Towards a better understanding of loneliness in autistic adults:

examining measurement tools and lived experiences

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Abstract

Loneliness is a universal feeling that people might feel when there is a gap between the ideal and actual states of their social relationships. Historically, it has been thought that autistic people do not have a desire for social connection and instead show a preference for aloneness. However, recent research, coupled with first-hand accounts of autistic individuals, has shown that not only do autistic people experience loneliness, but they may be particularly vulnerable to it (e.g., due to the challenges they experience in social environments and/or due to a lack of supportive environments in which to cultivate social relationships).

To date, there has been limited research on loneliness in autistic adults. In this thesis, I used both quantitative and qualitative methods to further our current understanding of loneliness in autistic adults, with a focus on examining the measures used to assess loneliness in autistic adults, as well as autistic people's lived experiences of loneliness. In Chapter One, I introduce my motivation for this research as a neurodivergent individual and provide an overview of research into both autism and loneliness. In Chapter Two, I use a systematic review to synthesise the current evidence base on loneliness in autistic adults, and to identify gaps in research that can guide subsequent work. In Chapter Three, I use mixed-methods to examine if, and how accurately, existing measures of loneliness capture the experiences of autistic adults. In Chapter Four, I use qualitative methods to explore the unique experience of loneliness in autistic adults. In Chapter Five, I use mixed-methods to investigate experiences of loneliness in autistic adults before, and during the early stages of, the COVID-19 pandemic. In Chapter Six, I discuss the contributions of my research to knowledge on autistic adults' experiences of

loneliness, outline future directions for such work, highlight the strengths and limitations of my research, and present my personal reflections.

Impact Statement

There are four key ways that the research presented in this thesis could generate impact. First, I have advanced knowledge on loneliness in autistic adults by addressing two key areas for investigation highlighted in the latest tackling loneliness evidence review from the UK Department of Digital, Culture, Media and Sport (DCMS). Specifically, Qualter et al. (2022) reported that one of the key areas for research on loneliness is examining ways to accurately measure loneliness in different groups of people. Linked to this, in Chapter Three, I evaluated the measures to assess loneliness in autistic adults and this work has been accepted as a poster presentation at "It Takes All Kinds of Minds", an international conference on neurodiversity (in March 2023, in Edinburgh, Scotland). Qualter et al. (2022) also reported that improving our understanding of loneliness in socially stigmatized groups is a key area for research. Throughout this thesis, I have characterized loneliness in autistic adults: identifying their experiences of loneliness, what underpins their loneliness, and what could alleviate their loneliness. Previous research on this topic has been largely quantitative (as detailed in my systematic review, presented in Chapter Two). However, in my research, I have amplified the voices of autistic adults on an issue that matters to them. By using inclusive, online methods, autistic adults had the opportunities to share their views and experiences.

Second, in the systematic review presented in Chapter Two, I identified areas for future research on loneliness in autistic adults. While some of these areas were beyond the scope of this PhD research, the review was published open-access in Autism: The International Journal of Research and Practice in March 2022. The recommendations from this review could be used to guide future research on loneliness in autistic adults.

Third, based on the findings from this doctoral research, I have made suggestions for alleviating loneliness in autistic adults to build bridges between research and practice: cultivating acceptance of autistic differences in autistic adults, using social prescribing, making accommodations in social settings, creating resources for mental health professionals to learn about loneliness in autistic adults, and creating trainings for non-autistic people to learn about autism to improve the societal understanding and acceptance of autism.

Finally, one of the most significant aspects of this research is that it was conducted by an insider-researcher. I am autistic and have ADHD, and I have conceptualized, designed, conducted, analyzed, and written up the research presented in this thesis. Furthermore, my completion of this thesis adds to the growing number of neurodivergent individuals completing a PhD and may bring hope for the next generation of neurodivergent minds to pursue higher education.

Declaration

I, Kana Umagami, confirm that, the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that I have indicated it in this thesis. I developed the questions in the surveys used in Chapters Three, Four and Five, except for the standardized measures used to assess loneliness: the UCLA Loneliness Scale Version 3 (Russell, 1996), Social Emotional Loneliness Scale for Adults (DiTommaso & Spinner, 1993), and the direct measure of loneliness (Office for National Statistics, 2018). Jade Davies, a research assistant at CRAE, acted as a second coder in the systematic review presented in Chapter Two, the thematic analysis presented in Chapter Three, and the thematic and content analysis presented in Chapter Five.

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My PhD research took place at the Centre for Research in Autism and Education (CRAE), and I am very grateful that I had the privilege to work alongside with the brilliant minds who are working to make the world a better place for autistic people. Thank you to the CRAE team who has inspired me, especially Jana, Mel, and Jade, whom I worked most closely with.

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Table of Contents

Chapter Three: Evaluating Measures to Assess Loneliness in Autistic Adults

3.3.1 Quantitative data: Correlation between three loneliness measures

List of Tables

List of Figures

<u>Chapter One</u>

General Introduction

1.1 Motivation

1.1.1 My story

I simply want to be helpful for other people. This desire has become the anchor of my major career choices through my journey of self-discovery. I am autistic and have ADHD, and this PhD research was inspired by my personal experiences of being different in a world where people appreciate conformity. I have experienced a lot of social and non-social challenges in my life that have prevented me from doing what I wished I could, including staying in the UK for the duration of my PhD (I could not do so because I needed day-to-day support in managing daily life, so I returned to Japan to be with my family). Even though I outwardly grow older like everyone else, and so my knowledge, experiences, and interests (including autism) grow, I stay the same in a lot of ways and struggle with things that people of my age would not normally struggle with (e.g., completing everyday tasks).

Growing up, I was often told that I was different from others, but I was not aware of my differences then. When I was a child, I looked at the particles in the air that others did not see, and I had particular likes and dislikes for certain numbers. I did not know that how I see the world deviated from the "norm" of other people. What I reasoned was that I must be stupid because I could not read books no matter how hard I tried. In elementary school (around age 6-11), I was continuously told to try harder with my reading, and not to be lazy. I became more and more aware of the way that I differed from my peers in secondary school (around age 12-14). Every morning when I arrived at school, I sat alone in the classroom and read my favorite book series, "Royal Ballet School Diary" since ballet always took me to my happy

place. In my first year in middle school, I had to ask my teacher to help me make friends. In high school (around age 15-17), while I liked to be on my own, I felt sad and lonely for eating lunch by myself when my peers around me were eating in groups and did not even care to invite me. My focus growing up had been ballet and academic study, and I always had some good friends in ballet (but perhaps they were acquaintances, as I cannot easily distinguish friends from acquaintances). As such, I did not care too much about my social "peculiarity" in school.

It was when I started living on my own to go to university that I became acutely aware of my differences from others, socially and non-socially. In my first year at university, I focused on getting good grades and doing as much as I could to socialize like other university students. During that time, I also tried hard to lose weight, since I had total control over what I ate when living away from home. In the middle of my second year in university, I experienced burnout from trying so hard in university, both in academic and social aspects. Worst of all, I found all my efforts to be meaningless. I was not at all interested in what I was learning in university, and it was difficult to continue with my studies because my brain rejects taking in information that I am not interested in. University was also when I first went to see counselors and psychiatrists. I was told that I was experiencing depression and I was prescribed medication. While I was not entirely sure if depression was the thing I was experiencing, I liked the environment of counselling and appreciated how my counselor created the only space I felt safe and comfortable in within the university. Going to university became harder and harder as my anxiety on campus increased and I felt tingling and numbness in my fingertips, arms, and legs. This was in addition to the kind of headache I experience when around people, which feels as if my brain has been tightened with a piece of string. As normal as this headache was and still is

in my life, now that I have learned more about myself, I recognize that it is not "normal" in other people's daily lives.

At the age of 21, I was diagnosed as autistic. At the age of 24, around the beginning of the second year of my PhD, I was also diagnosed with ADHD. The ADHD medication, Strattera, saved my life. Until I was prescribed Strattera, I had to do intense workouts, particularly cardio, for around four hours every day, to work off all the energy I had, and to be able to concentrate on my daily tasks and research. Otherwise, I felt that I had so much energy, and this energy was sometimes directed towards self-harm (e.g., hitting and scratching myself) and suicidal ideation. I still have to do workouts to feel ready to concentrate on my work, but the length of time I need is now reduced to one hour. This change made a huge difference, as it allowed me to have more time to work on my PhD. Thus, despite all the hair that has been lost and the occasional nausea I experience due to the medication, I am thankful and not at all ashamed that I need this medication.

When I first started to learn about autism through my diagnostic process, I became very intrigued, and autism has become my passion since then. I was diagnosed as autistic during the time I was doing my Master's in Counselling Psychology, so that I could become a mental health counselor. I was drawn towards the path of counselling because I had been seeing therapists and psychologists, and I had met some great clinicians who helped me along the way. I wanted to be like them and help others like myself. When I was seeking and getting the diagnosis of autism, it became clear to me that I wanted to help others who are also autistic. However, I felt that working as a mental health counselor was not perfectly suited for me, at least at that point in my life, so I sought to do autism research as a helpful means of learning more about autism.

Until I became a PhD student at the Centre for Research in Autism and Education (CRAE), I was a nobody in the field of autism, and people were not interested in what I had to say about being autistic and being different. While I do not care what others think of me, with or without a PhD, I care about getting the opportunities to talk about autism and to advocate for other autistic individuals. It is unfortunately the case that the world tends to respect and listen more to those with qualifications such as a PhD, as opposed to those without such qualifications. Academic research has the power to make the unheard heard. Going forward, I am looking forward to being able to support autistic individuals and their families with the expertise gained from my PhD.

Therefore, this PhD is not for me, but for all autistic people, their families and anyone who cares about them. The following Bible verse summarizes the purpose of my PhD: "Speak up for those who cannot speak for themselves, for the rights of all who are destitute. Speak up and judge fairly; defend the rights of the poor and needy" (Proverbs 31: 8-9, *The Holy Bible, New International Version*). My hope is that my PhD research and this thesis have been, and will be, an outlet for the hidden and ignored experiences of loneliness among autistic adults. I am humbled knowing that I did not get here (to the point of completing my PhD thesis) on my own. There have been many people who have supported me. I can now appreciate my differences and consequent struggles because they have equipped me with a better sense of humility, by bringing me closer to other people. In a way, my differences prompted me to recognize how important and necessary connections to others are, and how terrible it is to feel left out, misunderstood, and lonely. With the knowledge

that this PhD journey has given me, I would like to keep serving the autistic and broader autism communities[1] to direct them to the Light.

Fundamentally, I chose loneliness as a topic for my PhD because I firmly believe that there is a need to belong in *every* human being and I hope for a world where autistic people feel that sense of belonging and connection in/to whatever forms/degrees individuals may prefer. To learn about the experiences of belonging and connection in autistic adults, I decided to investigate the opposite experience (i.e., loneliness); a decision that was inspired by a TED talk by Brene Brown in 2011. In the Ted talk, Brene explained her research, where she asked her participants (from the general population) about belonging, and the participants explained excruciating experiences of being excluded. Chevallier et al. (2012) argue that humans, as social beings, get several benefits from building relationships with others and they discuss how social bonds - especially some close relationships - are necessary to achieve happiness. It is equally notable that a lack of such relationships has negative impacts on people's lives, such as anxiety, depression, unhappiness, stress, and even suicide (Baumeister & Leary, 1995; Chevallier et al., 2012; Gere & MacDonald, 2010). Baumeister and Leary (1995) claim that a need to belong, a need to build, and a need to keep a minimum quality of interpersonal relationships, is embedded in all humans regardless of cultures (Dunbar, 2018).

1.1.2 Broader research context for the PhD

While I knew what loneliness was like for autistic people (at least, my own experience of loneliness), I struggled to explain what loneliness felt like. Fundamentally, the significance of this PhD research is twofold. First, this research

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[1] The autistic community refers to a collective of autistic individuals, and the autism community refers to a collective of family members, allies, autism practitioners, and/or researchers (Roche et al., 2021).

can help non-autistic people learn about the experiences of loneliness among autistic adults. Second, this research can empower autistic people by giving them words to describe their experiences.

Academic research can be a powerful tool to share autistic experiences. However, autistic experiences have not been a primary area of research, and a discrepancy between community priorities and research funding/publications has been noted. For example, Pellicano et al. (2014) investigated whether UK autism funding priorities aligned with community priorities. Community, in this context, included anyone with a connection to autism, including autistic people, their families, and those who work with them (Pellicano et al., 2014). Pellicano et al. (2014) reported that most autism research funding was allocated to basic science research (e.g., investigating 'causes' of autism). While stakeholders did see value in such research, they hoped for more research that made an impact/difference in their day-to-day lives (Pellicano et al., 2014). For example, stakeholders highly valued research that aimed to identify effective support and services, and research that aimed to foster better understanding and acceptance of autism in practitioners and the general public (Pellicano et al., 2014) . As I began engaging with the literature on loneliness in autistic adults, it became clear that autism research has not prioritized the topic of loneliness, despite autistic self-advocates long expressing their voices regarding their personal experience of loneliness (Anja Melissa, 2017; Higashida, 2013; Hiromi Asperger, 2017). Nonetheless, it is important to note that research on priority settings itself has not been truly inclusive since it tended to exclude children, adolescents, those from low/middle income countries, and those with additional communicative challenges (Roche et al., 2021).

Autism research has long been conducted from a deficit-based, medical model view of autism; focusing on finding a "cause" or "cure" for autism and determining how to "normalize" autistic people (i.e., making them more like non-autistic people) (Chown et al., 2017; Milton & Bracher, 2013). The dominant conceptualization of autism, focused on the medical model, will be explained in Section 1.2.1. In my view, autism research has seen some positive changes stemming from the autistic self-advocacy movement in recent years (Milton & Bracher, 2013). Autism research can be more beneficial and relevant for autistic people with the involvement of autistic autism researchers (Milton & Bracher, 2013). The concept of "nothing about us without us" has been more fully embraced by autistic advocates in recent years, and more participatory research has emerged. Participatory research means "incorporating the views of autistic people and their allies about what research gets done, how it is done and how it is implemented" (Fletcher-Watson et al., 2019, p. 493). Emancipatory research is closely linked to participatory research but also involves social change as a consequence of research (Chown et al., 2017). Chown et al. (2017) have proposed that good autism research involves both participation and emancipation. Reflecting on the criteria for emancipatory research in the field of disability (Stone & Priestley, 1996), Chown et al. (2017) discussed the following general requirements for good practice in autism research: 1) involving autistic researcher(s) in the initial development of research; 2) approaching autism from the perspective of the social model of disability (i.e., aiming to remove barriers autistic people face rather than attempting to change autistic people; see Chapter 1, section 1.2.1); 3) letting autistic people have whole or partial control over the research; and 4) aiming to improve autistic people's day-to-day life. This PhD research fulfils almost all of the criteria for good practice in autism research

proposed by Chown et al. (2017): 1) the research was conceived of and designed by an autistic autism researcher; 2) autism and loneliness research was approached from the perspective of the social model of disability; 3) a group of autistic adults were involved in the development of research materials alongside an autistic researcher; and 4) the research aimed to positively impact autistic people's daily lives by enhancing the understanding of autistic adults' experiences of loneliness. It is my hope that this PhD research plays a role in bridging a chasm between autistic and non-autistic people, and moving from 'us and them' (Wood & Milton, 2018) to just 'all of us' as a diverse human race.

1.2 What is Autism?

While this thesis specifically focuses on autistic adults, a sizeable body of autism research focuses on autistic children. As such, within this section of the thesis, I focus on autism research broadly (including work on both children and adults).

Reported prevalence of autism has changed over time due to a number of factors, including the broadening of the autism diagnostic criteria (to include those without intellectual disabilities) and increased awareness of autism among professionals and the general public (Fombonne, 2001; Gernsbacher et al., 2005). Specifically, there is a tendency that the more recent the study is, the higher the rates of autism are reported. For example, in the United Kingdom (UK), the most recent and largest national prevalence study (n=7,047,238) showed that about one in 57 children (1.8%) is autistic (Roman-Urrestarazu et al., 2021), and these rates are higher than previous UK-based studies (e.g., one in 64 people (1.6%); Baron-Cohen et al., 2009). More broadly, previous studies have reported approximately 1%

of global prevalence of autism despite a substantial variance across countries (Zeidan et al., 2022). A systematic review and meta-analysis reported that autism appears to be more commonly diagnosed among males than females, with a ratio of 3 (males): 1 (females) (Loomes et al., 2017). However, these figures need to be treated with caution since the diagnostic criteria and diagnostic process are biased towards the diagnosis of autism in males more than females (Fletcher-Watson & Happé, 2019). But what is autism?

1.2.1 Conceptualization of autism

"What is autism" is not a simple question to answer, because autism is presented differently across each autistic individual, and also because different people may answer this question in different ways. It is crucial to understand different perspectives on autism and carefully think about how to approach and talk about autism, and this will be the focus of the next section of the thesis.

Medical model of disability

While autism has always existed (as seen in some folktales around the world; Fletcher-Watson & Happé, 2019), autism began to be clinically recognized when Kanner (1943), an American psychiatrist, described the features of "autistic disturbance of affective contact" that he saw in his child patients. Around the same time, Asperger (1944), a German pediatrician, also described shared features of "autistic psychopathy" in his child patients. The work by Asperger (1944) was written originally in German and was only translated into English after many decades (Asperger, 1991). Both Kanner (1943) and Asperger (1944) described similar sets of characteristics in their patients including life-long social differences, repetitive movements and sounds, a dislike of change, and peculiar "special interests". However, there were some differences in how Kanner (1943) and Asperger (1944)

described some features in the children they observed, particularly regarding their language, motor, and learning abilities. While Kanner (1943) reported on the children who used little speech to communicate, were clumsy in general but not in fine motor skills (e.g., writing), and often experienced learning difficulties, Asperger (1944) reported on the children who were often fluent in speech (sometimes to the point that they had arguments with adults), were clumsy in all ways including writing, and were often highly intelligent.

Subsequently, understanding of autism was developed by Wing and Gould (1979) who introduced the "triad of impairments", explaining the features of autism as difficulties in three areas: social interaction, communication, and imagination. Wing and Gould (1979) also introduced three sub-types of autism regarding social approaches: aloof (i.e., only socializing with others when necessary), passive (i.e., willingly engaging in social interaction with others as long as others keep them engaged) and odd (i.e., actively engaging in social interaction with others but in an "odd" and atypical manner). Later, Wing (1996) wrote a book introducing the idea of conceptualizing autism as a spectrum. Early clinical and academic understanding of autism highlighted the negative impact of autism and led to some misunderstanding and mistreatment of autistic people (e.g., interventions aimed at normalizing autistic people) (Fletcher-Watson & Happé, 2019).

The current diagnostic criteria for autism, both in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) and International Classification of Diseases (ICD-11) (World Health Organization, 2019), categorize autism as "autism spectrum disorder (ASD)", and represent the medical model. The term "disorder" pathologizes autism and autistic self-advocates tend to oppose the terminology (Fletcher-Watson & Happé, 2019). I agree with and respect

other autistic self-advocates' opinions, and I use the more neutral term 'autism' in this thesis. DSM-5 includes the following key diagnostic criteria for autism: "persistent *deficits* in social communication and social interaction across multiple contexts" and "*restricted, repetitive* patterns of behaviour, interests, or activities". Further, "*symptoms* must be present in the early developmental period", "*symptoms* cause clinically significant *impairment* in social, occupational or other important areas of current functioning", and "these *disturbances* are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay" (Autism Spectrum Disorder 299.00, American Psychiatric Association, 2013). Such negative terminology implies that autistic people are less than non-autistic people.

Social model of disability

From 1960s, disabled people and their allies, particularly in the UK and USA, started the disability rights movement, where they attempted to promote the idea that they are disabled by unaccommodating environments, not as an inevitable consequence of their differences (Oliver, 1990b). Approaching "disability" from the social model, autistic people have become pioneers in disability rights movement, to claim a role in influencing policies and services that impact on themselves (Fletcher-Watson & Happé, 2019). The social model of disability views autism itself as a difference rather than a disorder, and encourages society to make accommodations for those disabled by society's standards and expectations. The social model view of autism is clearly presented in an equation described by Beardon (2017): autism + environment = outcome. This equation demonstrates that autism presents itself negatively when environments are not appropriate for autistic people, and it presents itself positively when environments are right.

Development of the view of autism from the social model was impacted by the arrival of the Internet in the early 1990s, which contributed to connecting autistic people with each other and promoted an understanding of autism from autistic perspectives (Dekker, 2020; Fletcher-Watson & Happé, 2019). Some of the pioneers who have shaped the autistic autism advocacy movement include Jim Sinclair, who started Autism Network International in 1992 and Martijn Dekker who founded the Autistic Self-Advocacy Network in 2006 (Fletcher-Watson & Happé, 2019). Following work by autistic people (and their allies), understanding of autism has begun to shift from the medical model to social model. However, it is notable that, while more researchers are starting to view autism from the social model, views on autism are polarized and not all researchers advocate for this approach (Botha, 2021).

The Centre for Research in Autism and Education (CRAE), where I undertook my PhD research, is a world-leading autism research centre; viewing autism from the perspective of the social model of disability and attempting to make the environments better for autistic people. How autism researchers view autism greatly impacts how research is designed and conducted. As such, conceptualizing autism within a social model of disability was fundamental to my PhD research, as an autistic researcher. However, it is important to recognize that autistic individuals themselves sometimes view autism from the medical model. As an autistic person myself, I certainly have times when I wish I could be non-autistic and be like everybody else without my limitations; particularly social limitations in relation to the feelings of loneliness. It is, however, important to acknowledge that these feelings arise due to unaccommodating environments, rather than autism itself.

Earlier, in Section 1.1.1 of this Chapter, I described my experience of being different. Importantly, it is not only me who feels different in the world and

experiences challenges in daily life (e.g., Lewis, 2016; Stagg & Belcher, 2019).

Autistic people may struggle to navigate a world designed around the non-autistic

norm. The effects of this could lead to, for example, social exclusion, bullying in

schools and workplaces, stigma, and being forced to conform to the "norms" of non-

autistic people (Milton & Sims, 2016). This could result in negative impacts on

autistic individuals such as feelings of isolation, social alienation and mental health

problems (Milton & Sims, 2016). It may also lead to disadvantage in terms of

employment for autistic people, due to various reasons including autistic people's

skills not being recognized (Milton & Sims, 2016). This could also have an impact on

research. For example, a sense of powerlessness in meaningfully participating in

autism research to improve autistic people's lives (Michael, 2021). Therefore,

researchers need to recognize that one of the areas that disables autistic people is

the autism research environment itself and that autism research needs to embody

the social model by more effectively involving autistic people.

