (2012) On the ontological status of autism: The ‘double empathy problem’. *Disability & Society, 27*(6), 883-887. https://doi.org/10.1080/09687599.2012.710008

Moreno-Küstner, B., Martin, C., & Pastor, L. (2018). Prevalence of psychotic disorders and its association with methodological issues. A systematic review and meta-analyses. *PloS ONE, 13*(4), e0195687. https://doi.org/10.1371/journal.pone.0195687

Moss, P., Howlin, P., Savage, S., Bolton, P., & Rutter, M. (2015). Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study. *Autism, 19*(7), 832-841. https://doi.org/10.1177/1362361315585916

Mottron, L., & Burack, J. A. (2001). Enhanced perceptual functioning in the development of autism. In J. A. Burack, T. Charman, N. Yirmiya & P. R. Zelazo (Eds.), *The development of autism: Perspectives from theory and research* (pp. 131-148). Lawrence Erlbaum Associates Publishers.

Mottron, L., Dawson, M., Soulieres, I., Hubert, B., & Burack, J. (2006). Enhanced perceptual functioning in autism: An update, and eight principles of autistic perception. *Journal of Autism and Developmental Disorders, 36*(1), 27-43. https://doi.org/10.1007/s10803-005-0040-7

Muhle, R., Trentacoste, S. V., & Rapin, I. (2004). The genetics of autism. *Pediatrics, 113*(5), e472-e486. http://doi.org/10.1542/peds.113.5.e472

Myles, B. S., Barnhill, G. P., Hagiwara, T., Griswold, D. E., & Simpson, R. L. (2001). A synthesis of studies on the intellectual, academic, social/emotional and sensory characteristics of children and youth with Asperger syndrome. *Education and Training in Mental Retardation and Developmental Disabilities, 36*(3), 304-311. http://doi.org/10.2307/23879983

National Institute of Mental Health (2017). National survey on drug use and health. https://www.samhsa.gov/data/sites/default/files/cbhsq-reports/NSDUHDetailedTabs2017/NSDUHDetailedTabs2017.htm#tab8-56A

Neil, L., Olsson, N. C., & Pellicano, E. (2016). The relationship between intolerance of uncertainty, sensory sensitivities, and anxiety in autistic and typically developing children. *Journal of Autism and Developmental Disorders, 46*(6), 1962-1973. https://doi.org/10.1007/s10803-016-2721-9

Orlans, V., & Van Scoyoc, S. (2008). *A short introduction to counselling psychology*. Sage Publications, Inc.

O'Neill, M., & Jones, R. S. (1997). Sensory-perceptual abnormalities in autism: A case for more research? *Journal of Autism and Developmental Disorders, 27*(3), 283-293.

Ozonoff, S., Pennington, B. F., & Rogers, S. J. (1991). Executive function deficits in high-functioning autistic individuals: Relationship to theory of mind. *Journal of Child Psychology and Psychiatry, 32*(7), 1081-1105. https://doi.org/10.1111/j.1469-7610.1991.tb00351.x

Ozonoff, S., Young, G. S., Carter, A., Messinger, D., Yirmiya, N., Zwaigenbaum, L., Bryson, S., Carver, L. J., Cosntantino, J. N., Dobkins, K., Hutman, T., Iverson, J. M., Landa, R., Rogers, S. J., Sigman, M., & Stone, W. L. (2011). Recurrence risk for autism spectrum disorders: A baby siblings research consortium study. *Pediatrics*, *128*(3), e488-e495. https://doi.org/10.1542/peds.2010-2825

Pellicano, E., Smith, A. D., Cristino, F., Hood, B. M., Briscoe, J., & Gilchrist, I. D. (2011). Autistic children are neither systematic nor optimal foragers. *Proceedings of the National Academy of Sciences*, *108*(1), 421-426. https://doi.org/10.1073/pnas.1014076108