Neurodiversity

The term neurodiversity was coined by Judy Singer (Singer, 1988) who was a

member of an autistic online network called Independent Living on the Autism

Spectrum (InLv) set up by Martijn Dekker. Neurodiversity indicates diversity in how

people see and conceptualize the world. Neurodiversity promotes the idea that it is

natural for humans to be wired differently, neurologically; and such variations are

natural and necessary in the diversity of human beings, akin to biodiversity

(Chapman, 2020). Closely in line with the social model of disability (Shakespeare,

2006), neurodiversity promotes autism acceptance, considering autism as an

inherent part of autistic people's identity and experiences, and requires environments

(not people) to be changed when considering solutions to the challenges that autistic

people face in society (Pellicano & den Houting, 2022). Attitudes towards neurodiversity differ between cultures. A cross-cultural study reported that non-autistic Korean adults were less aware of and supported neurodiversity paradigm than non-autistic American adults (Kim & Gillespie-Lynch, 2022). Further, the neurodiversity paradigm is not without controversy. First, parents of autistic children with high support needs (e.g., those with co-occurring intellectual and communicative challenges) tend to feel that the neurodiversity paradigm does not apply to their children, instead serving the needs of autistic individuals who can advocate for themselves (Hughes, 2021; Lord et al., 2021). Yet it has been argued that the neurodiversity paradigm is for *all* autistic and neurodivergent individuals regardless their support needs, because neurodiversity is rooted in the view that all individuals should be treated respectfully (den Houting, 2019; Pellicano & den Houting, 2022). In addition, the neurodiversity paradigm could coexist with the medical model view of autism, in that one could view autism as a difference rather than a deficit, but still recognize challenges inherently associated with being autistic and seek relevant support (e.g., Nicolaidis, 2012). Supporting this view, Kapp et al. (2013) conducted an online survey to investigate views on autism and neurodiversity in 657 individuals with different connections to autism (e.g., autistic people, autistic/non-autistic parents of autistic people, relatives/friends of autistic people). Findings demonstrated the overlap between the endorsement of the medical model of disability and neurodiversity paradigm. Specifically, Kapp et al. (2013) reported that autistic people who endorsed the neurodiversity paradigm could consider autism as a deficit, difference, or both.

A further controversy associated with the neurodiversity paradigm is that those who promote neurodiversity may dictate how people should and should not be

engaging with the movement, thereby not allowing the diversity in individuals. Specifically, an autistic autism advocate, Martijn Dekker, stated the danger of autistic advocates becoming "more distrustful and defensive" in the neurodiversity movement in recent years (Dekker in Fletcher-Watson & Happé, 2019) and urged the need to go back to the roots of the neurodiversity paradigm and to learn to accept differences in people (Dekker in Fletcher-Watson & Happé, 2019). Similar to Dekker, I believe all humans, including autistic people, have to learn to accept those who are different from ourselves, in line with the core idea of neurodiversity (Singer, 1988).

Terminology used to describe autism

An essay by Sinclair (2013) first drew attention to how people could/should refer to autistic people. In this seminal essay, Sinclair outlined how he prefers identity-first language (i.e., autistic person) over person-first language (i.e., person with autism). Sinclair explained that autism cannot be separated from a person; an "autistic person" will always be autistic, but saying a "person with autism" suggests that autism is an add-on that can be distinct from the person (Sinclair, 2013). As an analogy, a person's nationality would be explained using identity-first language (e.g., a Japanese person), not person-first language (e.g., a person with Japanese-ness) (Sinclair, 2013). Sinclair emphasizes that autism does not make the person less of a human and the term "autistic person" shows acceptance and value (Sinclair, 2013). Gernsbacher (2017) noted how person-first language (e.g. , children with autism) is used significantly more often for disabled people than non-disabled people (where identity-first language is more common, e.g., typically developing children). Gernsbacher (2017) also discussed that person-first language is used more often for

individuals with highly stigmatized disabilities (e.g., autism) than for those with less stigmatized disabilities (e.g., deafness, giftedness).

A large UK-based online survey collected data from about 3,500 participants in the autistic and broader autism communities (i.e., including family members of autistic people, as well as professionals who work with autistic people) about the terms they preferred to use to describe autism (Kenny et al., 2016). Kenny et al. (2016) reported that community members had different preferences on the language used to describe autism, and that the closer they were to autism in everyday life, the more they preferred identity-first language. Notably, 60% of their autistic participants preferred identity-first language over person-first language. However, the importance of the study lies in showing the diversity in the preference of language on autism, which may also change given the audience and context (Fletcher-Watson, 2016; Kenny et al., 2016). Yet it should be noted that Kenny et al. (2016) shared a common limitation of online survey studies, in their limited representation. For example, Kenny et al. (2016) had a higher number of female participants (relative to other genders) and largely included individuals who were able to communicate their opinions in writing to a detailed online survey. While the debate on whether to use identity-first language or person-first language is on-going (e.g., Bury et al., 2020; Vivanti, 2020), there appears to be a consensus that autistic people in the UK dislike being described using person-first language (i.e., person with autism) (Botha et al., 2021). Therefore, I use identity-first language (i.e., autistic person) to be most respectful to autistic readers who may read my thesis. However, it is notable that people in different countries might have different preferences for the terminology used to refer to autism. For example, Buijsman et al. (2022) conducted an online survey with 1,026 Dutch autistic adults and 286 parents of autistic children and showed that both

groups preferred person-first language to identity-first language (i.e., 68.3% of autistic adults and 82.5% of parents of autistic children). Buijsman et al. (2022) did not report on the possible reasons for the difference in their preference for identity-first/person-first language between autistic adults and parents of autistic children. However, Buijsman et al. (2022) reported that, among autistic adults, predictors of a preference for identity-first language over person-first language included being younger in age, having higher self-/parent-reported IQ, and demonstrating more autistic characteristics measured on the AQ-Short (Hoekstra et al., 2011).

Choice of language on autism expands beyond identity-first or person-first language. Ableism must also be avoided in how one describes autism. Ableism is a form of discrimination against disabled people (Bottema-Beutel et al., 2021). Ableist language with respect to autism implies the superiority of non-autistic people over autistic people (Bottema-Beutel et al., 2021). Botha (2021) discussed how ableism has been firmly rooted in the field of autism, leaving autistic people objectified and dehumanized. Botha adds that being an autistic autism researcher is a constant exposure to such aggression. Ableist language concerns the ways one talks about autism, and not only the language one uses to describe autism (Botha, 2021). It has been suggested that researchers, clinicians and wider society carefully consider the language used to describe autism, avoiding ableist language (Bottema-Beutel et al., 2021). I followed suggestions from Bottema-Beutel et al. (2021) and referred to the suggested alternatives to avoid ableist language throughout this thesis. For example, this includes avoiding deficit-based language based on the medical model such as avoiding the term "autism symptoms", and instead referring to "autistic characteristics".

1.2.2. Autism as a unique *disability*

Heterogeneity of autism

The heterogeneity/variability is one of the notable aspects of autism. The term autism spectrum has been widely used (e.g., in current diagnostic manuals) to capture the heterogeneous nature of autistic people. However, it is increasingly recognized that the notion of autism as a spectrum does not capture the complexity of autism at a group or personal level. First, no two autistic people are the same, just as no two non-autistic people are the same (Lord et al., 2021). It is often quoted that "if you have met one person with autism, you have met one person with autism" (Hutchinson, 2019). For instance, some autistic individuals may be non-speaking and have co-occurring learning difficulties (e.g., Blackman, 2009); others may be fluent in multiple languages and gifted in certain areas (e.g., Tammet, 2007). Such heterogeneity and complexity of autistic presentations have been more recently described as a constellation rather than a linear spectrum (the term, autism constellation, was coined by Caroline Hearst, an autistic trainer/consultant; AutAngel, n.d.).

Second, autism presents itself differently within each autistic individual depending on the environment. Many autistic self-advocates feel that the term 'autism spectrum' does not capture their autistic experiences in different contexts, times, or domains (e.g., social interaction, sensory experiences) (Dwyer, 2020; Kapp, 2018). The extent to which their autistic characteristics become disabling completely depends on the environment they are in, and fluctuates moment-by-moment. Thus, sub-grouping autistic people depending on their "severity" of autism on the spectrum is thought to miscommunicate autistic people's everyday realities (Fletcher-Watson & Happé, 2019). However, it is important to note that some autistic people (of any age) need more intense support than others (e.g., needing constant

support and supervision) and the idea of considering sub-groups within autism has recently been reintroduced (Mottron, 2021). For example, the recent Lancet Commission on autism (Lord et al., 2021) proposed the term profound autism. Lord et al. (2021) explained that those with profound autism are likely to have intellectual disability and/or limited ability to verbally communicate with others and often have co-occurring conditions such as epilepsy (although the latter does not define profound autism). Lord et al. (2021) clarified that the term is not a formal diagnostic entity and only elaborates on the description in diagnostic manuals (e.g., presence of intellectual and/or language impairment; American Psychiatric Association, 2013).

Recently, Singer (2022), a parent of an autistic child that she describes as having profound autism, wrote a controversial article on the underrepresentation of profoundly autistic people in research, emphasizing how distant the reality for this group, compared to those who do not meet criteria for profound autism. There is certainly a need for research to ensure that the experiences of a more diverse range of autistic individuals are reflected (Fletcher-Watson, 2022) and I agree with the importance of recognizing the needs of, and support for, autistic people with high and complex support needs. However, using the term profound autism leads to "a false and misleading dichotomy within autism" (Fletcher-Watson, 2022), failing to describe the characteristics of individuals (e.g., likes/dislikes, strengths/challenges). Indeed, Singer (2022) described how her daughter's 'profound autism' meant that she "is minimally verbal and suffers from painful self-injurious behaviors, intellectual disability, aggression, anxiety, sleeplessness and seizures" and more. Fletcher-Watson (2022) further argued that adopting a more dichotomous perspective could lead to missed opportunities to better understand autism from the perspectives of autistic people who can describe their inner experiences, which may help understand

the experiences of autistic people who are less able to describe their experiences.
Rather than sub-grouping autistic people, I envisage that clearly describing each
autistic person's characteristics/needs and effectively communicating them with the
concerned parties would be more beneficial than introducing sub-groups such as
profound autism.

Invisibility of autism

It is important not to dismiss the fact that autism *is* a disability, even when
viewing autism from the neurodiversity paradigm, since autistic people are often
disabled by society (den Houting, 2019). More specifically, autism has been referred
to as a hidden disability, along with other neurodevelopmental disabilities (e.g.,
ADHD, dyslexia) because there are no physical indications that show one is autistic
(Broach et al., 2003; Fletcher-Watson & Happé, 2019). Because of the hidden nature
of autism, autistic people are prone to be stigmatized. A recent systematic review
showed that autistic people are acutely aware of being stigmatized and are likely to
internalize the stigma, which leads to negative outcomes such as poor mental health
(Han et al., 2021). Caregivers of autistic children also experience the impact of
autism-related stigma on their mental health (Papadopoulos et al., 2019). For
example, parents of autistic children may feel judged when their children have
meltdowns (i.e., "autistic experience of a crisis" Fletcher-Watson & Happé, 2019, p.
128) in response to stressful situations because others around them are not aware
that the children are autistic (Hutchinson, 2019). In some cultures (e.g., South
Korea), stigma towards autism is even greater than in others (e.g., the USA) (Kim &
Gillespie-Lynch, 2022).

Some people with hidden disabilities choose to conceal their identity, while
others choose to disclose (Clair et al., 2005; Goffman, 2009). Autistic people may

use concealment and/or disclosure strategies in coping with the stigma surrounding autism (Han et al., 2021). Specifically, some autistic individuals choose to conceal their autistic identity through strategies such as camouflaging to "pass" as non-autistic by mirroring non-autistic behaviors or social skills (e.g., Botha et al., 2020; Leedham et al., 2020; Leven, 2020; Schneid & Raz, 2020). Other autistic individuals choose to resist or manage stigma via disclosure (often referred as "diagnostic disclosure") and self-advocacy (e.g., Botha et al., 2020; Lee et al., 2021; Schneid & Raz, 2020), which are often accompanied by a positive reframing of identity (Botha et al., 2020; Han et al., 2021). The outcomes of disclosure are often mixed and could lead to discrimination and stigma (Leven, 2020; Romualdez, Walker, et al., 2021). As such, whether autistic people choose to disclose has to be carefully considered to avoid any potential harms for themselves. In the UK, sunflower lanyards can be used to identify when a person has a hidden disability, including autism (Carr et al., 2020). Some autistic people experience positive outcomes following the disclosure. For example, non-autistic people may have better first impressions of autistic adults when they have disclosed their autistic identity, and had even better impressions when non-autistic people had knowledge of autism (Sasson & Morrison, 2019). Likewise, when disclosing in the workplace, some autistic adults felt better understood (Romualdez, Heasman, et al., 2021). Other autistic people experience negative outcomes following disclosure (Botha et al., 2020; Leedham et al., 2020). For example, autistic people sometimes experience dismissive attitudes from non-autistic people with comments such as "but you are not autistic" or "everyone is a bit autistic" (Botha et al., 2020). Overall, autistic people encounter a dilemma, in that they recognize that they could be negatively perceived either when disclosing or not disclosing their autistic identity (Botha et al., 2020). While disclosure of autism

diagnosis has been the focus of a great deal of research to improve social experiences for autistic people (Thompson-Hodgetts et al., 2020), it is equally important to recognize the need to improve the societal understanding and acceptance of autism so that the onus is not solely on autistic people to improve their social experiences (Jones, DeBrabander, et al., 2021).

Camouflaging

Some autistic people use behavioural and cognitive strategies to get by in the predominantly non-autistic social world, which is often referred to as camouflaging (and also known as masking, compensation and adaptive morphing) (Cook et al., 2021). Camouflaging strategies could include "supressing repetitive hand movements, forcing eye contact, using conversational scripts, and using learned rules to respond to others' non-verbal behaviour" (Cook et al., 2021, p. 2). A recent systematic review on camouflaging in autistic people reported that greater engagement in camouflaging is associated with increased self-reported autistic characteristics, being female, and increased mental ill health (Cook et al., 2021). A higher rate of undiagnosed autism in women is thought to be linked to increased use of camouflaging in autistic women (Fletcher-Watson & Happé, 2019; Kirkovski et al., 2013; Lai et al., 2017).

High rates of self-reported camouflaging in autistic people despite its consuming and exhausting nature (Lai et al., 2017) challenge the social motivation account of autism explained later in this Chapter. In fact, autistic adults often explain that camouflaging is motivated by the desire for social connection with others and fitting in with other people (Hull et al., 2017). Notably, research has shown that feelings of loneliness among autistic women lead them to employ camouflaging strategies (Cook et al., 2018; Tubío-Fungueiriño et al., 2021). Camouflaging could

successfully serve its purpose of enabling autistic people to be perceived as "normal"

by others (Leven, 2020). However, camouflaging can also cause negative outcomes

such as exhaustion, stress, burnout, poor mental health, and negative impacts on

self-esteem (Cage et al., 2018; Cage & Troxell-Whitman, 2019; Cook et al., 2021;

Hull et al., 2017; Hull et al., 2020; Leedham et al., 2020; Leven, 2020; Punshon et

al., 2009).

Diagnosis of autism

Receiving a diagnosis can be a significant moment in autistic people's lives.

Some autistic adults actively seek an autism diagnosis to confirm their suspicion that

they could be autistic or to receive support (e.g., disability living allowance) (Crane et

al., 2018) while others receive it unexpectedly after seeing professionals for mental

health issues (Crane et al., 2018; Jones et al., 2014) or for the assessment of autism

in their children (Crane et al., 2018). It often takes a long time for people to receive

an autism diagnosis in the UK (Crane et al., 2016; Howlin & Asgharian, 1999) and

this waiting time causes stress (e.g., parents; Crane et al., 2016).

Receiving an autism diagnosis could be earlier in life for some and later in life

for others, and there are some patterns to this. First, those who were born before

1980s have often been undiagnosed or misdiagnosed (Geurts et al., 2016) because

autism was first clinically recognized around 1980s. Second, those who have

intellectual or language disabilities tend to be identified and diagnosed earlier in life

than those who do not (Crane et al., 2018; Howlin & Asgharian, 1999). Third,

females tend to be undiagnosed until later in life (Begeer et al., 2013; Gould, 2017;

Siklos & Kerns, 2007). This could be due to several reasons including the

understanding of autism deriving from male samples (Gould & Ashton-Smith, 2011;

Kreiser & White, 2014; Mandy et al., 2012), the presence of co-occurring mental

health conditions in autistic females (Mandy et al., 2012), and the greater tendency

for autistic females to camouflage (Cook et al., 2021).

Autistic adults receiving a diagnosis later in life often express a sense of relief

(Hearst, 2019; Leedham et al., 2020; Lewis, 2016) and find that the diagnosis

contributes to a better understanding of themselves (Leedham et al., 2020; Lewis,

2016; Stagg & Belcher, 2019), enabling them to find their own tribe/community

(Lewis, 2016). Despite some potential benefits of receiving a diagnosis, autistic

adults have reported that accessing a diagnostic assessment can be challenging

with multiple barriers (Crane et al., 2018; Lewis, 2016). These barriers include a lack

of knowledge of autism among professionals (particularly general practitioners)

which makes referrals challenging (Crane et al., 2018; Leedham et al., 2020; Lewis,

2016). Regarding the experiences of accessing an autism diagnosis, autistic adults

in Crane et al. (2018) reported that accessing a diagnosis was not a clear process

and they did not feel supported. During the diagnostic process, autistic adults

reported some negative experiences including professionals' focus on the negatives

of being autistic, as well as inaccessible environments (e.g., sensorily overloading)

and activities (e.g., designed for children). Autistic adults also reported their

dissatisfaction with the lack of support following the diagnosis (Crane et al., 2018; de

Broize et al., 2021; Jones et al., 2014), leaving them feeling "where to from here?"

(Hearst, 2019, p. 5). It is important to note that not all autistic people have a formal

diagnostic label. Concerns have been raised that people may mis-identify as autistic,

when in fact they are experiencing something else, which should be supported

differently (Crane et al., 2018; Fletcher-Watson & Happé, 2019). Indeed, some

autistic people are dismissed as they are perceived as not meeting the "threshold" to

be diagnosed as autistic (Crane et al., 2018). However, some autistic people are

unwilling and/or unable to seek a formal diagnosis from professionals (e.g., due to the expense involved, or general anxiety about talking with professionals).

1.2.3. Theoretical accounts of autism linked to loneliness

Social motivation theory

Social motivation theory is grounded in the medical model of autism, viewing autism as a social disorder (American Psychiatric Association, 2013; Asperger, 1944; Kanner, 1943). The theory proposes that autistic people have low motivation for social interaction early in life, which leads to little social engagement through their life time (Chevallier et al., 2012). Chevallier et al. (2012) explained that diminished social motivation explains the unusual behaviors characterizing autistic people. Jaswal and Akhtar (2019) challenged the social motivation theory of autism due to three reasons: 1) the theory is not consistent with autistic people's first-person accounts of interests in social interaction (i.e., autistic people report that they appear uninterested in people yet long for social connections) (e.g., Higashida, 2013; Suskind, 2016; see the appendix in Jaswal and Akhtar (2019) for a list of autistic narratives), 2) the theory misses the possibilities that the behavioral differences in autistic people (e.g., less eye contacts, less declarative pointing, frequent motor stereotypies/stimming, and frequent echolalic speech) could be due to reasons unrelated to social disinterest, and 3) the theory overlooks how social motivation is bi-directional (grounded in the context of social interactions). Jaswal and Akhtar (2019) added that postulating that autistic people are not interested in social interaction is dehumanizing, since motivation for belonging is thought to be embedded in all human beings (Baumeister & Leary, 1995; Tomasello, 2014). However, it is important to note that some autistic people *do* have diminished (or even absent of) motivation to socially engage with other people, at least at times

(e.g., Calder et al., 2013). Nonetheless, the important insight from Jaswal and Akhtar (2019) is that the diminished or lack of social motivation does not have to be considered negatively, and that variability in autistic people's sociality should be embraced (Fletcher-Watson & Crompton, 2019). Indeed, Jaswal and Akhtar (2019) suggested that some autistic people might show their desire for social connections differently from non-autistic people, instead of lacking social motivation per se.

While agreeing that autistic people may show social interest in unconventional ways, Heasman and Gillespie (2019) noted that it also needs to be recognized that socially motivated behaviors might be perceived differently between autistic and non-autistic people.

Heasman and Gillespie (2018) recorded and analyzed how autistic adults (n=30) built shared understanding during a collaborative video game and qualitatively analyzed the conversations between participants to examine how the ideas were built over a course of interactions. Heasman and Gillespie (2018) showed that the behaviors that non-autistic people might consider as indicators of social disinterest (e.g., echolalia) (Jaswal & Akhtar, 2019) were not perceived as socially disengaging by autistic individuals in autistic-autistic interactions.

Social motivation theory has had some negative impacts on both research (e.g., overly focusing on differences rather than similarities between autistic and non-autistic people) and practice (e.g., interventions to force autistic people to stop engaging in stimming) (Jaswal & Akhtar, 2019). However, increasing investigation of autistic people's lived experiences have started to reveal that autistic individuals benefit from what could be considered unconventional social behaviors by non-autistic people (e.g., stimming; Kapp et al., 2019). Instead of forcing autistic people to behave in non-autistic way, Jaswal and Akhtar (2019) proposed that research and

practice in autism need to consider broadening the views of accepted behaviors in society. Indeed, if autistic adults experience loneliness despite their desire for social relationships, this thesis could further debunk the social motivation account.

Double-empathy theory

Double-empathy theory reframed the Theory of Mind (ToM) account of autism, which dominated the discourse of autism research for many years. ToM refers to the ability to understand the intentions and beliefs of others (Premack & Woodruff, 1978) (e.g., understanding the reasons behind others' emotional states). In applying ToM to autistic people, Baron-Cohen et al. (1985) tested whether autistic and non-autistic children and those with Downs Syndrome pass or fail a false-belief task (i.e., a task that examines understanding of a belief that is inconsistent with the reality), specifically using the Sally-Anne task. In this task, two dolls, Sally and Anne, were initially in the scene with a basket, box, and marble. Sally puts a marble in the basket and walks out of the scene. In Sally's absence, Anne moves the ball from the basket to the box. Then, Sally comes back to the scene. In the experiment, Baron-Cohen et al. (1985) asked the participants where Sally would look for her marble. Baron-Cohen et al. (1985) found that autistic participants failed the task more than non-autistic people and those with Downs Syndrome (i.e., answering that Sally would look for her marble in a box, instead of a basket where she had last left the marble), suggesting a lack of ToM in autistic people.

While the ToM account (Baron-Cohen et al., 1985) is a unidirectional approach in understanding autistic people's social difficulties (i.e., only looking at autistic people's social competence), double-empathy theory proposed that social interaction is, in fact, bi-directional and thus social difficulties in autistic people should also be considered in context (i.e., depending on who/what autistic people

are interacting with). Double-empathy theory explains that both autistic and non-autistic people equally have difficulties in understanding each other (Crompton et al., 2021; Milton, 2012). Just because autistic people do not socially engage with others in the way most people do, it does not automatically mean that autistic people are 'impaired' or 'disordered'. As such, the double-empathy theory is in line with the social model and neurodiversity perspectives of autism. If the double empathy theory is true, autistic-autistic interactions would be easier than autistic-non-autistic interactions. Some studies have tested this prediction and reported that social difficulties lie in interaction between different neurotypes (i.e., in autistic-non-autistic interactions).