Perou, R., Bitsko, R. H., Blumberg, S. J., Pastor, P., Ghandour, R. M., Gfroerer, J. C., & Huang, L. N. (2013). Mental health surveillance among children—United States, 2005–2011. Centers for Disease Control and Prevention. https://www.cdc.gov/mmwr/pdf/other/su6202.pdf

Premack, D., & Woodruff, G. (1978). Does the chimpanzee have a theory of mind? *Behavioral and Brain Sciences, 1*(04), 515-526. https://doi.org/10.1017/s0140525x00076512

Rivet, T. T., & Matson, J. L. (2011). Review of gender differences in core symptomatology in autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*(3), 957-976. https://doi.org/10.1016/j.rasd.2010.12.003

Robertson, A. E. (2012). Sensory experiences of autistic individuals spectrum disorder and autistic traits: A mixed methods approach. (Unpublished doctoral dissertation). University of Glasgow. http://theses.gla.ac.uk/id/eprint/3769

Robertson, A. E., & Simmons, D. R. (2015). The sensory experiences of adults with autism spectrum disorder: A qualitative analysis. *Perception, 44*(5), 569-586. https://doi.org/10.1068/p7833

Rogers, S. J., Hepburn, S., & Wehner, E. (2003). Parent reports of sensory symptoms in toddlers with autism and those with other developmental disorders. *Journal of Autism and Developmental Disorders, 33*(6), 631-642. https://doi.org/10.1023/b:jadd.0000006000.38991.a7

Rogers, S. J., & Ozonoff, S. (2005). Annotation: What do we know about sensory dysfunction in autism? A critical review of the empirical evidence. *Journal of Child Psychology and Psychiatry, 46*(12), 1255-1268. https://doi.org/10.1111/j.1469-7610.2005.01431.x

Rodgers, S. J., Wigham, S., McConachie, H., Freeston, M., Honey, E., & Parr, J. R. (2016). Development of the anxiety scale for children with autism spectrum disorder (ASC-ASD). *Autism Research, 9*(11), 1205-1215. https://doi.org/10.1002/aur.1603

Romero, M., Aguilar, J. M., Del-Rey-Mejías, Á., Mayoral, F., Rapado, M., Peciña, M., Barbancho, M. A., Ruiz-Veguilla, M., & Lara, J. P. (2016). Psychiatric comorbidities in autism spectrum disorder: A comparative study between DSM-IV-TR and DSM-5 diagnosis. *International Journal of Clinical and Health Psychology, 16*(3), 266-275. https://doi.org/10.1016/j.ijchp.2016.03.001

Rubenstein, J., & Merzenich, M. M. (2003). Model of autism: Increased ratio of excitation/inhibition in key neural systems. *Genes, Brain and Behavior, 2*(5), 255-267. http://doi.org/10.1046/j.1601-183X.2003.00037.x

Rutherford, M. D., Baron-Cohen, S., & Wheelwright, S. (2002). Reading the mind in the voice: A study with normal adults and adults with Asperger syndrome and high functioning autism. *Journal of Autism and Developmental Disorders, 32*(3), 189-194. https://doi.org/10.1023/A:1015497629971

Sapey-Triomphe, L.-A., Leiros Costa, T., & Wagemans, J. (2019). Sensory sensitivity in autism mostly depends on contextual predictions. *Cognitive Neuroscience, 10*(3), 162-164. https://doi.org/10.1080/17588928.2019.1593126

Shah, A., & Frith, U. (1983). An islet of ability in autistic children: A research note. *Journal of Child Psychology and Psychiatry, 24*(4), 613-620. https://doi.org/10.1111/j.1469-7610.1983.tb00137.x

Shah, A., & Frith, U. (1993). Why do autistic individuals show superior performance on the block design task? *Journal of Child Psychology and Psychiatry, 34*(8), 1351-1364. https://doi.org/10.1111/j.1469-7610.1993.tb02095.x

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of* *the American Academy of Child & Adolescent Psychiatry, 47*(8), 921-929. https://doi.org/10.1097/chi.0b013e318179964f

Simmons, D., McKay, L., McAleer, P., Toal, E., Robertson, A. E., & Pollick, F. (2007). Neural noise and autism spectrum disorders. *Perception, 36,* 119-120.