As one example, Crompton, Ropar, et al. (2020) examined how well information was transferred between individual groups of eight autistic adults (autistic group), eight non-autistic adults (non-autistic group), and eight autistic and non-autistic adults (mixed group, where autistic and non-autistic adults alternated) (total sample = 72 adults). Specifically, Crompton, Ropar, et al. (2020) told a fictional story to the first participant in each group of eight, and then asked them to share it with the next person until everyone in each group heard the story. Crompton, Ropar, et al. (2020) found that autistic groups and non-autistic groups shared information well within the groups, but within mixed groups, much less information was shared. Additionally, Crompton, Ropar, et al. (2020) asked participants to rate levels of rapport within their groups, and reported that those in mixed groups had the lowest rapport ratings (see also Crompton, Sharp, et al., 2020). Their findings suggested that autistic people may communicate well with other autistic people but there is a selective problem of information sharing when autistic and non-autistic people interact.

In a follow-up study, Crompton, Hallett, et al. (2020) interviewed 12 autistic adults about their experiences of spending time with friends and family, and whether their experiences differ when spending time with autistic or non-autistic friends and family. Using thematic analysis, three themes were identified. Under the first theme (cross neurotype understanding), autistic adults reported that they experienced difficulties when interacting with non-autistic people, but felt understood and at ease when interacting with other autistic people. Under the second theme (minority status), autistic adults reported their experiences when interacting with non-autistic friends and family: autistic people felt they were in a social minority and felt the need to 'fit in' with others, that social activities were not accessible to them (e.g., sensory overwhelming or too busy), and that they were expected to behave according to non-autistic people's social interaction preferences. Under the third theme (belonging), autistic adults reported their experiences when interacting with autistic friends and family members: autistic individuals felt understood by others and reported understanding others too; they felt able to be their authentic selves; and added that interacting with other autistic people contributed to their happiness, mental health/wellbeing, and resilience for daily life in a majority non-autistic world. Not only corroborating the previous findings that social interaction is challenging between different neurotypes (Crompton, Ropar, et al., 2020; Crompton, Sharp, et al., 2020), it was significant that Crompton, Hallett, et al. (2020) reported that autistic-autistic interactions benefit autistic people. In reality, autistic people are often the ones to make accommodations to confirm to non-autistic ways of communication (Crompton, Hallett, et al., 2020; Milton, 2012).

Recent studies have demonstrated that non-autistic people tended to have negative first impressions of autistic people (e.g., seeing them as "awkward")

(Sasson et al., 2017). Further, disclosure of an autism diagnosis and increased knowledge of autism improve first impressions of autistic people (Sasson & Morrison, 2019). One could hypothesize that the experiences of loneliness among autistic adults may be due to difficulties regarding reciprocal understanding between autistic and non-autistic people.

Monotropism theory

The term monotropism refers to the tendency of autistic people to intensely focus their attention on a small number of things at once (Murray et al., 2005). Monotropism explains that individuals' interests determine where their attention goes, while the amount of attention one could give at any given time is limited. Further, autistic people tend to pay a large amount of attention to their "leading interest" (p. 2954) (i.e., the thing they are currently paying attention to), leaving little attention for what is outside of their interests (Murray, 2018). Proponents of monotropism argue that, compared to autistic people who have a monotropic focus, most non-autistic people have a polytropic focus, which allows them to pay attention to multiple things at the same time (Murray et al., 2005). Monotropism explains that autistic people's strengths (e.g., depth of knowledge in the area of interest) and challenges (e.g., shifting focus from one to another) are due to "which interests have been fired into monotropic superdrive and which have been left unstimulated by any felt experience" (Murray et al., 2005, p. 143). Monotropism claims that core characteristics of autism can be explained by a monotropic tendency in the distribution of one's attention (i.e., so-called restrictive and repetitive behaviors, difficulties with social communication/interaction) (Murray et al., 2005). In a social context, autistic people's challenges in social interaction are due to their difficulties with processing multiple sensory inputs including "spoken words, body language and

eye contact" (p. 46) while there is an expectation to promptly process the inputs and respond in social interaction (Murray, 2019). Monotropism explains autistic people's difficulties with executive functioning, which some people refer as autistic inertia (i.e., difficulties with planning, switching between tasks), is due to their monotropic tendency in leaving little attention for what is outside of their current attention (Murray, 2019). Monotropism suggests that sensory experiences in autistic people can also be explained by one's attention to certain sensory stimuli (i.e., hyper-sensitivity) and hypo-sensitivity to the stimuli outside of one's attention (Murray et al., 2005). Many autistic individuals feel that monotropism aligns with their lived experiences of being autistic compared to other theories of autism (Dwyer, 2021). While monotropism was first introduced in 2005 (Murray et al., 2005), it has just started to be recognized by psychologists more recently (Murray, 2019). As yet, there have not been any empirical evaluations of monotropism and more work is needed to determine the extent to which monotropism may explain autism. Monotropism could, however, be associated with how autistic adults become lonely and how they overcome loneliness and reconnect with others. For example, monotropism may mean that it can be difficult for autistic people to bring their attention to social relationships with others (e.g., arranging and meeting with others) while they have other things that regularly require their attentions such as completing everyday tasks (e.g., chores, work). Indeed, a qualitative study on perceptions of loneliness in autistic adults (Elmose, 2020) reported that autistic adults feel so consumed from everyday activities (e.g., personal hygiene) that they sometimes need to isolate themselves from others to recover from the exhaustion. Furthermore, because autistic people are gravitated towards their 'leading interest' or 'hook', engaging in spontaneous social interactions (e.g., promptly responding to messages,

attending meetings) could be challenging when their current focus is on something other than social interaction (e.g., work). This tendency, in turn, could erroneously lead non-autistic people to think that autistic people are not interested in social interactions, which eventually leads to challenges in maintaining relationships. Conversely, given autistic people's monotropic attention, loneliness in autistic people may be eased by building relationships with like-minded people as similar interests could be the anchored focus in their social interactions and might make socialising more comfortable or acceptable for autistic people.

1.2.4. Social relationships among autistic people

A sense of belonging is thought to be embedded in every individual (Baumeister & Leary, 1995). A sense of belonging has been defined as a "subjective feeling of value and respect derived from a reciprocal relationship to an external referent that is built on a foundation of shared experiences, beliefs or personal characteristics" (Mahar et al., 2013). The common assumption that autistic people do not want/seek a sense of belonging could be due to the emphasis on preference of aloneness in early descriptions of autism. Kanner (1943), for example, described one of his autistic patients as being happiest when he was left alone and observed autistic people's "powerful desire for aloneness" (p. 249). Further, Asperger (1944, p. 38) noted that: "human beings normally live in constant interaction with their environment and react to it continually. However, 'autists' have severely disturbed and considerably limited interaction". Over time, these perceptions have changed. Research has shown that many autistic people *are* interested in social relationships with other people, despite sometimes experiencing difficulties with social interaction (Benford & Standen, 2009; Causton-Theoharis et al., 2009; Davidson, 2008). Nonetheless, the desire for social relationships does not make it easier for autistic

people to make and maintain social relationships with others. From the outset, challenges with social communication and interaction have been highlighted as one of the major characteristics of autism (Asperger, 1944; Kanner, 1943). These perceptions are also echoed within many accounts of autistic individuals (e.g., Grandin & Scariano, 1986; James, 2017; Robison, 2008; Tammet, 2007). As explained earlier in this Chapter, social interaction between autistic and non-autistic people can be mutually challenging for both parties who experience the world differently (i.e., double-empathy theory). However, social interaction is often on non-autistic people's terms because they are the neuromajority in society (Crompton, Hallett, et al., 2020). This idea that being autistic is simply being part of a social minority, rather than being "atypical", is reflected in the writings of Beardon (2017; forthcoming), who refers to the non-autistic population as being the 'predominant neurotype' (PNT), as opposed to using the term 'neurotypical'. Due to social interactions being formed on non-autistic people's terms, some autistic adults report feeling that they have to conform to non-autistic people's ways of social interaction and find it easier and more comfortable to interact with other autistic people than non-autistic people (Crompton, Hallett, et al., 2020; Sinclair, 2010). Further, researchers have discussed the possibility that autistic people may anthropomorphise non-human agents to alleviate feelings of social disconnection and to feel connection (Negri et al., 2019; White & Remington, 2019). However, it is also important to note that there may be some autistic people who actively seek connections with non-human agents (e.g., animals; Holliday-Willey, 2014; Isaacson, 2010); not as a last resort, but as a special and important source of connection.

Peer relationships

A systematic review on the experiences of peer relationships among autistic adolescents (Cresswell et al., 2019) reported that this group find it challenging to develop peer relationships despite a desire for such relationships. As a result, this group experience loneliness, peer rejection and victimisation; experiences that are more commonly experienced among autistic adolescents compared with their non-autistic peers (Sterzing et al., 2012). Difficulties with peer relationships appear to persist into adulthood for autistic individuals. Previous research reported that autistic adults' peer relationships can be more easily and comfortably developed when they are with autistic peers rather than with non-autistic peers (Crompton, Hallett, et al., 2020; Morrison et al., 2020). Autistic adults have been found to share information well with other autistic adults and experience good rapport; however, sharing information becomes challenging when autistic and non-autistic people interact (Crompton, Ropar, et al., 2020), in line with the double-empathy theory (Crompton et al., 2021; Milton, 2012). Despite some evidence on autistic-autistic relationships, it does not mean autistic-non-autistic relationships could not be positive experiences. For example, previous research (Sasson & Morrison, 2019) has suggested that increased knowledge of autism in non-autistic people could make experiences of social interactions (between autistic and non-autistic people) better for autistic adults. Specifically, Sasson and Morrison (2019) assessed the first impressions of autistic adults (n=20) and matched non-autistic controls (n=20) made by non-autistic observers (n=215) who watched the recordings of each adult doing a one-minute mock audition for a show. Sasson and Morrison (2019) reported that prior knowledge on autism among non-autistic observers was associated with better first impressions.

Much of the literature on peer relationships in autistic people has examined friendships. Research has shown that some autistic adults often struggle to make

friendships despite their desire for such relationships (Forster & Pearson, 2020; Sedgewick et al., 2016; Sosnowy et al., 2019). Autistic adults also rate their friendship quality to be lower than non-autistic adults do (Baron-Cohen & Wheelwright, 2003; Sedgewick, Leppanen, et al., 2019), in line with findings from autistic children (Calder et al., 2013). Autistic adults may struggle to form and maintain friendships because of negative experiences in childhood, when parents/teachers placed expectations on their friendships that were based on how non-autistic children typically engage in friendships (Calder et al., 2013). However, there have also been reports that making friendships becomes easier with age (Forster & Pearson, 2020). Further, another study reported that making friends with those who accept autism/social differences, or who share interests, leads to positive and satisfying friendship experiences for autistic adults (Sosnowy et al., 2019). Of relevance to the topic of my thesis, autistic adults report that better quantity/quality of friendships is associated with reduced loneliness (Mazurek, 2014). Quality of friendships may be particularly important in mitigating feelings of loneliness. For example, autistic adults reported more emotional closeness in their best-friendships (and romantic relationships) than non-autistic adults (Sedgewick, Leppanen, et al., 2019).

Romantic relationships

Research has reported that autistic adults are interested in romantic relationships (Strunz et al., 2017) and appear to have a similar understanding of romantic relationships to non-autistic adults (Sala et al., 2020). Yew et al. (2021) conducted a systematic review to identify the factors that both facilitate and hinder autistic people's romantic relationships with non-autistic partners. Yew et al. (2021) reported that social and communication challenges are associated with the

difficulties autistic people face in romantic relationships. Yew et al. (2021) also reported that the quality of non-autistic partners (e.g., their support for autistic partners) is associated with positive experiences of romantic relationships among autistic people. The research focus on romantic relationships in autistic people has tended to be on women, with limited evidence available on men or other genders. Kock et al. (2019) conducted interviews with eight autistic women who were diagnosed as autistic within five years of taking part in the study, to examine their experiences of romantic relationships. Some participants in Kock et al. (2019) reported that they engage in dating because they find someone attractive or because they feel the pressure to meet social expectations that they felt they should have in such relationships. Other participants reported that they do not engage in dating because they are not confident in their ability to identify others' interests or because they do not understand how dating works and find dating effortful. Further, participants reported that they experience some challenges in romantic relationships: difficulties understanding and being understood by their partners, difficulties with their routine being disrupted by the spontaneous nature of romantic relationships, and concerns about more demands on intimacy or inter-dependency in the future (e.g., living together). Regarding positive experiences in romantic relationships, participants added that they valued time doing activities together with their partners.

In a larger sample that also featured a non-autistic comparison group, Sedgewick, Crane, et al. (2019) examined the similarities and differences in friendships and romantic relationships experienced by autistic and non-autistic women, using mixed methods. From their thematic analysis on the interviews with 19 autistic women and 19 non-autistic women, Sedgewick, Crane, et al. (2019) reported that autistic women are more likely to experience negative social experiences

including being victims of crimes in romantic relationships (e.g., domestic violence, rape) compared to non-autistic women. Sedgewick, Crane, et al. (2019) further reported that autistic women felt that such vulnerability in romantic relationships was due to their challenges with interpreting others' intentions. As such, there is some emerging research on romantic relationships among autistic people, especially women.

While there has been limited research on experiences of marriage in autistic adults of any genders, with most research focusing on marriage of non-autistic parents of autistic children (Sedgewick, Leppanen, et al., 2019), Smith et al. (2021) conducted interviews with 13 participants who were in autistic-non-autistic intimate relationships: six married couples and one non-autistic partner in a de facto relationship[2] (i.e., living together but not legally married; Federal Circuit and Family Court of Australia, 2022). The goal of the work was to explore the challenges and facilitators in autistic-non-autistic intimate relationships. Smith et al. (2021) reported that autistic-non-autistic intimate relationships developed similarly to intimate relationships between non-autistic people; through learning about each other and identifying/refining effective ways of communication (Reese-Weber, 2015). Smith et al. (2021) reported that autistic-non-autistic couples often experienced difficulties with communication (i.e., difficulties being understood and understanding their partners) and also difficulties understanding/expressing emotions to each other. Additionally, non-autistic partners found it challenging to understand and accommodate for autistic characteristics/needs (e.g., sensory differences, needing to follow their routines). Regarding facilitators of autistic-non-autistic intimate

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[2] In the country Smith et al. (2021) conducted their study (i.e., Australia), de facto relationship is defined as a status of two individuals living together as a couple but not being married (Federal Circuit and Family Court of Australia, 2022).

relationships, Smith et al. (2021) reported that autistic-non-autistic couples had some strategies to overcome communication difficulties with each other and often leveraged each other's strengths (e.g., non-autistic partners supporting autistic partners to navigate social situation outside of their relationships, autistic partners bringing rationality when the couples face problems). Smith et al. (2021) reported that getting an autism diagnosis and thereby understanding the underlying reason for challenges in their relationships helped autistic-non-autistic couples to continue their relationships. Autistic-non-autistic couples also felt that professionals lacked understanding of autism and participants also reported a lack of support groups for couples like them.

1.2.5. Mental health in autistic people

Some studies reported that as many as 80% of autistic adults have co-occurring mental health diagnoses (Eaves & Ho, 2008; Lever & Geurts, 2016). Mental health in autistic people is an area of research that is getting increasing attention, given that it is consistently shown to be a community priority for research (Pellicano et al., 2014; Roche et al., 2021). Anxiety and depression are the most common co-occurring diagnoses among autistic adults across ages (Buck et al., 2014; Lever & Geurts, 2016; Wigham et al., 2017). Autistic adults who experience depression report high rates of suicidal ideation and attempts (Cassidy et al., 2014; Hirvikoski et al., 2016), and suicide is a leading cause of premature death among autistic people (Hirvikoski et al., 2016). The rates of each mental health diagnosis, however, are difficult to determine among autistic adults due to many overlaps between the characteristics of autism and mental health conditions (e.g., depression, anxiety) (Kerns et al., 2015; Stewart et al., 2006) and also due to how symptoms of

depression/anxiety present differently in autistic adults compared to non-autistic people (Stewart et al., 2006).

Autistic adults often struggle to know they are experiencing mental health problems (Crane, Adams, et al., 2019), and they also struggle to access support for their mental health (Camm-Crosbie et al., 2019; Crane, Adams, et al., 2019). Even when autistic adults get access to mental health services, professionals often have limited knowledge on autism (Camm-Crosbie et al., 2019; Maddox et al., 2020; Raja, 2014) and are often not confident in supporting them with their mental health issues (Brede et al., 2022; Maddox et al., 2020). Autistic adults reported unmet needs for support in general, and the paucity of support is positively associated with increased rates of depression and suicidal ideation (Cassidy, Bradley, Shaw, et al., 2018; Hedley et al., 2017). As a way to overcome mental health issues, the importance of engaging with other autistic people for autistic adults has been emphasized (Crompton, Hallett, et al., 2020; Crompton, Ropar, et al., 2020), and autistic community connectedness was found to be linked to better mental health (Botha, 2020). Additionally, Linden et al. (2022) recently reported, via a systematic review and network meta-analysis (comparing different types of interventions) that psychological therapies including cognitive behavioural therapy (i.e., changing one's maladaptive thinking patterns) and mindfulness therapy (i.e., bringing awareness to one's own emotions or feelings) may decrease symptoms of depression and anxiety in autistic adults.

1.3 What is loneliness?

In this section, I will discuss loneliness in the general population, which is essential context for the rest of the thesis on loneliness in autistic adults specifically.

1.3.1 Conceptualization of loneliness

Loneliness is a painful and subjective emotional state arising from the discrepancies between desired and actual social relationships (Peplau & Perlman, 1982). Wang et al. (2017) conducted a conceptual and methodological review on social isolation and related concepts and explained that social isolation can be objective and/or subjective, and loneliness is a sub-set of subjective social isolation. Subjective social isolation is the perceived adequacy in the quantity or quality of one's social relationships and incorporates perceived social support as well as loneliness. In contrast, objective social isolation relates to the actual amount of social contact someone has (e.g., less frequent social interaction, having fewer friends) (Wang et al., 2017). Transient loneliness is a pattern of loneliness people feel after distressing events (e.g., loss of someone close to them) and recover from after some time (Martín-María et al., 2020). From an evolutionary perspective, transient loneliness serves a self-protective role (Cacioppo & Hawkley, 2009) by motivating lonely individuals to reconnect with others (Qualter et al., 2015). Another pattern of loneliness is chronic loneliness, which people feel when loneliness is a constant and stable feeling in their life over the years without successful reconnection with others (Shiovitz-Ezra & Ayalon, 2010). Notably, transient and chronic loneliness have not been distinguished and have instead been investigated together in loneliness research (Martín-María et al., 2020).

There has been an ongoing debate as to whether the concept of loneliness is unidimensional or multidimensional (Pollet et al., 2021). One of the most prominent multidimensional conceptualizations of loneliness was proposed by Cacioppo et al. (2015). Cacioppo et al. (2015) proposed three dimensions of loneliness (intimate, relational and collective loneliness) by extending a previous report from Weiss

(1973) who reported two dimensions of loneliness (social and emotional loneliness). Cacioppo et al. (2015) explained that 1) intimate loneliness refers to the perceived absence of someone significant and emotionally close to the individual (e.g., a spouse), which Weiss (1973) called emotional loneliness, 2) relational loneliness refers to the perceived absence of the people who are relatively close (e.g., friends, family), which Weiss (1973) called social loneliness, and 3) collective loneliness refers to the perceived absence of belonging within larger groups in society (e.g., national identity), and Weiss (1973) did not report this type of loneliness.

1.3.2 Mechanisms of loneliness

Some researchers have previously proposed hypotheses about the mechanisms underlying how loneliness develops and how it may become chronic in the general population. However, there have not yet been any studies that have tested these hypotheses, and much is still unknown about the mechanisms of loneliness. Researchers have suspected different pathways to loneliness in different populations and recommended future research to investigate mechanisms of loneliness by subgroups of individuals (e.g., in groups of people who are experiencing mental ill health) (Qualter et al., 2022). Notably, the hypotheses proposed so far in relation to mechanisms of loneliness (Cacioppo & Hawkley, 2009; Qualter et al., 2015; Spithoven et al., 2017) have been about the general population. In this section, I will explain prominent models of the mechanisms of loneliness (see Figure 1.1).

Loneliness

Reaffiliation motive
(RAM)
(Qualter et al., 2015)

Feeling and
acting more
negatively
towards others
(e.g., avoiding
people,

Being
hypervigillant to
social threats

Self-reinforcing loop model
(Cacioppo & Hawkley, 2009)

Being reacted
negatively
others (i.e.,
validation of the
negative soial
expectations)

Acting coldly
towards others

Social Information Processing (SIP) model (Spithoven et al., 2017)

Encoding of
cues

response
action and
decision

Memory

Interpretation
of cues

Clarification
of goals

Figure 1.1. Models of the mechanisms of loneliness

The self-reinforcing loop model (Cacioppo & Hawkley, 2009) is the most recognized and prominent model of the mechanisms of loneliness in the general population. The self-reinforcing loop model assumes that loneliness causes people to be highly alert for social threats (Cacioppo & Hawkley, 2009; Hawkley & Cacioppo, 2010). Compared to individuals who are not lonely, lonely individuals perceive the social world as more threatening, expect more negative impressions of others, and remember negative social interactions (Cacioppo & Hawkley, 2009; Hawkley & Cacioppo, 2010). Such negative social expectations are likely to become a self-fulfilling prophecy (i.e., lonely individuals experience negative social interactions) due to "self-protective and paradoxically self-defeating interactions with others" (Cacioppo & Hawkley, 2009, p. 452) (e.g., negatively (re)acting towards others). Finally, lonely individuals end up avoiding social situations more and even "pushes away the very people to whom he or she most wants to be close to better fulfil their social needs" (Cacioppo & Hawkley, 2009, p. 452), and their loneliness gets amplified (Cacioppo & Hawkley, 2009; Hawkley & Cacioppo, 2010). This self-reinforcing loop model is based on evidence that loneliness is related to decreased cognitive capacities in animals and humans (e.g., poor executive-functioning skills, poor emotional regulations) and the deriving hypothesis that lonely people are hypersensitive to negative social information (Cacioppo & Hawkley, 2009).

Qualter et al. (2015) refined the loneliness model developed by Cacioppo and Hawkley (2009) by introducing the reaffiliation motive (RAM), which is a motivation to reconnect with others after experiencing loneliness. Qualter et al. (2015) assumed that loneliness leads to the RAM and behaviours to achieve reconnection, and thus loneliness is often a transient experience. However, the RAM sometimes does not lead to reconnection with others and, instead, people become hypervigilant to social

threats, which leads to the self-reinforcing loop (Cacioppo & Hawkley, 2009). Therefore, they suggest that any loneliness interventions (i.e., to exit from the loop) have to come at the point when individuals experience hypervigilance for the social world and view social situations as potential social threats (Qualter et al., 2015).