Simmons, D. R., Robertson, A. E., McKay, L. S., Toal, E., McAleer, P., & Pollick, F. E. (2009). Vision in autism spectrum disorders. *Vision research, 49*(22), 2705-2739. https://doi.org/10.1016/j.visres.2009.08.005

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* Sage Publications, Inc.

Smith, J. A., Larkin, M., & Flowers, P. (2017, May 18-19). *Interpretative Phenomenological Analysis: 'Where are we now?'* [Conference session]. The International Interpretative Phenomenological Analysis Conference, Glasgow, United Kingdom.

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), Qualitative psychology: A practical guide to research methods (2nd ed., pp. 53–80). Sage Publications, Inc.

Smith, R. S., & Sharp, J. (2013). Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with Asperger syndrome. *Journal of Autism and Developmental Disorders, 43*(4), 891-910. https://doi.org/10.1007/s10803-012-1633-6

South, M., & Rodgers, J. (2017). Sensory, emotional and cognitive contributions to anxiety in autism spectrum disorders. *Frontiers in Human Neuroscience, 11*, 20. https://doi.org/10.3389/fnhum.2017.00020

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A Brief Measure for Assessing Generalized Anxiety Disorder. *Archives of Internal Medicine, 166*(10), 1092. https://doi.org/10.1001/archinte.166.10.1092

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Sage Publications, Inc.

Tager-Flusberg, H. (1996). Brief report: Current theory and research on language and communication in autism. *Journal of Autism and Developmental Disorders, 26*(2), 169-172. https://doi.org/10.1007/bf02172006

Tantam, D. (2003). The challenge of adolescents and adults with Asperger syndromes. *Child and Adolescent Psychiatric Clinics of North America, 12*(1), 143-163. https://doi.org/10.1016/s1056-4993(02)00053-6

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation, 27*(2), 237-246. https://doi.org/10.1177/1098214005283748

Thompson, A. R., Smith, J. A., & Larkin, M. (2011). Interpretative phenomenological analysis and clinical psychology training: Results from a survey of the group of trainers in clinical psychology. *Clinical Psychology Forum*, *222*(222), 15-19.

Tomchek, S. D., & Dunn, W. (2007). Sensory processing in children with and without autism: a comparative study using the short sensory profile. *American Journal of Occupational Therapy, 61*(2), 190-200. https://doi.org/10.5014/ajot.61.2.190

Tse, J., Strulovitch, J., Tagalakis, V., Meng, L., & Fombonne, E. (2007). Social skills training for adolescents with Asperger syndrome and high-functioning autism. *Journal of Autism and Developmental Disorders, 37*(10), 1960-1968. https://doi.org/10.1007/s10803-006-0343-3

Turner, M. (1999). Annotation: Repetitive behaviour in autism: A review of psychological research. *Journal of Child Psychology and Psychiatry, 40*(6), 839-849. https://doi.org/10.1111/1469-7610.00502

Uljarević, M., Lane, A., Kelly, A., & Leekam, S. (2016). Sensory subtypes and anxiety in older children and adolescents with autism spectrum disorder. *Autism Research, 9*(10), 1073-1078. https://doi.org/10.1002/aur.1602

Vermeulen, P. (2012). *Autism as context blindness.* AAPC Publishing.

Volkmar, F. R., & McPartland, J. C. (2014). From Kanner to DSM-5: Autism as an evolving diagnostic concept. *Annual Review of Clinical Psychology, 10*(1), 193-212. https://doi.org/10.1146/annurev-clinpsy-032813-153710

Watling, R. L., Deitz, J., & White, O. (2001). Comparison of Sensory Profile scores of young children with and without autism spectrum disorders. *American Journal of Occupational Therapy, 55*(4), 416-423. https://doi.org/10.5014/ajot.55.4.416

Wechsler, D. (1974). *Manual for the Wechsler intelligence scale for children, revised (WISC-R).* Psychological Corporation.

Wheelwright, S. J., Auyeung, B., Allison, C., Baron-Cohen, S. (2010). Defining the broader, medium and narrow autism phenotype among parents using the Autism Spectrum Quotient (AQ). *Molecular Autism, 1(1),* 10–19. https://doi.org/10.1186/2040-2392-1-10

White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review, 29*(3), 216-229. https://doi.org/10.1016/j.cpr.2009.01.003

World Health Organisation. (1993). *The ICD-10 classification of mental and behavioural disorders: Diagnostic criteria for research.* Switzerland World Health Organization.

Wigham, S., Rodgers, J., South, M., McConachie, H., & Freeston, M. (2015). The interplay between sensory processing abnormalities, intolerance of uncertainty, anxiety and restricted and repetitive behaviours in autism spectrum disorder.

Journal of Autism and Developmental Disorders, 45(4), 943-952. https://doi.org/10.1007/s10803-014-2248-x

Willig, C. (2013). *Introducing qualitative research in psychology: Adventures in theory and method.* Open University Press.

Wing, L. (1996). Autistic spectrum disorders. *British Medical Journal, 312*(7027), 327.

Woolfe, R. (1990). Counselling psychology in Britain: An idea whose time has come. *The Psychologist, 3*(12), 531–535

Woolfe, R., Strawbridge, S., Douglas, B., & Dryden, W. (2009). *Handbook of counselling psychology*. Sage Publications, Inc.

Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., & Blumberg, S. J. (2015). *Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey.* Centers for Disease Control and Prevention.

Zantinge, G., van Rijn, S., Stockmann, L., & Swaab, H. (2017). Physiological arousal and emotion regulation strategies in young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 47*(9), 2648-2657. https://doi.org/10.1007/s10803-017-3181-6

Ziring, P. R., Kastner, T., Friedman, D. L., Pond, W. S., Barnett, M. L., Sonnenberg, E. M., & Strassburger, K. (1988). Provision of health care for persons with developmental disabilities living in the community: The Morristown model. *JAMA*, *260*(10), 1439-1444. https://doi.org/10.1001/jama.1988.03410100129038

Appendix A – Interview Schedule

We are going to begin with some questions about your sensory experiences.

1. **Could you tell me about your sensory experiences, in general?**

Prompts:

How do you experience sensation in your everyday life?

Do you consider any of your experiences as unusual?

What is your relationship with your sensory experiences?

Now, let's talk about emotions.

2. **Could you tell me about your experience with emotions in your everyday life?**

Prompts:

Which emotions do you experience more often?

What does "feeling good" emotionally, or "feeling bad" emotionally mean to you?

How would you describe your world of (emotions reported by participants, e.g. sadness)?

What is the link between your sensations and emotions?

Now, let's talk about how emotions can affect your physical sensations in your body. We can talk about positive emotions, and we can also talk about negative emotions.

3. **Which has the biggest effect on your physical sensations, positive emotions or negative emotions?**

Prompts:

Can you tell me a little more about that?

How much have you thought about the connection between your emotions and your sensations? How much has that been a struggle for you? Why? How?

Is it something you have not really thought about? Why?

Have people talked to you about these stuff before, or tried to teach you about it; or is it a bit of a mystery for you?

Can you give me an example of a particular emotion that has a big effect on how you feel in your body?

Can you think of situations where this happened recently? Tell me about this.

How did it affect you? Did it worry you, or have some other effect on you?

Were there any particular situations that happened to you, that were affected more by this emotion; or by positive/negative emotions generally? So, when you are happy/sad/anxious, or feeling good/bad emotionally, are there any certain kinds of sensation that happen more often?

Do you sometimes mistake emotions for sensations, or do some emotions just appear purely as sensations for you? Are there any sensations that create pure emotion for you?

Now I am going to ask you about your experience of describing your sensory world.

4. **How is the process of talking about your sensations like for you?**

Prompts:

How do you find the process of talking about all these today and in general?