While loneliness models describe a negative cognitive bias as the underlying cause of loneliness (e.g., negative perception of others, expecting negative social experiences) (Cacioppo & Hawkley, 2009; Qualter et al., 2015), the nature of the cognitive bias in loneliness remains unclear (Spithoven et al., 2017). Spithoven et al. (2017) proposed that such cognitive bias in loneliness could be explained better with some of the phases in the Social Information Processing (SIP) model, which was initially developed to understand social maladjustments in children, and that studies examining cognitive bias in loneliness could be best interpreted using the SIP. Spithoven et al. (2017) explains the cognitive bias in loneliness occurs at four cognitive stages of the SIP (encoding of cues, interpretation of cues, clarification of goals, and response access and decision), resulting in behaviours and memory that affects, and is affected by, every cognitive processing phase (Spithoven et al., 2017). At the first stage of encoding of cues, individuals pay attention to social cues and identify the positive and negative stimuli (Spithoven et al., 2017). The self-reinforcing loop model explains that, at this stage, lonely individuals become hypervigilant to social threats (Cacioppo & Hawkley, 2009; Spithoven et al., 2017). Hypervigilance towards social threats is initiated by one's broad attention to social stimuli (i.e., broad examination of the social environment) and then led by one's narrow attention to the negative social cues. Current evidence suggests that those who feel lonely could adjust their behaviours based on others' social cues (e.g., facial expressions) and that their judgement of other's social cues seem to be accurate (Spithoven et al.,

2017). At the second stage of interpretation of cues, individuals try to understand the social environment using one's past experiences with social interactions (Spithoven et al., 2017). Lonely individuals expect rejection from others, interpret the intentions of others negatively, and evaluate others and relationships with others negatively (Cacioppo & Hawkley, 2009; Spithoven et al., 2017). The current evidence suggests that while transiently lonely individuals attribute the causes of negative social experiences to internal factors, chronically lonely individuals attribute them to external factors and thus view loneliness as uncontrollable state (Spithoven et al., 2017). At the third stage of goal clarification, individuals clarify what they would like to achieve in social interaction with others. The current evidence suggests that lonely individuals tend to engage in social interaction with others because they want to avoid social isolation, not because they want to socially connect with others (Spithoven et al., 2017). At the fourth stage of response access and decision, individuals consider possible response options in a given social situation and decide their action based on their memory of their past social experiences. Current evidence suggests that lonely individuals have social strategies to successfully interact with others but fail to apply these to their own circumstances (Spithoven et al., 2017). The cognitive bias in all four stages of information processing leads them to negatively act towards others, thereby confirming their negative expectations of others and relationships with others (Cacioppo & Hawkley, 2009; Spithoven et al., 2017). Unlike the previously proposed models of loneliness, which suggested that loneliness results in the cognitive bias (Cacioppo & Hawkley, 2009; Qualter et al., 2015), Spithoven et al. (2017) suggested that loneliness results in and from the social cognitive bias.

Importantly, it is consistent in all three hypotheses outlined above that loneliness is developed and becomes chronic due to a negative cognitive bias in how social information is processed. Such hypotheses appear to be consistent with reports that changing maladaptive social cognitions has much more effect in reducing loneliness than increasing social opportunities or enhancing one's social skills (Masi et al., 2011). However, as mentioned in the beginning of this section, these hypotheses have not been tested and there is still much unknown about the mechanisms of loneliness.

1.3.3 Factors associated with increased loneliness

Lim, Eres, et al. (2020) conducted an up-to-date review on correlates and predictors of loneliness. Demographically, factors associated with increased loneliness include being younger (<25 years old) or older (>65 years old) (e.g., Nicolaisen & Thorsen, 2016; Victor et al., 2012), being a woman (e.g., Nicolaisen & Thorsen, 2014; van den Broek, 2017), being unmarried (e.g., Cohen-Mansfield et al., 2016; Dahlberg et al., 2015), living alone (e.g., Cohen-Mansfield et al., 2016; van den Broek, 2017), being of low socio-economic status (e.g., low income, low educational level) (e.g., Ausín et al., 2017; Wen & Wang, 2009), and being migrants (e.g., De Jong Gierveld et al., 2015; Rich Madsen et al., 2016). Health-wise, factors associated with increased loneliness include poor sleep (e.g., Kurina et al., 2011), social anxiety (e.g., Beutel et al., 2017; Mahon et al., 2006), depression (e.g., Cacioppo et al., 2010; Peerenboom et al., 2015), and poor emotion regulation (e.g., Kearns & Creaven, 2017). From the socio-environmental perspective, factors associated with increased loneliness in some people include the use of social media (e.g., Lemieux et al., 2013; Primack et al., 2017) while this is also associated with decreased loneliness in others (e.g., Erickson & Johnson, 2011).

In the latest tackling loneliness evidence review from the UK Department of Digital, Culture, Media and Sport (DCMS; Qualter et al., 2022), evidence gaps in loneliness research were reported, as well as how details of the evidence gaps found in their last review, in 2018, had been achieved. Qualter et al. (2022) reported that, since 2018, there had been growing evidence on factors associated with increased loneliness in UK citizens, mainly referring to the findings from the Office of National Statistics (2018). The Office of National Statistics (2018) reported the characteristics of individuals who reported increased loneliness in their Community Life Survey, which were: being female, being young adults (<25 years old), being widowed or single, poor general health, having long-term illness or disability, being unemployed, living alone, being renters (i.e., not owning a house), feeling little belonging to one's neighborhood, having little trust of others in their local area.

Another recent study is worthy of note here. In collaboration with Wellcome Collection, the British Broadcasting Corporation (BBC) recently conducted the world's largest loneliness study with 55,000 participants. The study reported that those who feel discriminated against feel increased loneliness. Likewise, Qualter et al. (2022) highlighted the importance of prioritizing investigation of the experiences of loneliness in under-researched populations who experience social stigma, which is associated with increased loneliness. As I have explained earlier, autistic people are vulnerable to social stigma and consequent discrimination. As such, researching loneliness in order to seek solutions to this issue is extremely important for autistic people.

1.3.4 Consequences of loneliness

A feeling of connection and belonging is not only beneficial for psychological health, but it also has a significantly positive influence on physical health (Uchino, 2006) and longevity (Holt-Lunstad et al., 2015; Holt-Lunstad et al., 2010).

Conversely, loneliness negatively affects people mentally and physically. In recent years, mental health researchers have been paying closer attention to loneliness as a risk marker of mental ill health (Lim, Holt-Lunstad, et al., 2020; Wang et al., 2020). Previous research reported that the consequences of loneliness include depression (Cacioppo et al., 2010; VanderWeele et al., 2011), Alzheimer's disease and dementia (Holwerda et al., 2014; Meltzer et al., 2013; Wilson et al., 2007; Zhou et al., 2018), elevated blood pressure (Hawkley et al., 2006), elevated cortisol level (Grant et al., 2009), cardiovascular diseases (e.g., stroke) (Valtorta et al., 2016), metabolic diseases (e.g., diabetes) (Lambert et al., 2010), higher levels of inflammatory responses (Steptoe et al., 2004), and early mortality (Holt-Lunstad et al., 2015; Holt-Lunstad et al., 2010). A recent mixed methods study (Quadt et al., 2021) reported that autistic adults reported greater loneliness and loneliness distress (i.e., negative feelings about being lonely as opposed to chosen solitude) than non-autistic adults, and that loneliness and loneliness distress are associated with mental ill health such as depression and anxiety in autistic adults (Quadt et al., 2020; Quadt et al., 2021).

1.3.5 Solutions to loneliness

While the factors associated with decreased loneliness have not commonly been studied in the general population, researchers have suggested some solutions to loneliness. In a literature review on correlates, risk factors, and solutions to loneliness (i.e., preventing and alleviating loneliness), Lim, Eres, et al. (2020) suggested four types of solutions (i.e., individual, relationship, community, and societal) to loneliness. Researchers have reported that the most effective solutions to loneliness are changing maladaptive thoughts about others using individual-focused solutions (e.g., counselling) and increasing social opportunities with others using relationship-focused solutions (e.g., texting friends more often) (Lim, Eres, et

al., 2020; Masi et al., 2011). Community-focused solutions aim to provide individuals with a sense of belonging to a community (e.g., shared interest groups) (Lim, Eres, et al., 2020). Providing community to individuals has been considered important to make healthcare sustainable since lonely people tend to visit doctors more often than non-lonely people, thereby increasing the burden in primary care (Lim, Eres, et al., 2020). One promising approach of community-focused solutions is social prescribing, which enables healthcare professionals to refer their lonely patients to non-medical community-based support (Bickerdike et al., 2017). Compassionate communities are similar to social prescribing, except that they bring communities to people instead of referring them to external communities, thus becoming more accessible to those with mobility or health issues (Abel, 2018). There has been little research on social prescribing and compassionate communities in general, and more research is needed to evaluate these approaches in alleviating/preventing loneliness (Bickerdike et al., 2017; Lim, Eres, et al., 2020; Pescheny et al., 2020). While there is even less evidence on social prescribing for autistic adults, a commentary on potential barriers and recommendations for social prescribing for autistic adults (Charlton et al., 2021) purported that this would need to carefully consider and accommodate for day-to-day challenges experienced by autistic people (e.g., sensory experiences) to make support/services accessible for autistic adults.

Societal-focused solutions aim to make societal impacts whilst combating loneliness (Lim, Eres, et al., 2020). For example, societal-focused solutions could include implementing a new educational policy for adolescents to learn how to make and maintain friendships, and a public awareness campaign to increase people's awareness of loneliness (Lim, Eres, et al., 2020). In considering solutions to loneliness, Lim, Eres, et al. (2020) emphasized that they have to consider each

individual's circumstances and resources. Consequently, it is important to understand each individuals' unique causes of loneliness, as well as any barriers to accessing social resources (Lim, Eres, et al., 2020).

1.4 Conclusion

In this Chapter, I discussed the facets of autism that might make autistic individuals vulnerable to loneliness, presented key concepts and theories of autism that are relevant to this thesis, and provided an overview of loneliness in the general population (i.e., what loneliness is, how people become lonely, what impacts loneliness has on individuals, how loneliness could be alleviated). In the next Chapter, I will bring together what we know about autism and loneliness, and then examine and present the extent of, and gap in, knowledge on loneliness in autistic adults, via a systematic review.

Chapter Two

Loneliness in autistic adults: a systematic review

2.1 Introduction

One could hypothesize that some autistic people are likely to experience loneliness because of their difficulties in social relationships (American Psychiatric Association, 2013), as loneliness is closely associated with social experiences (Perlman & Peplau, 1981). While autistic people's challenges in social settings have often been explained by referring to the commonly-used diagnostic criteria, which describes difficulties in social interaction and communication as one of the core characteristics of autism (American Psychiatric Association, 2013), such an explanation is one-sided and grounded within the medical model of disability.

Considering the social model of disability, autistic people's difficulties in social interaction may not only derive from autism itself but also from how the society reacts to autistic people. For example, autistic people are likely to experience negative social experiences such as exclusion and bullying due to autism-related stigma (Botha et al., 2020; Treweek et al., 2018). Moreover, autistic people struggle to understand, and to be understood by, non-autistic people, and vice-versa (Crompton et al., 2021; Milton, 2012). It has therefore been suggested that interaction between autistic people could be easier than interaction between people of different neurotypes; a suggestion supported by quantitative and qualitative research (Crompton, Hallett, et al., 2020; Crompton, Ropar, et al., 2020; Morrison et al., 2020).

Before reflecting on loneliness in autistic adults, it is important to consider loneliness in autistic children and adolescents. Indeed, previous research has tended to focus on this population. Such work has shown that autistic children experience

loneliness more intensely and more frequently than their non-autistic counterparts

(Bauminger & Kasari, 2000; Bauminger et al., 2003). Autistic children also seem to

experience loneliness qualitatively differently from their non-autistic peers. For

example, studies have found that autistic children define loneliness solely based on

being alone, while non-autistic children define loneliness in terms of both emotional

and social-cognitive loneliness (Bauminger & Kasari, 2000). Other research has

proposed a lack of friendship to be a key indicator of loneliness (Bauminger &

Kasari, 2000; Locke et al., 2010), with many autistic children reported to have low

levels of friendship quality and to be on the periphery of their school social networks

(Calder et al., 2013; Locke et al., 2010). Although loneliness does not seem to be

associated with an understanding of friendship among autistic or non-autistic

children (Bottema-Beutel et al., 2019), low levels of friendship quality and/or being on

the periphery of school social networks could lead to social withdrawal, isolation and

loneliness in adolescence (Sumiya et al., 2018; White & Roberson-Nay, 2009;

Whitehouse et al., 2009).

Little is known about the consequences of autistic people's early experiences

of loneliness. However, there are several reasons to suspect that loneliness will

persist across the lifespan for autistic people. First, a lack of social relationships is

often associated with loneliness; and difficulties with social

interaction/communication, as well as difficulties with social participation, have been

commonly reported in autistic adults (American Psychiatric Association, 2013; Myers

et al., 2015). Second, once people grow up and are no longer in the mandatory

social setting of school, the workplace is a major source of social interaction. Yet

research has consistently shown that autistic people have lower rates of employment

than other disability groups (Office for National Statistics, 2021a). Finally, support

services for autistic individuals significantly decrease when they reach adulthood, with many autistic adults and their carers not being well informed about the social supports that are available to them (Anderson et al., 2018).

There is an emerging body of published research on loneliness in autistic adults, comprising quantitative, qualitative, and mixed methods studies. These studies have examined a broad range of topics related to loneliness in autistic adults, including autistic people's experiences of loneliness, as well as the factors (positively and negatively) associated with loneliness. Although I initially considered completing a literature review on this subject, I recognized the breadth of the emerging research around this topic and considered it essential to systematically identify the current evidence base, synthesise findings across studies, and establish the extent of, and gaps in, current knowledge to guide priorities for future research. A scoping review was another potential option, but I chose to complete a systematic review over scoping review because: (1) the aim was not only to synthesise the existing literature on the topic and identify the knowledge gap (as a scoping review would do) but also to inform areas for future research; and (2) the review questions went beyond identifying the research gaps and providing an overview of research on the topic (as a scoping review would do), by investigating loneliness measures used and loneliness dimensions explored in the literature. Conducting the first systematic review on loneliness in autistic adults, I aimed to identify quantitative and qualitative data on the following five review questions.

- Review question 1: what do we know about autistic adults' first-hand descriptions of loneliness? To improve our understanding of loneliness in autistic adults, it is invaluable for research to investigate their lived experiences of loneliness which provide insights into the subjective

experiences (Robertson et al., 2018). Therefore, it is vital for this review to examine the extent to which this has been investigated and what has been reported in previous studies.

- Review question 2: how is loneliness in autistic adults measured? To accurately interpret research findings on loneliness in autistic adults, it is indispensable to identify how loneliness was measured in autistic adults and what the measures are. Using measurement tools that are not validated in autistic adults, for example, could result in inaccurate results (Nicolaidis et al., 2020) and unreliable conclusions (McConachie et al., 2018).

- Review question 3: what dimensions of loneliness (intimate, relational or collective) have been reported in research on autistic adults? The discrepancy of research priorities between researchers and autistic individuals has been indexed in autism research (Pellicano et al., 2014), and it is beneficial for this review to examine what types of loneliness have been reported in research on autistic adults to understand the gap between research priorities and reported descriptions of loneliness (as in 2.1.1). To explore this review question, one of the most prominent multidimensional conceptualizations of loneliness was selected (Cacioppo et al., 2015; see Chapter One, Section 1.3.1).

- Review question 4: what factors are associated with increased loneliness in autistic adults? It is important to understand the factors associated with increased loneliness in autistic adults as this will help researchers to explore pathways to loneliness in autistic adults and examine how they may or may not be similar to those in the general population (e.g., Cacioppo & Hawkley, 2009).

- Review question 5: what factors are associated with decreased loneliness in autistic adults (including interventions)? It was vital to understand the factors associated with decreased loneliness in autistic adults as this will help researchers to explore how loneliness in autistic adults could be overcome. This is important because, while loneliness is a universal feeling anyone could experience (Cacioppo et al., 2015), some autistic individuals could experience increased loneliness due to their social challenges/differences and even less social opportunities in adulthood as explained earlier in this Chapter. Regarding both review questions 4 and 5, a higher prevalence of loneliness has been reported in disabled people compared to those who are not disabled (Office of National Statistics, 2019), yet it is still unclear what factors are associated with increased/decreased loneliness in disabled people and how they might differ from those who are not disabled (Qualter et al., 2022). Qualter et al. (2022) mentioned autistic people as one of the subgroups that need more attention in this area.

2.2 Methods

This review, registered on the PROSPERO database (registration number: CRD42019141853), adhered to the Preferred Reporting for Items for Systematic Reviews and Meta Analyses (PRISMA) statement (Page et al., 2021).

2.2.1 Search strategy

The search strategy was developed in consultation with a specialist librarian at the UCL Institute of Education, and via scoping searches of other autism-related systematic reviews (see Appendix 2.1). Articles were selected based on the relevance to the topic. Twelve sets of search words (autis* OR Asperger* OR

Pervasive developmental disorder OR PDD OR ASD OR ASC) AND (lonel*OR

social isolation) AND adult* plus one complete search term (autism AND loneliness

AND adults) were used to adapt to the databases that did not respond to

permutations of the words. Keywords "adult*" and "adults" were added to focus on

the population of interest. On the advice of a specialist librarian, these words were

searched as broadly as possible without applying limits to the search (i.e., searching

within all fields) to bring up more relevant literature than when the searches were

applied in limited ways (e.g., in keywords). The following bibliographic databases

were searched: PsycINFO, Scopus, ERIC, Web of Science Core Collection, Medline,

British Education Index (BEI) and Applied Social Sciences Index and Abstracts

(ASSIA). I conducted an initial search in early 2019, an updated search in early

2021, and a final search on April 9, 2021. The Cochrane library and PROSPERO

were also searched, to ensure no other systematic reviews on the topic existed. In

addition to the bibliographic databases, dissertations/theses on the topic were

searched through ProQuest Dissertations and Theses Global database. National and

international experts in the field were contacted (in February 2019) to identify any

work in progress/grey literature.

2.2.2 Review criteria

Literature published in English from any country was included. Inclusion and

exclusion criteria focused on three domains: (1) diagnosis: studies were included

when the results were separately reported for at least one autistic adult (formally

diagnosed/self-identified[3]), and excluded when participants had high levels of autistic

traits or were amongst the broader autism phenotype but were without an autism

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[3] Self-identified autistic adults are those who identify as autistic but do not have a formal diagnosis. For example, they may be waiting to get a diagnosis, may not seek a diagnosis, or may have difficulty accessing a diagnostic assessment (Lewis, 2016).

diagnosis; (2) age: studies were included when they specifically stated that they collected data from adult participants (even if the mean age or age range was not stated), or when the mean age of the adults was over 18 years and at least one adult participated in the study; and (3) study type: quantitative, qualitative and mixed method studies were included, including interventions; studies were excluded if they did not report data on loneliness. Dissertations/theses of any academic level were considered.

2.2.3 Study selection process

After the initial database search, duplicates were removed using EndNote X9 and also by hand searching copied references on Microsoft Excel. Screening of titles and abstracts was conducted by myself and a research assistant at CRAE with reference to the inclusion/exclusion criteria. After agreeing on the articles eligible for full-text assessment, a full-text review (of 65 articles and dissertations) was conducted independently by two reviewers, myself and a research assistant at CRAE (see Figure 2.1). The two of us had an agreement rate of 92% and resolved discrepancies through discussion. A list of the excluded studies at the full-text assessment stage is presented in Appendix 2.2.
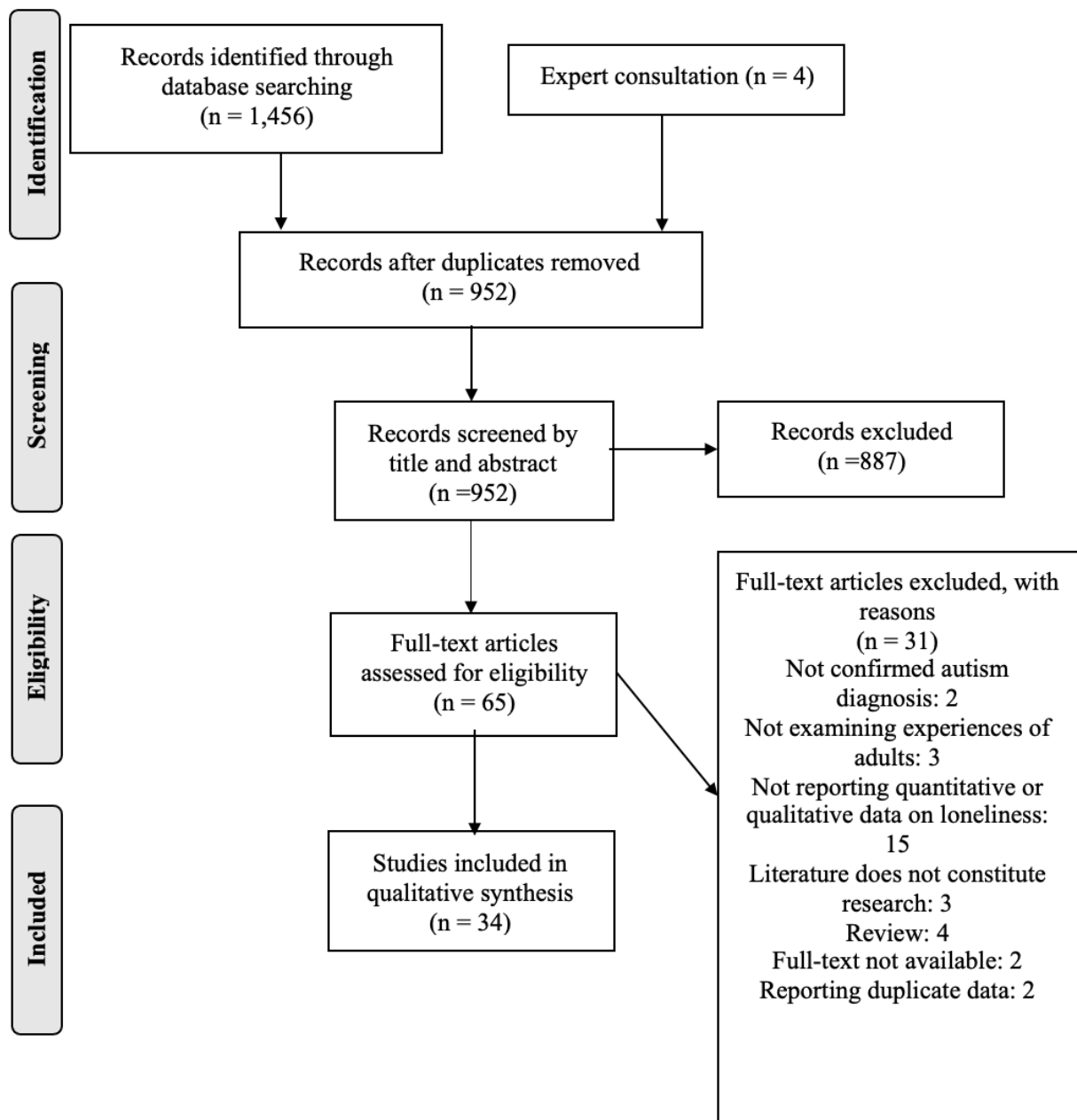
Figure 2.1. PRISMA diagram

2.2.4 Data extraction

Using a form developed specifically for this study (in Microsoft Excel), data extraction from all articles was conducted independently by myself and a research assistant at CRAE. With support from my primary supervisor, the research assistant and I met to discuss the findings and resolve any discrepancies. Studies were coded for: (1) origin of the study (i.e., the country the work was conducted in); (2) study design (i.e., whether the studies were qualitative, quantitative or mixed methods); (3) sample characteristics (i.e., gender, age, intellectual and communicative abilities, co-occurring diagnoses, living situation, employment status, highest level of education, and race/culture/ethnicity of the participants); (4) study description (i.e., what each study was about); and (5) key outcomes (i.e., what each study found). Studies were also coded for answers to the review questions.