Do you find the use of words to describe this part of your world difficult?

What helps; or what you think would help?

5. **Before we finish, is there anything you would like to add?**

Prompts:

Have you got any questions for me?

How has this interview been for you?

What pseudo-name do you want me to use for you in my project?

Appendix B – Advertising Sheet

PARTICIPANTS NEEDED!

Would you like to take part in a research study exploring **the sensory world of verbal autistic individuals***?

*anyone with a clinical diagnosis of autism with no additional intellectual disability or language impairment

Are you eligible?

- Adult individual aged 18 to 65 years
- English-speaking
- Have a clinical diagnosis
- Experience **unusual sensory experiences**
- Have **no** severe anxiety and/or depression
- Have **no** language impairment
- Have **no** intellectual disability

Participation in this study involves:

- Engage in a Skype interview
- £10 Amazon gift voucher

"I am interested in learning about your understanding of the impact of emotions on your sensory world for my doctoral research. I believe that better understanding of this may help mental health professionals provide better care to autistic individuals."

Get in touch!

If you wish to **take part in this study**, please contact Alexia Georgiou at **alg0610@my.londonmet.ac.uk**

Appendix C – Participant Information Sheet

Dear participant,

I am a trainee counselling psychologist at London Metropolitan University currently carrying out research to understand more about the sensory world of verbal, autistic individuals (anyone with a clinical diagnosis of autism with no additional intellectual disability or language impairment).

Very little is known about the topic and as a population, autistic individuals are underrepresented as clients in the counselling profession, even though they do seek help. Equally, very limited research has been conducted in this area which has not yet helped to ensure adequate therapeutic care for individuals on the spectrum. My hope is that by carrying out this research we will be able to gain a better understanding of the sensory experiences of autistic individuals so that they are able to get the support, help and services they need.

I am writing in the hope that you will be interested in helping me in this endeavour and share your sensory experiences by participating in an interview. The interview will last approximately one to two hours (depending on your comfortability) and will be voice recorded. Data from your interview will be used for my Doctoral level counselling psychology project.

Participation is entirely voluntary. If you choose to participate you are free to withdraw at any point up until four weeks after the interview day without question. Interviews will be voice recorded and strictly confidential. All recordings will be kept securely and destroyed once the project is completed.

Before you decide to participate it is important that you understand that the interview, even though rare, might evoke some distress for you, especially if you are finding social communication and interaction overwhelming. In line with this it is also important that you are older than 18 years of age, and that you have completed and returned the PHQ-9 and GAD-7 sheets sent out to you. Therefore please take your time in deciding whether or not you wish to take part. You will have the opportunity to discuss any feelings evoked at length post interview with the researcher and be given information on sources of support if you would like this.

Thank you so much for your time, if you have any further queries please do not hesitate to ask by emailing me at: alg0610@my.londonmet.ac.uk

I look forward to hearing from you soon.

Yours Sincerely,

Alexia Georgiou

Appendix D – PHQ-9 and GAD-7 Scales

PHQ-9: Depression questionnaire

Over the last two weeks, how often have you been bothered by any of the following problems? *(Circle or highlight to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too long	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have left yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that the other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or hurting yourself in some way	0	1	2	3

Column totals: ___ + ___ + ____ + ___ = ***Total Score*** _____

GAD-7: Anxiety questionnaire

Over the <u>last 2 weeks</u>, how often have you been bothered by the following problems? *(Circle or highlight to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Column totals: ___ + ___ + ___ + ___ = ***Total Score*** _____

If you checked off <u>any</u> problems, how <u>difficult</u> have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	**Somewhat difficult**	**Very difficult**	**Extremely difficult**

Scoring Notes

PHQ-9 Depression Severity

Scores represent:

0-4 = minimal depression

5-9 = mild depression

10-14 = moderate depression

15-19 = moderately severe depression

20-27 = severe depression

GAD-7 Anxiety Severity

Scores represent:

0-4 = minimal anxiety

5-9 = mild anxiety

10-14 = moderate anxiety

15-21 = severe anxiety

Appendix E – Sample Annotated Transcript (IPA Steps 2-4)

Step 3: Developing themes

Improvement of experience (affected by awareness/lack of)?

Autism's "usual": beliefs/knowledge about autism

Reaction to situation (to cope)

Feelings produced (overwhelmed, suffering, uncomfortable)

Coping strategies

Researcher: We're going to begin with some questions about your sensory experiences, first - could you tell me about your sensory experiences, in general?

Paul: Um, when I was—I suppose when I was younger, it was a lot worse. I was—I had the usual: very sensitive to sounds, very sensitive to lights. Well, I wasn't so aware of it cause I was quite young, but my mom told me whenever we went to restaurants, um, I would actually climb under the table and do stuff under there [laugh] because I think, the sounds were too loud and it was all quite overwhelming. Um, I still do suffer from it mildly today - it's not too bad. If I'm under it for too long though, it does make me a lot more uncomfortable. Um, as a result I mainly—I always pretty much wear headphones whenever I'm outside, just to play music and stuff, just to kind of draw it out, um…

Researcher: To minimise the sounds?

PROMPT: talk about sensory experiences

Step 2: Phenomenological coding
Paul directly answers question
Talks about sensitivity to sound and lights
Gives general example of a situation of when he was younger
Remembers associated feelings produced (overwhelmed) in situation but at the time was not aware that he had sensory sensitivities (attributes this to age)
Paul's mother noticed his reactions in these situations
Talks about improvement in sensory sensitivities over time yet, time of exposure significant
Developed coping strategies (e.g., headphones when out)

Step 4: Interpretative coding
Possibly needs to show at as a grown-up he is able to better cope ("suffer" but "mildly") as opposed to when younger when he was not even aware of it and acted "child-like" (climbing under tables)
Mother then was possibly a means to making sense for him, hence Paul's awareness improved with age
Better awareness helped him develop coping strategies

Paul: Pardon?

Researcher: To minimise the sounds? The external sounds?

Paul: Yeah, yeah. Um, whenever I'm in a stressful situation um, and I don't have something to kind of—if I don't have my headphones on and I'm in a stressful situation with sounds and noises, I do find it very difficult. It is manageable, I *can* deal with it; I used to have full-blown attacks, like panic attacks, but I haven't had one in years. Just uh—I have been able to deal with it so to say, but I certainly do feel that I'm not really a fan of going to like, nightclubs or bars, in general, anything where there is lots of sounds, lights and I can't really escape.

Researcher: Do you consider these experiences as unusual?

Paul: Um, to my understanding, I know that it's not common for people to feel like that. Obviously, when I was a *little* bit younger, like when I was in college, I didn't really understand it because a

Step 3: Developing themes

Feelings produced (stress, panic)
Necessity of coping strategy

Own ability to manage (improved)

“Preferences”
Avoidance as coping str.?

Reaction: escape

Normalising?

Step 2: Phenomenological coding
Paul associates his experience of sounds, noises, and lights with stress
Talks about his ability to now (vs. when younger) deal with and manage distress – something that even though is very difficult, he manages
Affecting his life – no joy from nightlife (vs. other 20-year-olds/peers?)

Step 4: Interpretative coding
“not a fan”: understatement?
Seems like his ability to cope shapes his sense of self
Implies that he sometimes goes – pushes himself to go places he finds very difficult = cost, possibly because he doesn’t want to miss-out (peers/social life) = gain

Step 2: Phenomenological coding (continues in following page)
Even though my question was leading, he did not answer with a yes or no. “unusual” vs. “not common”

Step 3: Developing themes

Normalising

Comparing to others/finding similarities

Need to make sense?

lot of my friends wanted to go to clubs and I did not and obviously, I hated it. I became aware that it was normal for *me* and I didn't really—I was aware enough to know that everyone is *different* and then recently, when obviously I was on the autism support group and talked to more autistic people, I found it was quite a common trait. Um, so I never really felt alienated for it, but I was aware that it was—it was *different* from norm—it was different for ‘neurotypical’ people, but quite common in the autistic community.