2.2.5 Quality assessment

Studies were assessed using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). The MMAT was considered most appropriate because it is designed for quality assessment in systematic reviews that include quantitative, qualitative, and mixed methods studies (Hong et al., 2018). Within the MMAT, five categories of study design (qualitative, quantitative randomized controlled trials, quantitative non-randomized, quantitative descriptive, mixed methods) are identified, with each category having different criteria. Unlike earlier versions of the MMAT, calculation of a score for each paper is discouraged; instead, a description of how the studies meet MMAT criteria is advised. Overall, the studies in the present review tended to meet many/all MMAT criteria, except that the participants tended not to be representative of the target population. Due to the limited research in this area, no studies were omitted after the quality assessment. However, the issue of sample

representativeness in research on loneliness in autistic adults is specifically

discussed later. The quality assessment was independently conducted by two

reviewers, myself and a research assistant at CRAE (see Appendix 2.3 for details).

2.2.6 Data synthesis

A narrative approach was used to synthesize data. This process involved

collating key information from every included article that had addressed the review

questions. I led this process, supported by my supervisors and a research assistant

from CRAE.

2.2.7 Procedure

I followed key steps for a systematic review, including pre-registering the

protocol, having a pre-planned, documented and repeatable search strategy, and

following PRISMA reporting guidelines (Page et al., 2021). Ethical approval was

given via Department of Psychology and Human Development at IOE, UCL's Faculty

of Education and Society. This systematic review did not involve any collection of

new data or analysis of secondary data, so did not involve any major ethical issues.

However, I ensured that the review was presented in a way that was respectful of the

autistic community.

2.3 Results

In total, 34 of the 1,460 identified studies met all inclusion criteria (see Figure

2.1). The studies were conducted in the USA (n=15), the UK (n=7), Australia (n=7),

Taiwan (n=3), Hungary (n=1), the Netherlands (n=1), Belgium (n=1), and Denmark

(n=1) [note that two studies (Caruana et al., 2021; Chen et al., 2016) included

participants from two different countries]. Study design included quantitative (n=20),

qualitative (n=8), and mixed methods (n=6). The publication year of the included

studies ranged from 2007 to 2021, and it appeared that the topic received increased

attention in recent years; for example, 17 of the included studies (50%) were published between 2018 and 2021.

In the 34 studies included in this review, 2,923 autistic participants were represented. As seen in Table 2.1, autistic participants were typically more likely to be: male rather than female; in young to middle adulthood; of average/above average intellectual and communicative ability; experiencing mood disorders as their most common co-occurring diagnosis; living with parents, family members or caregivers; unemployed rather than employed; highly educated; and Caucasian (see Appendices 2.4 and 2.5 for details).

As noted above, most studies met some or all of the MMAT criteria (see Appendix 2.3). Common weaknesses identified with the studies included a failure to report the response rate (in quantitative descriptive studies) and a lack of clear descriptions of the target population (in quantitative non-randomized and quantitative descriptive studies)[4]. In addition, most of the included studies failed to represent the diversity of the autistic adult population (e.g., minority ethnic groups were under-represented).

I considered the design of the studies that contributed to each review question. As such, for each question below, I first delineate whether the results are derived from quantitative, qualitative, or mixed method studies. For the mixed methods studies, I clarify whether the results reported in the section were derived

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[4] On the MMAT, the criterion on participants representativeness of the target population was included only in three study designs: quantitative non-randomized, quantitative descriptive, and mixed methods studies.

from quantitative data, qualitative data or both. For review questions 4 and 5, I clarify

the design of each study in parentheses.

Table 2.1. Autistic participant demographics[5]

Demographics	Numbers of studies in which the demographic breakdowns were reported	Categories	Value
Gender	29 (n= 2,234)	Male	n = 1,172 (52%)
		Female	n = 982 (44%)
		Other gender identities[6]	n= 68 (3%)
		Not reported	n = 12 (1%)
Age	25 (n = 2,260)	Range	14-80
	22 (n = 1,688)	Median of the Mean	29.6
Intellectual and communicative abilities[7]	8 (n= 471)	Please refer to the Supplementary Appendix 2.5 for details.	
Co-occurring diagnoses[8]	3 (n = 175)	Mood disorders	n = 51 (29%)
		Anxiety	n = 26 (15%)
		Attention deficit hyperactivity disorder (ADHD)	n = 26 (15%)
Living situation[4]	15 (n= 1587)	Living with parents, family members or caregivers	n = 843 (53%)
		Living independently (alone, with a partner, or with roommates)	n = 614 (39%)
		Living in other situations (e.g., supported	n = 111 (7%)

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[5] Note: numbers do not add up to total due to rounding/missing data.

[6] Other gender identities were included in three recent studies: Cage et al. (2018, n=15, 14% of the study sample), Ee et al. (2019, n=10, 5% of the study sample), Hull et al. (2017, n=7, 8% of the study sample), Jackson et al. (2018, n=4, 7% of the study sample) and Levinson (2020, n=32, 26% of the study sample).

[7] The data is not showed in this category because the measures used to assess the intellectual and communicative abilities are varied in all four studies where the data on this were reported, and additionally, where the data were reported, the measures used to assess only the general descriptions on the intellectual and communicative abilities of their participants were reported in the other four studies.

[8] A range of other co-occurring conditions were mentioned, and some of which (e.g., anxiety, mood disorders, ADHD) (presented in Table 2.1) were reported more frequently than others (e.g., eating disorders, borderline personality disorder, dyspraxia and dyslexia) (see Table 2.1).

		housing, community home)	
Employment status[4]	12 (n = 1,268)	Unemployed (unable to work, retired, volunteer, living on disability allowance)	n = 670 (53%)
		Employed (full-time, part-time, self-employed, student or carer)	n = 547 (43%)
Highest level of education[4]	16 (n =1,552)	University qualifications or above	n = 296 (19%)
		High school level qualifications or below	n = 196 (13%
		Currently in higher education	n = 175 (11%)
		A certificate, diploma, associate's degree or higher vocational education	n = 97 (6%)
Race	10 (n =1,194)	Caucasian	n = 921 (77%)
		Other ethnic groups (e.g., Asian, Black, Hispanic)	n = 273 (23%)

2.3.1 Review question 1: what do we know about autistic adults' first-hand descriptions of loneliness?

Five of the 34 studies (15%) reported autistic adults' first-hand descriptions of loneliness (Ee et al., 2019; Elmose, 2020; Hickey et al., 2018; Smith & Sharp, 2013; Van Hees et al., 2015). All five studies were qualitative in design or featured qualitative elements (i.e., in mixed-methods studies). Only one article, by Elmose (2020), focused exclusively on loneliness; in the other articles, loneliness was mentioned within a broader focus of investigation (e.g., socialization, diagnosis, sensory experiences, higher education). In four of the five studies (Elmose, 2020; Hickey et al., 2018; Smith & Sharp, 2013; Van Hees et al., 2015), autistic adults'

descriptions of loneliness were elicited using individual or focus group interviews, while Ee et al. (2019) used open-ended surveys.

Elmose (2020) used phenomenological thematic analysis to analyze focus group and individual interview data from 25 autistic adults (18 males, seven females; 18-71 years) who self-reported as autistic. Elmose (2020) reported that autistic adults' understanding of loneliness was similar to that of non-autistic adults. Yet findings also demonstrated that being autistic was perceived to have a major influence on people's social relationships: "Persons with autism have a different perception compared to neurotypical persons. It is evident that this will lead to loneliness" (P15) (Elmose, 2020, p. 11). Elmose (2020) further reported that discrepancies between desired and actual social relationships caused loneliness in autistic adults. These discrepancies were felt to be caused by several factors, including feeling not understood or misunderstood, creating boundaries that could hinder the possible development of close relationships, and masking in an attempt to connect with others. Elmose's (2020) participants also described their experiences of loneliness: "when you are lonely, then it is because you are not able to do anything about it yourself. You do not have the energy. You do not have the tools" (P1), "being locked tightly in a position that you do not wish for" (P4) (Elmose, 2020, p. 11).

Ee et al. (2019) conducted a mixed methods study using data from a questionnaire-based longitudinal study with 220 autistic adults (86 males, 124 females, 10 other; 25-80 years) and 146 non-autistic adults (29 males, 117 females; 25-79 years). Quantitative approaches were used to measure loneliness in autistic adults, with qualitative approaches (thematic analysis) used to analyze optional

open-ended responses on socialization. Autistic participants in this research emphasized the barriers to, and challenges of, socializing. They also highlighted how the manner in which they experienced loneliness was not the same as being alone: "I like being with myself a lot'', "I'm alone but not lonely" (p. 188)".

Hickey et al. (2018) thematically analyzed qualitative semi-structured interview data from 13 late-diagnosed autistic adults (ten males, three females; 51-71 years) who did not have intellectual disabilities and could take part in a verbal interview. Participants reported on their experiences of getting an autism diagnosis, getting support and getting older. One of the three themes identified from these data was longing for connection, which included the sub-theme of isolation and loneliness. It was mentioned that: "it's not to do with not having friends and stuff like that. It's to do with I just feel that I'm totally isolated in myself" (Hickey et al., 2018, p. 362). A desire for connection was reported both before and after a diagnosis of autism, and Hickey et al. (2018) concluded that social isolation and loneliness were continual challenges faced by autistic people throughout adulthood.

Smith and Sharp (2013) used modified Grounded Theory (Charmaz, 2006) to analyze semi-structured interview data from nine autistic adults (possibly five men and four women, assumed from their assigned anonymous names), aged 25-49 years. Interviews focused on sensory experiences and were conducted online, via Instant Messenger. Under one of the nine themes identified from these data ('isolation'), a participant discussed the negative effects of loneliness: "it is hell I feel so alone and lonely" (Smith & Sharp, 2013, p. 902). Helplessness regarding trying to foster connections with others was also described: "I don't think you can stop it

(avoiding to go out with friends) or make it go away you just have to accept that's how it is and learn to live with it" (Smith & Sharp, 2013, p. 902).

Finally, Van Hees et al. (2015) used principles of Grounded Theory to analyze semi-structured interview data about the experiences of higher education among 23 autistic young adults (17 men, six women; 18-25 years). Participants' methods of communication were not reported, but all of them were attending university at the time of the interviews (giving some indication of their cognitive ability). Under the sub-theme of 'awareness of social problems' (within one of five themes: 'exhausting but necessary social contacts'), one participant explained: "I'm a lonely person socially. I do not meet many people. I'm lonely" (Van Hees et al., 2015, p. 1679). The same participant also described their social life, challenging the notion of autistic adults not wanting to socialise: "I do not take the initiative. But if there is an offer, I accept it and want to go out" (Van Hees et al., 2015, p. 1679).

In summary, the results highlighted autistic adults' desire to have social connections with others, even though social interactions could be challenging. Loneliness was not perceived to be synonymous with being alone, but was a negative and persistent feeling for the autistic adults.

2.3.2 Review question 2: how is loneliness in autistic adults measured?

Twenty-two of the 34 (65%) studies used self-report questionnaires to measure loneliness in autistic adults (with autistic sample sizes ranging from 17-220) (see Supplementary Appendix 2.6). Data that contributed to this review question were all quantitative (from both quantitative and mixed methods studies). Eight different loneliness questionnaires were used across the studies. Four

questionnaires were different versions of the UCLA Loneliness Scale: the UCLA

Loneliness Scale Short Form (ULS-8) (Hays & DiMatteo, 1987) (used in Ee et al.,

2019; Hedley, Uljarević, Foley, et al., 2018; Lin & Huang, 2019; Mazurek, 2013;

Mazurek, 2014; Sundberg, 2018; Syu & Lin, 2018), the UCLA Loneliness Scale

Version 3 (Russell, 1996) (used in Brooks, 2014; Hedley, Uljarević, Wilmot, et al.,

2018; Hillier et al., 2018; Jantz, 2011; Russell, 2020), the Revised UCLA Loneliness

Scale (Russell et al., 1980) (used in Caruana et al., 2021; Levinson, 2020), and the

3-item UCLA Loneliness Scale (Hughes et al., 2004) (used in Jackson et al., 2018).

One further study, by van der Aa et al. (2016), used six items based on the Revised

UCLA Loneliness Scale (Russell et al., 1980) to measure loneliness in autistic

adults, yet further information about the rationale for selecting these particular items

could not be gathered from the authors. The other questionnaires used were the

Social and Emotional Loneliness Scale for Adults (SELSA) (DiTommaso & Spinner,

1993) (used in Bourdeau, 2020; Gantman et al., 2012; McVey et al., 2016; Merkler,

2007; Schiltz et al., 2020), the Loneliness in Context Questionnaire (LiCQ) (Asher &

Weeks, 2014) (used in Han et al., 2019) and Isolation and Affect measure

(developed and used in Merkler, 2007). Importantly, the UCLA Loneliness Scales,

SELSA and LiCQ, were developed to measure loneliness in the general population

and the validity of these measures for the autistic population has not yet been

established. One study (McVey et al., 2016) used the SELSA (DiTommaso &

Spinner, 1993) and reported the internal consistency (.71) within their autistic sample

(see Supplementary Appendix 2.6).

In just one study, a measure of loneliness was specifically developed for

autistic adults. Merkler (2007) created an Isolation and Affect measure to distinguish

isolation and affect as two distinct components of loneliness among autistic adults

and neurotypical university students. This scale was based on the Peer Network and Dyadic Loneliness Scale (PNDLS) (Hoza et al., 2000), designed to assess loneliness in children within the context of both social peer networks and dyadic relationships. Merkler (2007) modified the wording of items to be applicable to adult participants and included 28 items (15 on social network isolation, 13 on dyadic isolation), each answered on five-point scale (1 = not at all to 5 = absolutely) (e.g., I fit in with a group of people). The respondents were also asked to choose their emotional responses to each item among the five emotions (happiness, sadness, anger, anxiety and loneliness) and rate the intensity of their emotions on five-point scale (1 = not at all to 5 = most intense). The scale comprised of four subscales (dyadic isolation, dyadic distress, social network isolation and social network distress). The scores for the dyadic/social network isolation subscales were calculated by averaging the scores given to the items. The scores for the dyadic/social network distress subscales were calculated by averaging the scores given on each of the five emotional responses (for happiness, scores were reverse-coded). Through a confirmatory factor analysis and by correlating the measure with other similar measures (e.g., the SELSA), the Isolation and Affect measure was shown to be valid in their sample.

Seven studies (Brooks, 2014; Ee et al., 2019; Han et al., 2019; Levinson, 2020; Lin & Huang, 2019; Russell, 2020; Sundberg, 2018) included comparison groups in their studies and reported loneliness scores for both autistic and non-autistic adults (indicated with asterisks in Supplementary Appendix 2.6). In all seven studies, the autistic group had higher levels of loneliness than the non-autistic comparison group. Two of these studies included additional comparison groups of non-autistic adults who had other diagnoses. In one study, Russell (2020) reported

that non-autistic adults who suffered from insomnia reported loneliness that was

equivalent to that of autistic adults. In the other study, Han et al. (2019) reported that

non-autistic adults who were clinically depressed at the time of the study reported

higher levels of loneliness than autistic and non-autistic adults who were not clinically

depressed (Han et al., 2019). See Table 2.2 for details.

Table 2.2. Comparison groups and matching procedure

Study	Comparison group	Matching procedure
Brooks, 2004	Typically developing (TD) participants	TD participants were recruited through ResearchMatch.org, an online database to match participants for research. TD participants with scores greater than 25 on the Autism Spectrum Quotient (AQ) (Baron-Cohen et al., 2001) were excluded.
Ee et al., 2019	Non-autistic adults	NR
Han et al., 2019	TD-depressed, TD-controls	The ADOS-2 Module 4 was administered for all participants in the ASD group and any participants who exceeded the clinical cut-offs on social responsiveness scale (SRS-2) (Constantino & Gruber, 2012) or AQ (Baron-Cohen et al., 2001). Using the Structured Clinical Interview for DSM Disorders (SCID-5) (First et al., 2016) depression module and the Mini International Neuropsychiatric Interview (MINI 5.0) (Sheehan et al., 1998), all participants were assessed for emotional health history.
Levinson, 2020	Neurotypical	NR

Lin & Huang, 2019	Neuro-typical adults	The exclusion criteria for neuro-typical adults included having "(a) any physical disabilities, visual impairment, hearing impairment, or developmental disabilities; and (b) attending special education schools or classes" (Lin & Huang, 2019, p. 3).
Russell, 2020	Typically developing individuals (NT), adults show showed at least subthreshold insomnia symptoms (INS)	Autistic adults' autism diagnoses were confirmed using the Autism Diagnostic Observation Schedule—2nd Edition (Lord et al., 2012). INS group included those who scored ten and above on the Insomnia Severity Index (ISI; Bastien et al., 2001). NT group did not have "history of severe head trauma or neurological condition" (Russell, 2020, p. 24) and scored seven or below on the ISI.
Sundberg, 2020	Control	NR

Note: NR = not reported. Terminology to describe autism corresponds to the exact terms in each article and it is not the intention of the review.

2.3.3 Review question 3: what dimensions of loneliness (intimate, relational or collective) have been reported in research on autistic adults?

I categorized every included study (quantitative: n=20, qualitative: n=8, and mixed methods: n=6) into one of the three dimensions of loneliness: intimate, relational or collective (see Table 2.3). In the mixed methods studies, both quantitative and qualitative aspects of the data contributed to this review question. Next, I report on the dimension(s) of loneliness that were evident from the context of the studies (e.g., if a finding was reported on friendship, this was categorised as

relational loneliness) and/or I report on the dimensions of loneliness that the
measure(s) used within the study appeared to assess.

Relational loneliness (i.e., peer relationships) was researched most, featuring
in every included study; quantitative (n=20), qualitative (n=8), and mixed methods
(n=6). Intimate loneliness (i.e., romantic relationships) was explored in ten studies
(Baldwin & Costley, 2016; Bourdeau, 2020; Chen et al., 2016; Gantman et al., 2012;
Hickey et al., 2018; Hull et al., 2017; Jackson et al., 2018; McVey et al., 2016;
Merkler, 2007; Schiltz et al., 2020); comprising quantitative (n=7), qualitative (n=2)
and mixed methods (n=1) studies. Collective loneliness (i.e., a sense of belonging in
society) was explored in six studies (Ashbaugh et al., 2017; Elmose, 2020; Hull et
al., 2017; Hwang et al., 2017; Jantz, 2011; Milton & Sims, 2016); quantitative (n=1),
qualitative (n=4), and mixed methods (n=1) studies.

Table 2.3. Dimensions of loneliness

Study	Loneliness measures	Study design	Dimensions of loneliness		
			Relational	Intimate	Collective
Ashbaugh et al., 2017	NA	Quantitative	✓		✓
Baldwin & Costley, 2016	NA	Mixed methods	✓	✓	
Bourdeau, 2020	SELSA	Quantitative	✓	✓	
Brooks, 2014	The UCLA Loneliness Scale, Version3	Quantitative	✓		
Caruana et al., 2021	Revised UCLA Loneliness Scale	Quantitative	✓		
Chen et al., 2016	NA	Quantitative	✓	✓	
Ee et al., 2019	ULS-8	Mixed methods	✓		
Elmose, 2020	NA	Qualitative	✓		✓

Gantman et al., 2012	SELSA	Quantitative	✓	✓	
Han et al., 2019	LiCQ	Quantitative	✓		
Hedley, Uljarević, Foley, et al. (2018)	The UCLA Loneliness Scale, Version3	Quantitative	✓		
Hedley, Uljarević, Wilmot, et al. (2018)	ULS-8	Quantitative	✓		
Hickey et al., 2018	NA	Qualitative	✓	✓	
Hillier et al., 2018	The UCLA Loneliness Scale, Version3	Mixed methods	✓		
Hull et al., 2017	NA	Qualitative	✓	✓	✓
Hwang et al., 2017	NA	Qualitative	✓		✓
Jackson et al., 2018	3 item UCLA Loneliness Scale	Quantitative	✓	✓	
Jantz, 2011	The UCLA Loneliness Scale, Version3	Mixed methods	✓		✓
Levinson, 2020	Revised UCLA Loneliness Scale	Quantitative	✓		
Lin & Huang, 2019	ULS-8	Quantitative	✓		
Mazurek, 2013	ULS-8	Mixed methods	✓		
Mazurek, 2014	ULS-8	Quantitative	✓		
McVey et al., 2016	SELSA	Quantitative	✓	✓	
Merkler, 2007	SELSA and Isolation and Affect measure	Quantitative	✓	✓	
Milton & Sims, 2016	NA	Qualitative	✓		✓
Orsmond et al., 2013	NA	Quantitative	✓		
Russell, 2020	The UCLA Loneliness	Quantitative	✓		

	Scale, Version3			
Schiltz et al., 2020	SELSA	Quantitative	✓	✓
Smith & Sharp, 2013	NA	Qualitative	✓	
Southby & Robinson, 2018	NA	Qualitative	✓	
Sundberg, 2018	ULS-8	Quantitative	✓	
Syu & Lin, 2018	ULS-8	Quantitative	✓	
Van der Aa et al., 2016	Loneliness Scale based on the Revised UCLA loneliness scale	Mixed methods	✓	
Van Hees et al., 2015	NA	Qualitative	✓	

2.3.4 Review question 4: what factors are associated with increased loneliness in autistic adults?

Factors positively associated with social isolation and/or loneliness in autistic adults were reported in 18 of the 34 studies (53%), including quantitative (n=10), qualitative (n=5), and mixed (n=3) methods studies. The factors identified are presented in the order of frequency (from most to least commonly reported). Note that most of the quantitative studies tended to be correlational in nature (as opposed to causal).