Researcher: Do you mind me asking, when did you receive the diagnosis?

Paul: Um, I received my diagnosis—it was between—it would have been between five and seven [pause] I was quite young.

Researcher: Okay, and how old are you now?

Paul: I am 20.

Step 2: Phenomenological coding (continues from previous page)

When he went to college he noticed that he hated [vs. “not a fan” (24)] things that people his age/friends liked. Made sense of it by normalising

Now aware that difficulties and preferences are due to autism

Explains it is not a matter of whether or not his experiences are unusual. It rather depends with what one compares it to. If compared to neurotypical people then it is different/possibly not normal, but if compared to autistic people then it is normal/common/not unusual

Step 4: Interpretative coding

Adaptive/flexible statements depending on control variables - there is a need for normality (32) (33) (38)

Normality ensures he feels included and “normal”

Sought to talk to other autistic people possibly to help make sense of why he was different from friends

Interesting that he corrected wording (37): political correctness or normalising (if he states that neurotypicals = normal, then that would imply he’d never been normal)

Appendix F – Salient Points for Each Participant (IPA Step 5)

Paul	Mary	Zoe
• Sensory improvement due to awareness, coping methods, time. No improvement in emotions (don't always make sense) • Coping - filtering (making sense), compromising, headphones, avoidance, own time and pace • Noticing reactions (emotional, physical) – improves awareness • Autism is: Own and other's ideas/preoccupations, a constant battle with too much information, being autistic Vs. neurotypical • Need for normality (protective process) – normal and included • Sense of self - ability to cope/learn all by himself vs. need for support, comparing to others, labelling • Need to know what to expect/minimise uncertainty • Changes in sensory sensitivities – emotions & sensations = two-way relationship • Describing ("it's like it", scenarios, dialogues, sharing actual past stories, use of words, picturesque descriptions, referring to movies, video games, difficult, no words to describe the particulars) • Liking, hating, not a fan of, disliking sensory experiences (normalising?)	• Sensory experiences: as likes and dislikes, worse since diagnosed – other factors • Noticing reactions (emotional, physical) • Sense of self: labelling, how she thinks she comes across, good ability to cope • Making sense • Awareness (due to diagnosis/reading/learning about autism) • Coping: withdrawing, escaping, negotiating/compromising, need of own pace, talking/seeking support, expressing through writing) • Experiencing an overloading of sensations, emotions – too much to process all the time • Normalising: "normal for me", protective process, finding similarities to others • Changes in sensitivities (certainty – less information to process – better experience) • Autism is... (beliefs, preoccupations, normal vs. abnormal) • Describing (scenarios, simile, sharing actual stories – anecdote, dialogue, referring to videos, first time describing, difficult) • Need to know what to expect/minimise uncertainty/fear for the unknown	• Sensory experiences: struggles, likes and dislikes (normalising?) • Consequences/reactions (physical, emotional, effect on relationships) • Difference in experience of sensations: affected by emotions, the amount of information needing to be processed • Ideas/preconceptions about autism • Describing (scenario, anecdote, dialogues, simile, used a live example from during the interview) • Coping strategies (helping others understand her, withdrawing, earplugs, compromising for social life?, taking time/own pace • Awareness/lack of (better since diagnosis – learning, reading: better experiences as a result) • Sense of self: comparing to others, other's view of her, labelling, ability to cope • Need to make sense/understand • Normalising • Fear for the unknown/new situations – reducing uncertainty • Too much information to process

Appendix G – Looking for Patterns across Cases (IPA Step 7)

Theme 1. Experiencing Sensations and Emotions

- Physical reactions
- Emotional reactions
- Differences in experience of sensations (affected by: emotions – two-way relationship, uncertainty and amount of information needed to be processed – reducing information by reducing uncertainty?)

Theme 2. Coping with the Consequences

- Compromising – negotiating
- Headphones, earplugs, writing on a blog, etc.
- Need for time/own pace
- Avoiding/escaping
- Withdrawing
- Minimising uncertainty

Theme 3. Making Sense: “The Base Part of What I Have to Do in My Everyday Life”

- Sense of self – what’s like to be autistic, ability to cope, not “normal”, comparing and contrasting?
- Making sense – helping other’s understand them
- Increasing awareness by learning & reading
- Normalising to protect – apparent in descriptions (dislikes and preferences), “normal for me”, comparing and contrasting?

Theme 4. The Process of Describing It

- “It is like..” simile

- Scenario
- Anecdote
- Inner dialogues
- Referring to videos and movie scenes
- A very difficult process
- No words to describe

Appendix H – Participant Informed Consent

Title of research: The sensory world of verbal, autistic individuals: An Interpretative Phenomenological Analysis.

Description of procedure: In this research you will be asked a number of questions regarding your sensory experiences within a voice recorded interview.

If you agree with the following, please sign at the bottom of the form, in the provided space.

- ✓ I understand the procedures to be used.
- ✓ I understand I am free to withdraw at any time during the study without question. However, all data will be aggregated by the [specific date to be confirmed]; therefore if I wish to withdraw it has to be done by [specific date to be confirmed].
- ✓ I understand that participation in this study is anonymous. My name will not be used in connection with the results in any way, a pseudonym will be used on the digital voice recording and all information that may otherwise identify me (e.g., address, friend’s names) will be changed prior to transcription. There are limits to confidentiality however; confidentiality will be breached if any information is disclosed that indicates a risk to safety of myself or of anybody else.
- ✓ I understand that the results of the study will be accessible to others when completed and that excerpts from my interview (except from explicit identifying information) may be used within the study.
- ✓ I understand that I may find this interview upsetting and that it may evoke a number of difficult and distressing feelings for me. I will be offered support and the opportunity to discuss these feelings at length post interview with the

researcher. The researcher will also give information on further support available if required.

- ✓ I understand that I have the right to obtain information about the findings of the study and details of how to obtain this information will be given in the debriefing form.
- ✓ I understand that the data will be destroyed once the study has been assessed.

Signature of participant:……………..	Signature of researcher:…………………
Print name:…………………	Print Name:…………………
Date: …………………	Date: …………………

Appendix I – List of Services

If participation in this study has raised any concerns or issues that you wish to discuss further, a number of agencies can provide advice and support in confidence.

Autism Helpline (National Autistic Society)

Autism Helpline provides impartial, confidential information, advice and support for people with autism spectrum disorders and their families and carers. They can also help you find a person to talk to in your area.

Tel. 0808 800 4104

Web Site: www.autism.org.uk/helpline

Mind Infoline (Mind)

Mind is a mental health charity that provides support to everyone experiencing mental health difficulties. They can help you seek appropriate help and support, as well as advocate for you. Check their website for your local branch.

Tel. 0300 123 3393

E-mail: info@mind.org.uk

Web Site: http://www.mind.org.uk/

Samaritans

The Samaritans is a registered charity that provides 24h emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide throughout often through their telephone helplines. You can also check their website for your local branch.

Tel. 116 123

E-mail: jo@samaritans.org

Web Site: www.samaritans.org/

In case of emergency, consult your GP or attend your local A&E.

Appendix J – Debrief Sheet

Dear participant,

Thank you for taking part in this research study. This is part of a Doctoral project that the researcher is conducting.

If you are interested in the results of the study, or if you have any questions about this study, or if you wish to withdraw, please contact the researcher on the following email address: alg0610@my.londonmet.ac.uk. Emails will be checked regularly.

Please remember that if you wish to withdraw your data from this study it should be done within a month after the interview date as it may not be possible at a later stage.

Equally, if you have any questions or concerns you are more than welcome to address them now.

If you have any complaints regarding any aspect of the way you have been treated during the course of the study please contact my research supervisor Dr Philip Hayton on:

02071332685 or Email: p.hayton@londonmet.ac.uk

Thank you,

Alexia Georgiou