Autistic characteristics

Thirteen studies (nine quantitative, one qualitative, three mixed methods) identified autistic characteristics as a factor positively associated with loneliness

among autistic adults. Ten of the thirteen studies (Brooks, 2014; Caruana et al.,
2021; Ee et al., 2019; Hedley, Uljarević, Foley, et al., 2018; Hedley, Uljarević,
Wilmot, et al., 2018; Jantz, 2011; Mazurek, 2014; Schiltz et al., 2020; Syu & Lin,
2018; van der Aa et al., 2016) found an association between loneliness and scores
on variations of the Autism Quotient (AQ) (Baron-Cohen et al., 2001). Two of the
thirteen studies (Chen et al., 2016; Han et al., 2019) identified an association
between loneliness and scores on the Social Responsiveness Scale Second Edition
(SRS-2) (Constantino & Gruber, 2012). [See Table 2.4 for statistics reported in the
quantitative studies at the end of this section.] In one of the qualitative studies,
(Elmose, 2020), autistic adults reported that being autistic was linked to their
experiences of loneliness and underlying social experiences.

Heightened anxiety

Four studies (three quantitative, one mixed methods) reported heightened
anxiety as a factor positively associated with loneliness in autistic adults. Schiltz et
al. (2020) reported a positive correlation between social (r=.52-.59[9], p<.01) and
emotional (r=.40-.47, p<.01) loneliness subscales on the SELSA (DiTommaso &
Spinner, 1993) and social anxiety in autistic adults. Mazurek (2014) reported that
loneliness and social isolation were positively correlated with anxiety (r=.34, p=.001)
(as well as depression, low self-esteem and low quality of life) in autistic adults.
Further, Chen et al. (2016) found that greater severity of autistic characteristics on
the SRS was associated with more 'in-the-moment' anxiety (p. 1411) (β=-.07, p<.01).
The researchers added that anxiety might make autistic adults more self-aware of
social limitations and perceived social incompetence, leading to feelings of

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[9] A range of correlation coefficients were presented for the correlation between loneliness and social
anxiety in Schiltz et al. (2020), due to two different scales of social anxiety being used in the study.

loneliness. Finally, Ee et al. (2019) found that autistic adults with higher scores on the Severity Measure for Generalised Anxiety Disorder-Adult (Craske et al., 2013) were lonelier than those with lower scores (β=.216, *p*<.001).

Depression and suicidal ideation

Four studies (three quantitative, one mixed methods) reported depression and suicidal ideation as factors positively associated with loneliness in autistic adults. Mazurek (2014) found loneliness was positively associated with depression (*r*=.48, *p*<.001) in autistic adults. Also, Schiltz et al. (2020) reported that the social (*r*=.44, p<*.01*) and emotional (*r*=.72, *p*<.01) subscales on the SELSA were positively associated with depression in autistic adults. Furthermore, Jackson et al. (2018) found that lifetime suicidal behaviours were positively associated with loneliness in autistic adults (r_s(53) = .36, p<.01). Finally, Ee et al. (2019) identified that autistic adults with higher scores on Patient Health Questionnaire-9 (Kroenke et al., 2001) were lonelier than autistic adults with lower scores (β=.30, *p*<.001).

Negative experiences and learned helplessness

Three studies (two qualitative, one mixed methods) identified negative experiences and learned helplessness as factors positively associated with loneliness among autistic adults. Likewise, in Ee et al.'s (2019) mixed methods study, participants explained that their past experiences impacted their desire for socialization, with negative experiences such as bullying leading them to avoid socialization: ''people have been so cruel to me, I don't socialise ever anymore'' (p.189). Milton and Sims (2016) conducted a thematic analysis of the narratives of autistic adults in an autism-related magazine. They reported that loneliness in autistic adults was linked to negative experiences in social situations (i.e., bullying)

that arose as a result of having an "othered" identity. Smith and Sharp (2013) conducted semi-structured interviews on sensory experiences and their qualitative analysis suggested that autistic adults experienced rejection from others due to their unique sensory experiences and that such experience of rejection could lead to loneliness.

Lack of autism understanding and acceptance from others

Three qualitative studies reported others' lack of autism understanding and acceptance as a factor positively associated with loneliness in autistic adults. While Milton and Sims (2016) did not use the term loneliness, narratives of autistic adults in their research described how a lack of understanding from others caused them to feel "othered" and less connected. In turn, participants sought to connect with people who understood them:

> "I cannot talk about my real experience of life to most people, because they wouldn't understand or be interested. That makes me feel, as the saying goes, 'lonely in a room full of people' and I'm fed up with it. I would like to talk to caring, intelligent, honest people who understand Asperger's well and with whom I can talk openly" (Daniel, Pen Pal 95, issue 68, 7, Milton & Sims, 2016, p. 529)

Elmose (2020, p. 11) reported that autistic adult participants in her study felt "positioned by others" and misunderstood by those around them. Such feelings of misunderstanding were suggested to be associated with loneliness, as one participant explained: "it is probably in those situations I feel lonely" (P19, Elmose, 2020, p. 14). Finally, Hwang et al. (2017) reported that a lack of autism awareness

and understanding caused negative social experiences for autistic adults including

bullying and social isolation. A mother of an autistic adult in this study described the

way in which a lack of autism understanding and acceptance made her grown-up

child feel lonely:

> "People ignore him a lot... and they don't talk to him and they do avoid him
>
> and ignore him and given that he struggles with eye contact and then other
>
> people avoid eye contact with him... It affects him more than we realise. So I
>
> guess that's awareness... They get shunned and ostracised a lot, you know. A
>
> lot of loneliness... we're all intolerant aren't we. Intolerant. Ignorant." (Hwang
>
> et al., 2017, p. 2041)

Sensory avoidance

Two studies (one quantitative and one qualitative) identified sensory

avoidance as a factor positively associated with loneliness among autistic adults.

Smith and Sharp (2013) reported that sensory avoidance due to sensory stressful

environments render autistic adults socially isolated, which could lead to loneliness.

Further, Syu and Lin (2018) reported that autistic adults with higher scores on

sensory avoidance in the Chinese version of the Adult Sensory Profile (Tseng &

Chen, 2009) showed higher levels of loneliness (β=.413, *p*=.009).

Camouflaging

Camouflaging refers to "coping skills, strategies, and techniques that function

to 'mask' features of [autism] during social situations" (Hull et al., 2017, p. 2523).

Two qualitative studies reported camouflaging as a factor positively associated with

loneliness in autistic adults. Hull et al. (2017) argued that camouflaging makes it

easier to make connections with others because, in the words of an autistic participant, "connections have to be made initially on neurotypical terms" (Hull et al., 2017, p. 2523). Hull et al. (2017) further explained that relationships formed when camouflaging may be perceived as false by some autistic adults, which can leave them with feelings of loneliness (Hull et al., 2017). In addition, Elmose (2020) qualitative study also reported that autistic adults engaged in camouflaging and this was linked to their experiences of loneliness.

Unemployment

Just one mixed methods study reported unemployment as a factor positively associated with loneliness in autistic adults. Ee et al. (2019) included autistic and non-autistic adults in their study and, using regression analyses, reported that unemployment was associated with increased loneliness only among autistic adults (β=1.45, *p*=.045).

Table 2.4. Statistics on the association between autistic characteristics and loneliness

Study	Analysis	Statistics
Schiltz et al. (2020)	Pearson's correlations	(r=.41 - .49, p<.01) *Social (r=.49, p<.01) and family (r=.41, p<.01) subscales of the SELSA
Caruana et al. (2021)	Spearman correlation	(Spearman ρ=.278, p<.001) for autistic characteristics and anthropomorphism, (Spearman ρ=.242, p=.024) for anthropomorphism and loneliness
Brooks (2014)	Pearson's correlations	(r=.350, p=.05)
Hedley, Uljarević, Wilmot, et al. (2018)	Pearson's correlations	(r=.331, p< .01)
Hedley, Uljarević, Foley, et al. (2018)	Pearson's correlations	(r= .232, p< .05)
Jantz (2011)	Pearson's correlations	(r= .334, p≤ .05)
Mazurek (2014)	One-way ANOVA	(β=.28, p=.004)
Syu and Lin (2018)	One-way ANOVA	(β=.345, *p*=.004)

Ee et al. (2019)	Regression	(β=.104, *p*=.003)
van der Aa et al. (2016)	Regression	(β=-.54, *p*<.001) * The authors conducted a regression analysis using AQ as a measure of autistic characteristics as continuous variables afford a "statistically more robust result" (p.21) than dichotomous variables like diagnostic status. Thus, it should be noted that there was some overlap in the samples in the regression, with some autistic people not scoring above the cut-off on the AQ to be considered autistic and vice versa.
Chen et al. (2016)	Multilevel linear analyses	(β=-.10, *p*<.05) *Chen et al. (2016) reported that increased severity on the SRS moderated the relationships between loneliness and interactions with others at work/school.
Han et al. (2019)	Linear regressions	Capacity for social pleasure (t(96) = 2.52, P = 0.01), capacity for non-social pleasure (t(95) = 2.60, P = 0.01) *Han et al. (2019) found that higher levels of autistic traits predicted loneliness in autistic adults. This association, however, was moderated by anhedonia, loss of pleasure.

2.3.5 Review question 5: what factors are associated with decreased loneliness in autistic adults?

The factors negatively associated with loneliness in autistic adults were reported in 18 of the 34 studies (53%): a combination of quantitative (n=8), qualitative (n=6), and mixed methods (n=4) studies. The reported factors are presented in the order of frequency of reports (from most reported to least reported).

Note that most of the quantitative studies tended to be correlational in nature (as opposed to causal).

Having relationships

Sixteen studies (seven quantitative, six qualitative, and three mixed methods) reported having relationships as a factor negatively associated with loneliness in autistic adults. Ten of the sixteen studies (Bourdeau, 2020; Brooks, 2014; Hedley, Uljarević, Foley, et al., 2018; Jackson et al., 2018; Jantz, 2011; Mazurek, 2013; Mazurek, 2014; Schiltz et al., 2020) reported statistics on the association between having relationships (i.e., friendships, social participation/contacts in general) and loneliness (see Table 2.5 at the end of this section). In an evaluation of a social skills training for autistic young adults, Gantman et al. (2012) found that participants experienced a decrease in self-reported loneliness following the training. The authors suggested that the development of friendships during the training might explain the decline in participants' loneliness. Similarly, Hillier et al. (2018) investigated the impacts of a social intervention program for autistic adults on their loneliness, self-esteem and mental health, and suggested that the observed reduction in loneliness was because autistic adults were able to develop relationships with peers.

Three qualitative studies (Elmose, 2020; Milton & Sims, 2016; Southby & Robinson, 2018) indicated that having relationships, particularly through shared interests, may alleviate loneliness. For example, Southby and Robinson (2018) proposed that participants who attended the Leeds Autism AIM (advocacy, information, and mentoring) service felt less socially isolated as they had an opportunity to engage with "likeminded people" (p.514). Another qualitative study showed that married autistic adults felt less lonely than those who were not married

(Hickey et al., 2018). Explaining their findings, Hickey et al. (2018) proposed that having one close relationship provided some sense of connection and therefore reduced loneliness. Van Hees et al. (2015) used interviews to explore autistic adults' experiences of higher education and found that a scarcity of relationships was associated with higher levels of loneliness, while supportive relationships could alleviate feelings of loneliness. Finally, Smith and Sharp (2013) explored autistic adults' sensory experiences and reported that having positive relationships, such as with family or friends, could make autistic adults less vulnerable to social isolation and loneliness.

Participation in social skill interventions and/or experiencing fewer difficulties with social skills

Two studies (one quantitative and one mixed methods) reported that participation in social skills interventions and/or experiencing fewer difficulties with social skills was a factor negatively associated with loneliness in autistic adults. Gantman et al. (2012) adapted and tested the effectiveness of a social skills intervention for autistic adolescents, the Program for the Education and Enrichment of Relational Skills, (PEERS, Laugeson & Frankel, 2011), with autistic young adults. They found that PEERS social skills training was associated with reduced loneliness. However, it is worth noting that McVey et al. (2016) replicated this work and did not find PEERS to be associated with reduced loneliness in autistic young adults [$F(1, 16) = 4.73$, $p<.05$]. Using multiple regression, Ee et al. (2019) explored the factors that were associated with loneliness in autistic and non-autistic adults. They found that higher scores on the subscale of social skills on the AQ-Short (where higher scores indicate more autistic characteristics) (Hoekstra et al., 2011) were associated with decreased loneliness in autistic adults ($\beta=.446$, $p<.001$). The AQ-Short has 28

items with two major domains: social behavioural difficulties and fascination for numbers/patterns. The social behavioural difficulties domain contains the subdomain of social skills (e.g., "I find it hard to make new friends", "I would rather go to a library than to a party").

Positive views and acceptance of oneself

Three studies (one quantitative, one qualitative, one mixed methods) reported self-esteem and acceptance as factors negatively associated with loneliness in autistic adults. Mazurek (2014) reported that loneliness was negatively correlated with self-esteem ($r=-.38$, $p<.001$) and life satisfaction ($r=-.46$, $p<.001$) in autistic adults. Acceptance of autistic identity was also associated with lower feelings of isolation, according to a study involving a thematic analysis of issues of the magazine *Asperger United* (AU)[10] (Milton & Sims, 2016). From the quantitative data in Ee et al.'s (2019) mixed methods study, it was found that self-efficacy was associated with less loneliness in autistic adults ($\beta=-1.291$, $p<.001$).

Female gender

One mixed methods study (Ee et al., 2019) reported gender as a factor negatively associated with loneliness in autistic adults. In this study, being female was associated with decreased loneliness ($\beta= -2.62$, $p = 0.004$).

Time spent engaging in activities

Sundberg (2018) examined how online gaming affects friendships and loneliness in autistic teenagers and adults, finding that autistic individuals who played online games less than one hour per day experienced significantly less loneliness than those who played 2-3 hours ($p=.049$) or 3-5 hours per day ($p=.01$).

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[10] *Asperger United* is a quarterly newsletter published by National Autistic Society (a leading autism charity in the UK). It is written and edited by autistic people, with occasional contributions from professionals who work with autistic people.

Table 2.5. Statistics for the association between having relationships and loneliness

Study	Analysis	Statistics
Bourdeau (2020)	Repeated measures ANOVA	Wilks' Lambda=.29, F(1,36)=89.97, p=.71,ES=.714
Mazurek (2014)	One-way ANOVA	(β = −.22, p = .02) for close friendship and loneliness
Brooks (2014)	Pearson's correlations	r=-.47, p < .001 for friendship quality and loneliness
Jackson et al. (2018)	Regression	[rs(54)=−0.52, p<0.001] for the number of close friends and loneliness, [rs(54)=−0.61, p<0.001] for satisfaction with the number of close friends
Jantz (2011)	Pearson's correlations	(r = -.492, p ≤ .05) for the number of close friends and loneliness, (r = −.398, p ≤ .05) for the number of social engagements and loneliness
Mazurek (2013)	One-way ANOVA	β = -.30, p = .003 for the number of friends and loneliness
Schiltz et al. (2020)	Pearson's correlations	r=−0.53, p<0.01 for social loneliness, r=−0.27, p<0.05 for family loneliness on SELSA
Hedley, Uljarević, Foley, et al. (2018)	Regression	(β = .43, P < .001) for the number of social supports and loneliness, (β = −.47, P < .001) for satisfaction with social support and loneliness

2.4 Discussion

This chapter presents the first systematic review to examine loneliness in autistic adults. A key finding from this review was that research on this topic is in its infancy: few studies examined loneliness in autistic adults exclusively, with existing studies tending to examine loneliness as part of broader research investigations; no studies reported on the characteristics of autistic adults who are lonely versus those who are not; few studies included comparison groups of non-autistic adults; most

studies only report quantitative data on loneliness with less information provided on the qualitative descriptions of loneliness perceived by autistic adults; and there is a lack of diversity of research participants in work on this topic regarding age, gender, ability levels and race/culture/ethnicity. Despite these gaps in the literature, the work included in this review has provided several important contributions to our understanding of loneliness in autistic adults. For example, the results demonstrated that: autistic adults do desire connection and do experience loneliness; autistic adults report higher scores on measures of loneliness than their non-autistic peers; and some factors associated with loneliness are common among autistic and non-autistic groups, while others appear unique to the autistic population. These conclusions are based on both qualitative and quantitative work. Next, I reflect on the strength and nature of the existing literature on loneliness among autistic adults, using these findings to suggest both avenues for future research and implications for practice.

Research reporting on autistic adults' first-hand experiences of loneliness highlighted autistic people's desire for social connections, despite experiencing difficulties in social situations. While loneliness was negatively perceived, and sometimes viewed as an inevitable consequence of challenges in social situations, autistic adults expressed a desire for a sense of connection. The social motivation theory of autism (Chevallier et al., 2012) suggests that autistic children are less interested in social involvement than non-autistic children, and that such indifference eventually leads to poorer development in social communication and interaction. Yet existing research shows that autistic children *do* desire friendships (Bauminger & Kasari, 2000; Calder et al., 2013) and that this desire extends into adulthood (Gillespie-Lynch et al., 2017). Consistent with these findings, studies included in this

review note how autistic people may experience loneliness and long for connection and belonging in the same way that non-autistic people do. However, the way that autistic adults experience "the world of people" (Grandin & Scariano, 1986, p. 19) appears to be different. Despite a desire for connection, autistic adults may be less likely to have opportunities for such connection. For example, autistic adults are no longer in the mandatory social setting of school and are less likely to be in employment in order to forge social connections with colleagues. It is, therefore, essential to consider how to alleviate feelings of loneliness among autistic adults.

Results from this review demonstrate the value of autistic adults having social relationships to alleviate loneliness. For example, the autistic participants in Elmose's (2020) research reported that factors such as sharing interests, as well as a sense of safety, recognition and acceptance, made it easier for them to socially interact with others. Likewise, several studies demonstrated how autistic adults often found value in social relationships with other autistic people (Elmose, 2020; Milton & Sims, 2016; Southby & Robinson, 2018). These findings link with recent research outside the field of loneliness, which has shown that autistic/autistic interactions are perceived as easier and more comfortable than autistic/non-autistic interactions (Crompton, Hallett, et al., 2020; Crompton, Ropar, et al., 2020), and that interacting with other autistic friends and family members provides autistic adults with a sense of belonging (Crompton, Hallett, et al., 2020). This supports growing calls for autistic peer support, for which initial evaluations have yielded positive results (e.g., Crane, Hearst, et al., 2020). These findings do not, however, imply that autistic adults should *only* forge social connections with other autistic adults. Indeed, characteristics of successful autistic/non-autistic relationships have been documented (Smith et al., 2021).

The question then arises of how to measure loneliness in autistic adults. Standardized measures of loneliness were used in ~65% studies included in the review. The results of these studies consistently showed that autistic adults had higher levels of loneliness than their non-autistic peers. However, this finding should be interpreted with caution since (despite the high quality of the studies, as rated on the MMAT), most loneliness measures used in these research studies have not been specifically designed for, or validated with, autistic people. This issue is discussed further in Chapter Three.

Yet the findings of this review highlighted how some factors associated with loneliness appear similar among autistic and non-autistic adults. For example, loneliness has been linked to poorer mental health (e.g., depression, suicidality) among both autistic and non-autistic adults. Existing studies have not, however, examined whether there are autism-specific pathways to these outcomes. In a prominent model of loneliness discussed in Chapter One, Cacioppo and Hawkley (2009) describe a self-reinforcing loop where loneliness leads to hypervigilance for social threats and a bias towards negative social experiences. This, in turn, leads to people experiencing negative social events that confirm their negative social expectations, resulting in further negative social interactions and enhanced loneliness. The results of this review are broadly consistent with this model. For example, autistic characteristics may render autistic adults to be hypervigilant to social threats and, and camouflaging, particularly if unsuccessful, this may exacerbate their negative social experiences. Further, heightened anxiety as a driver of loneliness, as found in autistic people (Chen et al., 2016; Mazurek, 2014), has been previously reported in the general population (Caplan, 2007; Mazurek, 2014). Yet it should be noted that causal interpretation of research on the potential causes

of loneliness included from this review was limited as most of the studies used correlational data. Investigating shared/different mechanisms underpinning loneliness in autistic and non-autistic adults more rigorously is an important avenue for further research.

Once the mechanisms underpinning loneliness in autistic adults have been established, it is important to determine how autistic loneliness could be overcome. Existing work in this area is limited, with quantitative studies included in this review largely focusing on correlation as opposed to causation. In terms of developing this work further, one option is to address the internal, predisposing factors that render autistic people vulnerable to loneliness such as difficulties with social skills. Indeed, my review suggests that some evidence exists for the association between social skills training and decreases in loneliness (Gantman et al., 2012). However, my findings also suggest that trying to 'fit in' with the non-autistic population (e.g., via masking) can lead to increases in loneliness. As such, it is important to critically reflect on interventions that encourage autistic individuals to conform to non-autistic people's social norms. It is perhaps more important to promote interventions that support autistic people to cultivate positive views and acceptance of themselves. Indeed, self-acceptance was reported to be associated with decreased loneliness in a paper presented in this review (Milton & Sims, 2016).

Alternatively, one could address the external, contributory factors that lead to social isolation and feelings of loneliness amongst autistic people such as others' negative views of autistic differences. As outlined in Chapter One, Section 1.2.3, Milton's (2012) double-empathy theory explains how autistic people often struggle to empathize with non-autistic people, but equally the converse is also true. Applying this theoretical framework to loneliness research, this could explain a vicious cycle of

negative social experiences for autistic adults, which may render them more vulnerable to loneliness. Similarly, findings from this review indicate that the avoidance of stressful sensory experiences, common in environments set up for the non-autistic norm, may contribute to loneliness in autistic adults. Overall, further work should investigate ways to overcome loneliness in autistic people from both directions: examining what autistic adults can do to overcome feelings of loneliness, but also focusing on what non-autistic people and society in general can do to be more accepting and inclusive of autistic differences.

Finally, it is vital to reflect on the importance of autistic voice in determining priorities for future research. In the current review, there were both similarities and differences between the findings from quantitative and qualitative research studies. However, it was notable that, collective loneliness was only reported in 5% of the quantitative studies (one out of 20) compared to 50% of the qualitative studies (four out of eight). Collective loneliness was also reported in the qualitative data from one mixed-methods study (Jantz, 2011). Such differences between the focus of quantitative and qualitative studies suggests a potential discrepancy between the loneliness research priorities of autism researchers and autistic adults. It will be critical for future research to be guided by autistic adults' research priorities on this topic.

Limitations

It is important to address the limitations of the studies included in the current review, as well as the limitations of the review itself. Most studies included in this review focused on autistic adults in early to middle adulthood, despite loneliness having a huge impact on autistic people's quality of life as they age. Likewise,

studies tended to focus on adults who had average/above average intellectual and communicative abilities, despite difficulties with speech and cognition increasing the likelihood of social isolation in young autistic adults (Ashbaugh et al., 2017; Brooks, 2014; Chen et al., 2016; Hickey et al., 2018; Merkler, 2007; Syu & Lin, 2018). Russell et al. (2019) recently reported that more than 90% of autistic participants in research studies do not have co-occurring intellectual disabilities. As such, additional work on experiences of loneliness in this group is crucial.

Research studies featured in this review often included a rather narrow definition of loneliness. Specifically, there was a dearth of literature on collective loneliness in comparison to relational and intimate loneliness. It is also noteworthy that little research has been on autistic adults' relationships with non-human agents with just one included study investigating such relationships in association to loneliness (Caruana et al., 2021). A final limitation to note is that many of the studies featured in this review appeared to assume that loneliness and social isolation were synonymous experiences. For example, many studies used the two terms interchangeably or used level of isolation as a proxy for loneliness. However, qualitative experiences of loneliness and social isolation are likely to differ (Holt-Lunstad et al., 2015; Wang et al., 2017; Zavaleta & Samuel, 2014). It will be important for future research on loneliness in autistic adults to distinguish loneliness from social isolation.

In addition to the limitations of the studies included in this review, there are limitations associated with the review itself. First, only English language articles were included. Second, an examination of the broader context of loneliness (e.g., poor social economic status or housing) was beyond the scope of this review, but is an important consideration for future work. Third, as the studies included in this review

largely examined the factors associated with loneliness, as opposed to causal factors underpinning loneliness, this review cannot draw firm conclusions on what causes loneliness, but only on the factors potentially associated with loneliness in this population. Fourth, search terms in this review intentionally focused on loneliness and social isolation, however including more search terms such as social network and relationships might have generated broader results (e.g., Ma et al., 2020). Fifth, the majority of the included studies used loneliness measures developed for the general population and, until their validity and reliability has been established in autistic adults, the results need to be treated with caution (as they might have under/overestimated loneliness in autistic adults). Sixth, due to the lack of existing work on causation, some of the associations reported in review questions 4 and 5 are speculative and require further research to be confident of these associations. Finally, as the first review on this topic, I intentionally included broad review questions. Our search strategy for this broad field may therefore not have been fully comprehensive and I was only able to conduct a narrative synthesis of included studies.

2.5 Conclusion

Research on loneliness in autistic adults is in its infancy. While there were limitations associated with the studies included within this review, it represents an important first step towards a more comprehensive understanding of loneliness in autistic adults. The results of the review highlight how loneliness and the desire for social connection are shared human experiences, regardless of whether a person is autistic or not. While the consequences of loneliness in autistic adults appear to be similar to those in the non-autistic population, it has not been established whether

the mechanisms underpinning loneliness in autistic adults differ from non-autistic people. Underpinning all of this work should be the goal of making this research maximally beneficial to the lives of autistic adults (Pellicano et al., 2014).

2.6 Future research

The current review has highlighted many possible areas in loneliness research that could benefit from future research; more areas than it would be possible to examine within my thesis. However, there were two key areas that I was particularly keen to explore. First, given that most existing loneliness measures were designed for the general population and not specifically for autistic adults, I felt it was important for future research to investigate if, and how accurately, existing loneliness measures capture experiences of loneliness in autistic adults. This gap in the literature will be addressed in Chapter Three. Second, I was concerned that there was a lack of research reporting autistic adults' first-hand accounts of loneliness. Yet exploring lived experiences of loneliness in autistic adults could potentially provide insights into the nature of, and mechanisms underpinning, loneliness in this group. Importantly, I felt that such work could provide important clues around how loneliness could be overcome in autistic adults. As such, autistic adults' lived experiences of loneliness will be explored in Chapters Four and Five.

Chapter Three

Evaluating Measures to Assess Loneliness in Autistic Adults

3.1 Introduction

Measuring loneliness is challenging because loneliness is subjective, whereas objective social isolation is quantifiable (e.g., number of friends) (de Jong Gierveld & Havens, 2004; Wang et al., 2017). Yet measuring loneliness is important. First, measuring loneliness helps researchers to expand their knowledge and understanding of loneliness (Campaign to end loneliness, n.d.; Office for National Statistics, 2018). Second, loneliness is a distressing emotional state in its own right (Perlman & Peplau, 1981; Wang et al., 2017), which is associated with a wide range of negative physical and mental health outcomes (Cacioppo et al., 2015; Wang et al., 2018). It is therefore important to appropriately document rates of loneliness. Third, loneliness can be an outcome of treatment/intervention (e.g., Fakoya et al., 2020; Masi et al., 2011), or a predictor of some health conditions (e.g., Cacioppo et al., 2006; Qualter et al., 2010). Finally, in practice, measuring loneliness can help social care providers to develop evidence-based countermeasures for loneliness (Campaign to end loneliness, n.d.; Office for National Statistics, 2018).

Standardized measures can help identify the extent of loneliness that a person experiences, and can assess any changes over time. There are various psychometrically validated and standardized measures of loneliness for use in the general population. Some loneliness measures are multiple-item scales and others are single-item scales; and some loneliness measures are indirect scales (e.g., asking about emotions associated with loneliness) and others are direct scales (e.g., simply asking about feelings of loneliness) (Office for National Statistics, 2018). In the UK, the Office for National Statistics (2018) suggested that best practice in

measuring loneliness is to use both indirect and direct scales. Most existing

loneliness measures do not specify which aspects of loneliness they are evaluating

(e.g., intimate, relational or collective loneliness), while others do (Pollet et al., 2021).

Although there is no evidence regarding which measure is most frequently used

among the general population, several commonly-used measures include the

different versions of the UCLA Loneliness Scales and the Social Emotional

Loneliness Scale for Adults (henceforth SELSA; DiTommaso & Spinner, 1993).

In my systematic review on loneliness in autistic adults (see Chapter Two), I

reported that there were few studies that used valid/reliable[11] measures of loneliness

developed for autistic adults, and that in just one study (Merkler, 2007) a measure

was developed for, and validated in, autistic adults. Specifically, Merkler (2007)

developed an Isolation and Affect measure based on the Peer Network and Dyadic

Loneliness Scale (PNDLS) (Hoza et al., 2000) which was designed to measure

social network and dyadic loneliness in children. This measure included 28 items (15

on social network isolation, 13 on dyadic isolation), each answered on five-point

scale (1 = not at all to 5 = absolutely) (e.g., I fit in with a group of people). The

respondents were also asked to choose their emotional responses to each item

among the five emotions (happiness, sadness, anger, anxiety and loneliness) and

rate the intensity of their emotions on five-point scale (1 = not at all to 5 = most

intense). The scale comprised of four subscales (dyadic isolation, dyadic distress,

social network isolation and social network distress). The scores for the dyadic/social

network isolation subscales were calculated by averaging the scores given to the

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[11] Validity in this context refers to whether questionnaires actually measure the construct they intend to measure (e.g., whether a loneliness scale actually measures loneliness in a given population). Reliability in this context refers to whether questionnaires produce consistent results under the same conditions (e.g., whether the same respondents similarly score on a loneliness scale at two different time points).

items. The scores for the dyadic/social network distress subscales were calculated

by averaging the scores given on each of the five emotional responses (for

happiness, scores were reverse-coded). Merkler (2007) demonstrated the validity of

the measure using confirmatory factor analysis and correlation between the Isolation

and Affect measure and other similar measures (e.g., SELSA). Importantly, Merkler

(2007) did not involve autistic adults in developing this loneliness measure and the

measure has been only used within their study (i.e., it has not been used in other

research). The dearth of loneliness measures that have been developed for, and

validated in, autistic adults need greater attention in research. Indeed, the latest

tackling loneliness evidence review from the UK Department of Digital, Culture,

Media and Sport (DCMS) (Qualter et al., 2022) emphasized the importance of

investigating the suitability of loneliness measures in sub-groups of people,

especially disabled people. Further, in autism research specifically, Jones (2022)

highlighted the importance of critically evaluating the applicability of existing

measures, and if necessary, refining and developing measures that reflect autistic

experiences.

Using existing loneliness measures that are not validated in autistic adults

might be problematic for several reasons. First, using existing measures that are not

validated in autistic adults may result in inaccurate findings, as they may not reflect

the unique way that autistic people experience loneliness (Jones, 2022; Nicolaidis et

al., 2020). Further, this would mean that rates of loneliness between autistic and

non-autistic people cannot be accurately compared (McConachie et al., 2018).

Second, autistic adults may interpret items on questionnaires differently from the

general population, for whom existing measures were intended (Mason et al., 2022;

McConachie et al., 2018). For example, on the widely-used UCLA Loneliness Scale

(Russell, 1996), respondents are asked "how often do you feel close to people?",
which autistic adults may interpret literally (Mason et al., 2019). Likewise, some
frequently-used loneliness measures ask about friendships, but previous research
showed that autistic people may understand friendship differently from the general
population (Tavernor et al., 2013).

Outside the field of loneliness research, there have been several studies
examining measurements tools for autistic adults. Next, I present a summary of
some existing work in this area, which forms the basis of my own exploration of
measurements for loneliness in autistic adults.

Quality of life

To investigate the validity of the most frequently-used quality of life (QoL)
measure for autistic adults, Mason et al. (2022) asked 352 autistic adults to complete
the WHOQoL-BREF (Ayres et al., 2017). The WHOQoL-BREF (Skevington et al.,
2004) is a brief version of a quality of life measure developed by the World Health
Organization (WHO) and has 26 items about physical, psychological, social, and
environmental aspects in relation to QoL. The researchers used exploratory factor
analysis to confirm the validity of the WHOQoL-BREF for autistic adults and reported
that some items loaded differently to the way expected for the general population.
The researchers also conducted four discussion groups with autistic adults (n=20) to
further investigate the meaning of the items in the WHOQoL-BREF and its linked
WHOQoL-Disabilities module from the perspective of autistic adults. The WHOQoL-
Disabilities module (Power et al., 2010) was developed to measure QoL in people
with intellectual or physical disabilities and includes 13 additional items that are
administered alongside the WHOQoL-BREF. Qualitative analysis of autistic adults'
views on the measure found that autistic adults interpret the social aspects of

WHOQoL-BREF and some other items (e.g., bodily appearance, mental health) differently from how people in the general population interpret such items. The finding did not specifically highlight the issues with the items, however, the issues raised by their participants included not considering their sensory or social experiences and also the items having unclear terms (Mason et al., 2022). Caution therefore needs to be exerted in terms of how researchers interpret and make sense of autistic adults' results on those items.

Given the aforementioned findings, McConachie et al. (2018) developed and tested the reliability and validity of autism-specific items on QoL measures (ASQoL)[12]. In consultation with 20 autistic adults, McConachie et al. (2018) initially developed some autism-specific items to be used with the existing QoL measures (i.e., the WHOQoL-BREF and WHO Disabilities module). To refine the autism-specific items, they conducted cognitive interviews with 15 autistic adults and undertook a Delphi survey (i.e., a method that aims to answer a research question by identifying a consensus among the subject experts via a series of surveys, allowing the participants to reflect/reconsider their opinions based on the anonymized views of others; Barrett & Heale, 2020) with 139 autistic adults in the first round and 235 autistic adults in the second round. Based on autistic adults' feedback about the wordings of the items, the researchers made edits to the wordings between rounds one and two (the paper did not report the details about how the items were changed). The researchers then tested the reliability and validity of the WHOQoL-BREF, WHO Disabilities module, and ASQoL items. To assess the psychometric properties of the WHOQoL-BREF and validity/reliability of the

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[12] Although the study by Mason et al. (2022) was published after the study by McConachie et al. (2018), the findings of the former informed the latter.

WHOQoL-BREF, WHO Disabilities module, and ASQoL items, the researchers ran a number of quantitative analyses including confirmatory and exploratory factor analyses. The final ASQoL included nine items covering topics mostly relating to social factors (e.g., "can you 'be yourself' around your friends/people you know well?") (McConachie et al., 2018, p. 1601). The other additional items concerned sensory experiences, access to health services, and acceptance of autistic identity. On the basis of this work, the researchers reported that the WHOQoL-BREF, WHO Disabilities module, and ASQoL items are valid and reliable tools to be used to measure QoL in autistic adults.

Later, McConachie et al. (2020) conducted nine consultation groups with 38 autistic adults from four countries (i.e., Argentina, Australia, Singapore, and the UK) to identify items that were missing from the WHOQOL-BREF and Disabilities module yet significant to autistic adults. They found that autistic adults from four countries showed notable similarities in what they considered significant to include in such QoL measures, suggesting that creating cross-cultural autism-specific QoL items might be possible. These items included knowledge on autism and acceptance of difference, supports and services, lack of resources (e.g., financial, relational), support from family, unique sensory experiences, autism characteristics, autistic identity, autonomy (i.e., having control over one's decision), mental health, friends, and social interaction.

Suicidality

In a systematic review, Cassidy, Bradley, Bowen, et al. (2018) found that no measures of suicidality were developed for, or validated in, autistic adults. Cassidy, Bradley, et al. (2020) then conducted a study to examine the appropriateness of a suicidality measure. The focus was the Suicidal Behaviours Questionnaire-Revised

(SBQ-R; Osman et al., 2001), which they found had good psychometric properties in measuring suicidality in the general population. The SBQ-R includes four items each assessing lifetime suicidal behaviour, suicidal ideation over the past 12 months, communication of threat of suicidal attempt to others, and likelihood of suicidal behaviour in the future. Cassidy, Bradley et al.'s (2020) mixed-methods study first involved an online survey with 188 autistic adults and 183 non-autistic adults and then cognitive interviews with a sub-sample of 15 autistic adults. Cassidy, Bradley, et al. (2020) analyzed the SBQ-R using confirmatory factor analysis and measurement invariance analysis to examine whether the items were interpreted in a similar or different way between autistic and non-autistic groups. Cassidy, Bradley, et al. (2020) reported that some items on the SBQ-R were interpreted differently between autistic and non-autistic adults: items on likelihood of a future suicide attempt, and communication of threat of suicide attempt to others. In addition to the survey, Cassidy, Bradley, et al. (2020) conducted cognitive interviews (developed with the input of patient and public involvement focus groups) to investigate how autistic and non-autistic adults interpret the items on the SBQ-R differently. During the interviews, Cassidy, Bradley, et al. (2020) asked autistic adult participants to "think aloud" and share with the interviewer what they are reading and thinking about as they complete each item of the SBQ-R. Cognitive interviews were analysed item by item (instead of across the whole dataset). Consistent with the quantitative findings, the cognitive interviews showed that autistic adults interpret items on the likelihood of a future suicide attempt and the communication of threat of suicide attempt to others differently from originally intended. More specifically, autistic adults reported that communicating their suicidal attempts/thoughts was not an important determinant in their suicidality and that they had difficulties in interpreting and responding to the

questions due to unclear words (e.g., "commit suicide", "someday"), similar response options (e.g., "never" and "no chance at all)", and response options that did not reflect their experiences (e.g., participants felt that the response options did not capture the range of frequency or intensity in their suicidal thoughts over the past year).

Cassidy et al. (2021) adapted the SBQ-R by reflecting on the feedback from autistic adults in their preceding study (Cassidy, Bradley, et al., 2020) and developed the Suicidal Behaviours Questionnaire—Autism Spectrum Conditions (SBQ-ASC). Cassidy et al. (2021) then refined and finalized the SBQ-ASC through interviews with nine autistic adults and an online survey with 251 autistic adults. Cassidy et al. (2021) reported the issues in the SBQ-R and corresponding adaptations for each of the four items as well as for the overall questionnaire. The key concerns/adaptations were concerning the relevance of the items to autistic adults (e.g., communicating suicidal thoughts does not mean they do not have suicidal thoughts) and clarity in the wordings of the items and response options. Table 3.1 presents the details of the concerns and adaptations of the SBQ-R reported in Cassidy et al. (2021).

Cassidy et al. (2021) then asked 689 adults to complete the adapted SBQ-ASC in an online survey. Of 689 participants, 308 were autistic, 113 were those who suspected they were autistic themselves but had not yet received a diagnosis (the study referred to this group as "possibly autistic"), and 268 were non-autistic. Autistic and non-autistic participants (but not possibly autistic adults) were split into two groups stratified by gender and age: data in one group was used for exploratory factor analysis, and data in another group was used for confirmatory factor analysis. Then, the exploratory and confirmatory samples were recombined to conduct a multi-group confirmatory factor analysis to examine whether the SBQ-ASC had a similar

structure among the groups. Through the factor analyses, the study confirmed the

validity of the SBQ-ASC in autistic adults. Using measurement invariance tests,

Cassidy et al. (2021) also reported the structural equivalence of SBQ-ASC between

autistic and possibly autistic adults. Therefore, Cassidy et al. (2021) recommended

that future research could use the SBQ-ASC to identify suicidal thoughts/behaviors

in autistic and possibly autistic adults.

Table 3.1. Concerns and adaptations of the SBQ-R (Cassidy et al., 2021)

Item on the SBQ-R	Concern	Adaptation
Overall	Undefined terms (e.g., suicide plan. Suicide attempt)	To clarify the meanings of the terms.
	Self-harm was not considered.	To add an additional item on self-harm.
Lifetime suicidal behavior	The response options were not adequate to capture autistic adults' suicidality.	To change response options (they removed one item and added another).
	The item did not consider that autistic adults may attempt a suicide without a plan.	To add a follow-up question to identify whether respondents who attempted a suicide did so with or without a plan.
	The term was considered inappropriate/not sensitive (i.e., "kill yourself").	To replace the term with another (e.g., "end your life").
Suicidal ideation over the past 12 months	The timescale was unclear.	To split the item into two items to specify the timescale: one asks about frequency of suicidal thoughts over the past year, and another asks about the length of time intense suicidal thoughts last per day.
Communication of threat of suicidal attempt to others	The item did not consider that autistic people may not routinely communicate their suicidal thoughts to other but still experience them.	To add follow-up questions. If they have shared their suicidal thoughts with someone, a follow-up question asks about to whom they have shared. If they have not shared their suicidal thoughts with anyone, a follow-up question asks why not.
	Inappropriate term (i.e., "commit suicide")	To replace the term with more acceptable term (i.e., "end your life").
	Compound question	To simplify the item and response options.

Likelihood of suicidal behaviour in the future	Unspecified timescale	To specify what situation to consider in responding to the item.
	Unclear response options	To clarify the response options.

Anxiety

In this field, researchers first focused on measures to assess anxiety in autistic children. Among the existing measures to assess anxiety in autistic children, the Revised Child Anxiety and Depression Scale (RCADS; Chorpita et al., 2000) was reported as robust enough to be used in autistic children (Sterling et al., 2015; Wigham & McConachie, 2014). However, the RCADS was not originally developed for this group and had the chances to under/overrate anxiety in autistic children (e.g., due to the overlaps between autism and anxiety). As such, Rodgers et al. (2016) proposed to adapt the RCADS for autistic children. Rodgers et al. (2016) first modified the wording of all the 37 original items on anxiety in the RCADS based on an unpublished thesis (Jamieson, 2011) (therefore specific changes in the wording are unknown) and added 42 additional items based on the existing literature on sensory processing, uncertainty and phobias, while keeping the original format of the RCADS for scoring and layout of the questions. Through a consultation with a group of 12 parents of autistic children (neurotypes of the parents were not clarified), Rodgers et al. (2016) created a parent-report measure with 76 items and self (child)-report measure with 74 items (the original RCADS was a child-report measure). Rodgers et al. (2016) then asked 170 autistic children and their parents to complete the initially adapted measures by post. Using factor analysis, Rodgers et al. (2016) determined 24 items of the adapted measures (both parent-report and self-report) were reliable and valid and called the new measures the Anxiety Scale for Children –

ASD (ASC-ASD). The ASC-ASD (parent and self-report) included four subscales (i.e., performance anxiety, uncertainty, anxious arousal, and separation anxiety).

Following the development of the anxiety measure for autistic children, Rodgers et al. (2020) aimed to adapt the ASC-ASD for autistic adults. Rodgers et al. (2020) first conducted consultations with six professionals (with academic or clinical knowledge of working with autistic adults) and six autistic adults. In the consultation, Rodgers et al. (2020) presented the participants the 24-item ASC-ASD, whose items they had already reworded for adults, and asked for feedback (e.g., whether the items were recognizable as a feature of anxiety in autistic adults, whether the wording was clear and appropriate for autistic adults, and whether they thought anything was missing from the items). From the consultation, Rodgers et al. (2020) removed one item from the original measure for children that was not relevant to adults and added six additional items (which were not specified in the paper) to the preliminary measure. Second, Rodgers et al. (2020) asked autistic adults to complete the adapted 29-item measure by post or online (depending on the participants' preferences), now called the Anxiety Scale for Autism-Adults (ASA-A) and another self-report measure, the Hospital Anxiety and Depression Scale (HADS), to check the validity of the ASA-A. A total of 505 autistic adults who experienced anxiety at the time of the study (note: a clinical diagnosis of anxiety was not sought) completed the measures at two different time points (one month apart) to test the measure's reliability. To analyse data on the ASA-A, Rodgers et al. (2020) split the sample into two groups (stratified by age and gender so that any demographic differences were controlled for). For one group, Rodgers et al. (2020) conducted exploratory factor analysis (n=193) to identify the factor structure (i.e., correlation between the items on the ASA-A and measured construct, anxiety). For

the other group, Rodgers et al. (2020) conducted confirmatory factor analysis (n=312) to cross-validate the factor structure against the group analyzed using exploratory factor analysis. Further, to test the reliability of the ASA-A, Rodgers et al. (2020) calculated the internal consistency of the total and subscale scores on ASA-A using Cronbach's alpha and assessed test-retest reliability using Spearman's rank correlations. Using the correlation between the ASA-A and the anxiety factor on the HADS, Rodgers et al. (2020) assessed the validity of the ASA-A. Additionally, Rodgers et al. (2020) used receiver operator curve (ROC) analyses and reported that a score of 28 was a useful clinical cutoff, indicating anxiety that is likely to have an impact on someone's daily life. Overall, Rodgers et al. (2020) reported that the ASA-A is a useful measure for anxiety in autistic adults, and that the three sub-scales (i.e., anxious arousal, social anxiety, and uncertainty) provide 'profiles' of anxiety.

Generic guidance on adapting measurement tools for autistic adults

The three areas reviewed above (i.e., quality of life, suicidality, and anxiety) suggest the need for autism-specific measures of these constructs, since measurement tools developed for the general population were not ideal for autistic adults. More broadly, Nicolaidis et al. (2020) reviewed six independent studies of their own that used a community-based participatory (CBPR) approach (i.e., studies were co-produced with their community partners) to adapt survey instruments: five studies focused on autistic adults (from The Academic Autism Spectrum Partnership in Research and Education, or 'AASPIRE') and one focused on people with intellectual disabilities (the Partnering with People with Developmental Disabilities to Address Violence Consortium). Based on a review of these studies, Nicolaidis et al. discussed 11 steps for adapting or creating survey instruments for autistic adults

(note: the researchers used the term 'survey instruments' synonymously with

measures) – see Table 3.2.

Table 3.2. Process of adapting or creating measures for autistic adults (Nicolaidis et al., 2020)

Step #	General guideline	What the studies reviewed in Nicolaidis et al. (2020) did
1	To co-create collaboration guidelines with the community partners and providing them with background knowledge about the terms and process used in survey research	No details were provided.
2	To choose which constructs are important to measure	The Principal Investigator selected the constructs.
3	To discuss the selected constructs collaboratively with the community partners and ensure that there is a shared understanding of what they mean	This process appeared to be considered unnecessary due to "the fact that our community partners already had significant experience adapting other instruments and had a strong working relationship with AASPIRE academic partners" (Nicolaidis et al., 2020, p. 64).
4	To identify the existing measures of the selected constructs	The Principal Investigator identified the existing measures of the selected constructs.
5	To choose which existing measures to adapt or to decide creating a new measure if none of the existing ones are appropriate.	Via email, the Principal Investigator asked autistic adults in the community partner (AASPIRE) about which measures were easiest to complete, what issues they experienced with the measures, and what could be the potential solutions.
6	To examine what adaptations should be made	
7	To make any changes to the introductions, items, or response options of the measures	Based on the feedback from autistic adults, the Principal Investigator decided how to adapt the measures.
8	To clarify the terms used in the measures by providing definitions or examples	
9	To create new measures if necessary	
10	To consider whether creating proxy report versions of the adapted or new measures could be appropriate	Researchers considered whether or not someone other than autistic adults themselves could answer the measures on behalf of them (e.g., internal states are difficult to be reported by a proxy). If helpful,

		researchers reworded the measures and created proxy report versions.	
11	To examine the adapted or new measures' psychometric properties	Researchers evaluated and reported the psychometric properties in individual studies.	

In their own studies reviewed in Nicolaidis et al. (2020), the researchers used a CBPR and each of the 11 steps involved collaborating as equal partners with autistic adults and making decisions together using a consensus process. Nicolaidis et al. (2020) noted that the process could be time-consuming: for example, it usually took them a few hours of meeting to adapt one measure. As an alternative, Nicolaidis et al. (2020) advised researchers to at least consider an advisory model where autistic adults provide their feedback on existing measures and provide suggestions for improvement.

Nicolaidis et al. (2020) reported five common concerns about existing survey instruments and detailed how they addressed the concerns within their own work - see Table 3.3.

Table 3.3. Common concerns and adaptations of existing measures for autistic adults (Nicolaidis et al., 2020)

Concern	Adaptation	Example	
		Item/measure of concern	Adapted item/measure
Autistic adults found the language to be difficult to understand (e.g., difficult or confusing terms/phrases, complex sentence structure, double-negatives)	To simplify the terms/phrases	''confide in''	''share personal information''
	To add hotlinks which allows respondents to click and check the meaning or example of the terms	In the last month, how much have you been bothered or upset by being ''super alert'' or watchful or on guard?	On guard—constantly looking out for something bad.
Autistic adults felt that Linkert scales with unclear/undefined response options	To add explanation of each response option to the	(a) Always, (b) usually, (c) sometimes, (d) never (the item asked the	('Always' means around 100% of the time; 'Usually' means around 66% or 2/3 of the time;

were difficult to complete	preface in parenthesis	respondents' satisfaction regarding healthcare)	'Sometimes' means around 33% or 1/3 of the time; and 'Never' means around 0% of the time.)
	To add graphics that represent each response option (e.g., cylinders filled to different degrees, faces)	(a) Not at all, (b) a little bit, (c) moderately, (d) quite a bit, (e) extremely (the item asked about degrees to which respondents were bothered)	☺ Not at all / 😐 A little bit / ☹ Moderately / 😟 Quite a bit / 😣 Extremely Note: the faces closely represent what was presented in Nicolaidis et al. (2020), and were selected from the "icons" on Microsoft Word.
Autistic adults felt anxious about whether they could accurately answer the questions (e.g., numbers of time they participated in certain activities)	To add frequent reminders to "make their best guess"	No reminders were in the original measures.	"Please give your best guess from the provided answers."
	To add an open-box on every page to allow respondents to explain what they felt were not captured in the measures	No open-boxes were in the original measures.	'If you are not sure how to answer a particular question, please make your best guess and move on to the next question. If you would like to, you can write comments in the comment box below. (Note: information you choose to provide in the comment box will be read, but it will not be considered an answer to the survey questions.)"

Autistic adults felt that responding to the measures could not reflect their varying responses in different situations	To specify the situations respondents should think about when completing the measures (e.g., when, with whom)	The original measure asked respondents to think about certain behaviors of their healthcare providers over the past 12 months.	The adapted measure asked to only think about the last visit with their primary care provider.
Autistic adults felt that the measures did not capture autism-specific aspects of the constructs	To add new autism-specific items (e.g., regarding autistic ways of communication, sensory differences)	No autism-specific items were in the original measure.	The adapted checklist on barriers to healthcare included additional items about autistic adults' challenges with sensory environments and communication (this example was about a checklist instead of a measure).

Current study

As previous research in other fields adapted and created measurement tools for autistic adults, the research presented in this Chapter took an important first step towards this goal regarding loneliness measures. I had two key aims in this Chapter: 1) to examine if and how accurately existing loneliness measures capture the experiences of loneliness in autistic adults, and 2) to explore autistic adults' views/experiences of frequently-used measures of loneliness (to identify whether they need to be adapted for autistic adults and, if so, how). Specifically, I investigated whether autistic adults' scores on existing measures of loneliness related to one another (i.e., whether they scored similarly on different measures) and whether the scores aligned with autistic adults' subjective experiences of loneliness. I also investigated what autistic adults think is good/not so good about existing loneliness measures and how they think the measures could be improved (to better

reflect their experiences of loneliness). Based on the aforementioned background literature about measurements in autistic adults outside of loneliness research, I hypothesized: 1) that existing loneliness measures might not accurately capture the experiences of loneliness in autistic adults, and 2) that autistic adults might have difficulties in completing the questionnaires and feel that the existing measures could be improved to better reflect autistic adults' experiences of loneliness (via adaptation or addition of autism-specific items). While the recommendation from Nicolaidis et al. (2020) were published after the current study was designed and analysed, the current study generally followed the recommended process in adapting or creating measures for autistic adults: identifying whether existing instruments are acceptable or whether there is a need to create a new measure, and if existing measures are acceptable, to identify how existing measures could be improved to better reflect autistic adults' experiences.

3.2 Methods

3.2.1 Design

I used an online survey to collect quantitative and qualitative data on autistic adults' scores and views on widely-used measures of loneliness (presented in this Chapter). Note that I also collected information on definitions and experiences of loneliness (qualitatively) and these data are presented in Chapter Four.

3.2.2 Participants

Criteria for inclusion in the study were that participants needed to be (1) autistic (diagnosed or self-identified), (2) over 18 years of age and (3) currently living in the UK. The country of study was limited to the UK as cultural background impacts views and experiences of loneliness (Barreto et al., 2021; Rokach et al., 2001). The

research was advertised via social media, organizations and social groups for

autistic adults and via the CRAE database, between November 2019 and January

2020 (approximately six weeks). In total, 159 organizations and groups were

contacted via email and 36 organizations and groups confirmed that they advertised

the research through their networks. Efforts were made to include as diverse autistic

adults as possible, for example, by contacting Black, Asian, and Minority Ethnic

(BAME) and Lesbian, Gay, Bisexual, Transgender, Queer/Questioning and other

sexual identities (LGBTQ+) groups.

A total of 294 autistic adults participated in the research. Responses were not

considered for those who did not meet the inclusion criteria (n=7) or who only

partially completed the survey (n=84). Therefore, the final sample comprised 203

respondents. As can be seen in Table 3.4, many adults were formally diagnosed

with autism later in their life, grew up in the UK, had co-occurring condition(s)

(depression and anxiety were most common), used spoken language to

communicate, lived with their partner and/or children, were currently employed or in

education, educated in mainstream school, had gained higher educational

qualifications, were single, and tended to disclose their autism diagnosis with those

who are close to them. The sample included more females than males, who were

largely from a White ethnic background. The participant profiles are very similar to

those of other online survey research with autistic adults (e.g. Cage et al., 2018;

Cassidy, Bradley, Shaw, et al., 2018). The age band was decided with subsequent

analysis in mind which is based on the existing evidence that being young (<25

years old) or older (>65 years old) adults (Lim, Eres, et al., 2020; Office of National

Statistics, 2018) are associated with increased loneliness. More than a half of the

participants were in their middle adulthood, specifically between the age of 35 and

54. Of the 172 participants who reported age of autism diagnosis, the majority received their diagnosis in adulthood.

Table 3.4. Participant demographics (n= 203)

Demographic variables		n (%)
Autism diagnosis	Formally diagnosed	172 (84.7)
	Self-identified and in process of obtaining a diagnosis	14 (6.9)
	Self-identified but not seeking a diagnosis	17 (8.4)
Age of autism diagnosis (N=172)	M: years (SD)	34.7 (14.8)
	Range: years	1-70
	Diagnosed in childhood (<18 years old)	30 (17.4)
	Diagnosed in adulthood	142 (82.6)
Age	M: years (SD)	40.7 (12.5)
	Range: years	18-73
	Aged 24 and younger	28 (13.8)
	Aged 25-34	35 (17.2)
	Aged 35-44	58 (28.6)
	Aged 45-54	50 (24.6)
	Aged 55-65	28 (13.8)
	Aged 66 and above	4 (2.0)
Gender	Male (including transgender male)	65 (32.0)
	Female (including transgender female)	116 (57.1)
	Non-binary	17 (8.4)
	Other/prefer not to say	5 (2.5)
Ethnicity	White (including British, Irish or any other White background)	183 (90.1)
	Black or Black British Caribbean (including the Caribbean, African or any other Black background)	1 (0.5)
	Asian or Asian British (including Indian, Pakistan, Bangladesh or any other Asian Background)	4 (2.0)
	Mixed (e.g., White and Asian; or any other Mixed background)	10 (4.9)
	Other/prefer not to say	5 (2.5)
Location of growing up	In the UK	180 (88.7)
	In another country	23 (11.3)

Co-occurring conditions	Yes	144 (70.9)
	Yes, but I prefer not to disclose the diagnosis/diagnoses	9 (4.4)
	No	50 (24.6)
Co-occurring conditions (text-entry) *multiple answers were allowed (n=144)	Depression	67 (33.0)
	Anxiety	58 (28.6)
	Physical conditions	51 (25.1)
	Learning disabilities	27 (13.3)
	AD(H)D	23 (11.3)
	OCD	10 (4.9)
	Eating disorders	8 (3.9)
	PTSD	7 (3.4)
	Tourette's syndrome	2 (1.0)
	Other mental health conditions (e.g., Bipolar disorder, Personality disorders)	18 (8.9)
Ways of communication	Spoken language	189 (93.1)
	Sign language	4 (2.0)
	Communication devices and apps	10 (4.9)
Living arrangement	Living with parents and/or siblings	25 (12.3)
	Living with non-family members (including living in university accommodation)	19 (9.4)
	Living with partner and/or children	95 (46.8)
	Living alone	57 (28.1)
	Living in a residential home	1 (0.5)
	Other (e.g., combination of the above)	6 (3.0)
Employment	Full-time paid job (over 35 hours per week)	65 (32.0)
	Part-time paid job (less than	33 (16.3)
	Not employed – in full/part-time education (student)	29 (14.3)
	Not employed – not in education	41 (20.2)
	In voluntary employment	15 (7.4)
	Self-employed	9 (4.4)
	Retired	2 (1.0)

	Other (e.g., combination of the above)	9 (4.4)
Educational history	Mainstream school	189 (93.1)
	Special unit within a mainstream school	2 (1.0)
	Specialist school	6 (3.0)
	Home school	0 (0)
	Other/prefer not to say	6 (3.0)
Highest educational qualification[13]	GCSEs	11 (5.4)
	National Vocational Qualification	10 (4.9)
	A/AS Levels	26 (12.8)
	First degree (e.g., BA, BSc)	60 (29.6)
	Higher degree (e.g., MA, MSc, PhD)	80 (39.4)
	Other/no qualifications	16 (7.9)
Relationship	Married/in civil partnership	53 (26.1)
	Not married, but in a romantic relationship	43 (21.2)
	Divorced/separated	19 (9.4)
	Single	87 (42.9)
	Other (divorced and living with a new partner)	1 (0.5)
Disclosure of autism diagnosis	Tend to share with anyone I meet	41 (20.2)
	Tend to share with those close to me (family, friends, co-workers, etc.)	104 (51.2)
	Tend not to share with anyone I meet including those close to me	27 (13.3)
	Tend to share if needed/relevant	18 (8.9)
	Other (e.g., when people are knowledgeable about autism)	11 (5.4)
	Do not tend to share	2 (1.0)

3.2.3 Materials

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[13] In the UK's educational system, students are entered for GCSE (General Certificate of Secondary Education) at around the age of 14 to 16, and they are entered for A/AS levels at around the age of 16 to 18.

Using Qualtrics, the survey was designed by myself (an autistic autism researcher) with advice from my primary supervisor, Dr. Laura Crane. A small group of six autistic adults, not involved with the design of the survey, provided feedback and suggestions on the final draft of the survey. In response, one question (on changes in experiences of loneliness over time) was added to the survey. Overall, the feedback on the survey was positive (i.e., that it was easy and interesting to complete) and only minor changes were suggested (e.g., adding an additional open text box at the end of the survey, so respondents could add further comments about loneliness if they chose to). I designed the survey to be as accessible as possible. For example, I used a pale yellow background with black text, to increase readability for those with dyslexia (Rello & Bigham, 2017), which could be likely to co-occur with autism (Brimo et al., 2021). Additionally, I provided a link to a PDF file of the survey in the information sheet and made the entire survey available to be viewed before collecting consent to help autistic adults to decide whether to take part in this study (see Appendix 3.1 for the survey).

Background

To better understand the profile of the participants, they were asked to complete some background multiple-choice questions. This included collecting information about their diagnostic status (e.g., formally diagnosed, self-identified and in the process of obtaining a diagnosis), age of diagnosis, chronological age, gender, ethnicity, geographic location of growing up, co-occurring conditions, methods of communication (e.g., mainstream school, specialist school), living arrangements, employment status, mode of education attended, highest educational qualification, relationship status, and attitude towards disclosure about being autistic (regardless of being formally diagnosed or self-identified).

Measures of loneliness

To understand how autistic adults score on and view the widely-used measures of loneliness, autistic adults were asked to complete the UCLA Loneliness Scale Version 3 (Russell, 1996) and SELSA (DiTommaso & Spinner, 1993). The order of these were counterbalanced across participants. After completing each loneliness measure, participants were asked to provide their comments on the measure in open-textboxes, explaining what they thought was good about it, what they thought was not-so-good about it, and any improvements that they felt could be made so that it better reflects their experiences of loneliness. In addition, participants were asked to complete a direct measure of loneliness (Office for National Statistics, 2018) following the recommendation from the UK's Office for National Statistics to use both indirect and direct measures in measuring loneliness.

The UCLA Loneliness Scale Version 3 (Russell, 1996) and SELSA (DiTommaso & Spinner, 1993) were chosen for this study based on the results of my systematic review (Chapter Two) which demonstrated that the most commonly-used loneliness measures for autistic adults were variations of the UCLA Loneliness Scales and the SELSA (DiTommaso & Spinner, 1993). The eight-item UCLA Loneliness Scale Short Form (ULS-8) (Hays & DiMatteo, 1987) was most commonly-used (as used in seven out of 22 studies) and the 20-item UCLA Loneliness Scale Version 3 (Russell, 1996) was second most commonly-used (as used in seven out of 22 studies) among a variety of the UCLA Loneliness Scales for the use in autistic adults. The items on the ULS-8 are worded as statements (e.g., I lack companionship) and the items on the UCLA Loneliness Scale Version 3 are worded as questions (e.g., how often do you feel that you lack companionship). While there were slight differences how the items are worded (i.e., statements or questions), the

items included in the ULS-8 were also in the UCLA Loneliness Scale Version 3

except for one item ("I am unhappy being so withdrawn"). For the purpose of

exploring autistic adults' views on the loneliness measures in depth, I purposefully

chose the 20-item UCLA Loneliness Scale Version 3 (Russell, 1996) over the eight-

item ULS-8 so that autistic adults have more items to explore and give their feedback

to.

1) UCLA Loneliness Scale Version 3 (henceforth UCLA scale; Russell,

1996). The UCLA Loneliness Scale Version 3 (Russell, 1996) is a self-report

unidimensional scale, accessing the frequency and intensity of the current

experiences of loneliness (Cramer & Barry, 1999). Unidimensional scales such as

this regard loneliness as a unitary phenomenon captured by a single universal scale

and assumes loneliness is the same across circumstances (Cramer & Barry, 1999).

This scale consists of 20 items with four response options (1 = never, 2 = rarely, 3 =

sometimes and 4 = always) (e.g., "how often do you feel alone"). While the original

paper had a response option 4 as "always" (Russell, 1996), other resources

providing the scale sometimes had the response option 4 as "often" (Fetzer Institute,

n.d.) and this survey had the option 4 as "often". Any impacts this might have had on

the data are described later in the limitations. Some of the items are reverse-scored.

The potential range of total scores is 20 (low) to 80 (high), with higher scores

indicating higher levels of loneliness. The measure has good internal consistency

(Cronbach's alpha = .89-.94) and test-retest reliability (r = .73) (Russell, 1996).

2) SELSA (DiTommaso & Spinner, 1993). SELSA is a self-report

multidimensional scale accessing the frequency and intensity of the current

experiences of intimate and relational aspects of loneliness (Cacioppo et al., 2015).

This scale includes 37 items, each answered on a seven-point scale (1 = strongly

disagree to 7 = strongly agree) (e.g., "I don't have a friend(s) who understands me, but I wish I did"). The scale comprises three subscales (romantic, family and social subscales) and some of the items are reverse-scored. Scores range from 12 (low) to 84 (high) for the romantic subscale, 11 (low) to 77 (high) for the family subscale and 14 (low) to 98 (high) for the social subscale. Total scores range from 37 (low) to 259 (high), with higher scores indicating higher level of loneliness. The three subscales of the measure have good internal consistency (Cronbach's alpha = .89-.93). The test-retest reliability for the SELSA was not reported in DiTommaso and Spinner (1993) nor studies that used the measure in autistic sample.

3) The direct measure of loneliness (Office for National Statistics, 2018).
The direct measure of loneliness refers to a self-report unidimensional scale, directly asking respondents "(how often) do you feel lonely?" (Pollet et al., 2021). The UK government recommends the direct measure for the use in the general adult population as a national indicator of loneliness (Office for National Statistics, 2018), specifically asking "how often do you feel lonely?" with five answer choices (1 = often/always, 2 = some of the time, 3 = occasionally, 4 = hardly ever, 5 = never). However, since the direct measure of loneliness considers loneliness as a unitary construct, it does not give a clue as to the types of loneliness one experiences (e.g., social loneliness, emotional loneliness) (Pollet et al., 2021).

3.3.4 Procedure

Ethical approval was given via the Department of Psychology and Human Development at IOE, UCL's Faculty of Education and Society on October 30, 2019 (UCL Data Protection Registration Number: Z6364106/2019/10/155). The information sheet and consent form were all on Qualtrics. Once participants clicked the link to the survey, they proceeded to the information sheet. This sheet provided

information about the aim of this research (presented here and in Chapter Four), researchers involved in this research, criteria for inclusion in this research (see Section 3.2.2 for details), how they would be involved, a link to view the whole survey, information on data protection, and what would happen to all information gathered (see Appendix 3.1 for information sheet and consent form). On the information sheet, I added a sentence to encourage participants to contact the researchers, or discuss their decision with others, regarding their participation, or to ask any questions they might have. In the information sheet, participants were also reminded that they were free to withdraw from the study at any time, without giving reason and without any negative consequences. Participants were then taken to the consent form. All participants gave their written consent on an online form which recapped them with key point regarding the research, in addition to indicating that they read and understood the information sheet and were willing to participate. When they gave consent, participants proceeded to the questionnaires. Given the sensitivity of the topic, on the bottom of every survey page, participants were given contact details of who they could get in touch with if the study raised any negative feelings (e.g., Samaritans, who have a text and phone service).

3.3.5 Data analysis

Quantitative analysis

Analysis of quantitative data was completed using SPSS software. To determine whether there were any differences in how autistic adults scored on loneliness scales between those who were formally diagnosed and those who self-identified as autistic, independent samples t-tests (for data that met parametric assumptions) or Mann-Whitney U tests (for data that did not meet parametric assumptions) were run. Correlations among the three loneliness measures were

used to determine whether scores on each measure were related to one another and to see if the UCLA and SELSA scales align with the direct measure that reports autistic adults' subjective experiences of loneliness. Statistical tests were also conducted to better define the sample. Specifically, I compared the self-reported loneliness in autistic adults in relation to the general population in the UK and examined how individual differences impact the levels of loneliness. Descriptive statistics (mean, SD, range) and frequencies were used to present how autistic adults scored on the UCLA, SELSA, and the direct measure of loneliness. To examine individual differences on loneliness among this specific sample of autistic adults, hypotheses were made based on the evidence from previous research in the general population. Table 3.5 presents the hypotheses and corresponding analyses. Regarding hypotheses #2-9, the systematic review on loneliness in autistic adults (i.e., Chapter Two) reported that anxiety and depression have been frequently associated with increased loneliness in autistic adults.

Table 3.5. Hypotheses on individual differences on loneliness among autistic adults

#	Hypothesis	Analysis
1	Being young (<25 years old) or older (>65 years old) adults (Lim, Eres, et al., 2020; Office of National Statistics, 2018) is associated with increased loneliness.	To examine hypothesis #1, descriptive statistics were used and a clustered bar chart of age groups was presented to identify if there is a U-shaped like tendency between age and loneliness also in autistic adults (i.e., increased loneliness in younger and older adults).
2	Being female (Lim, Eres, et al., 2020; Office of National Statistics, 2018) is associated with increased loneliness.	To examine hypotheses #2-9, multiple hierarchical regressions were used in which hypotheses indicate a linear model with more than two variables (i.e., multiple regression) and predictors were
3	Having grown up in another country other than the UK but living in the UK at the time of the survey[14] (i.e., being migrant;	

[14] In Lim et al. (2020), being migrant was reported as a factor associated with increased loneliness in five previous studies (de Jong et al., 2015; Fokkema & Naderi, 2013; Rich Mdsen et al., 2016; Victor et al., 2012; Zhong et al., 2016) none of which had a clear definition of migrants but indicated migrants as people who migrated to the country of research from other countries. Similarly, I defined

Lim, Eres, et al., 2020) are associated with increased loneliness.

4   Depression[15] (Lim, Eres, et al., 2020) is associated with increased loneliness.

5   Anxiety[4] (Lim, Eres, et al., 2020) is associated with increased loneliness.

6   Living alone (Lim, Eres, et al., 2020; Office of National Statistics, 2018) is associated with increased loneliness.

7   Being unemployed (Office of National Statistics, 2018) is associated with increased loneliness.

8   Lower educational qualifications[16] (Lim, Eres, et al., 2020) is associated with increased loneliness.

9   Being single, divorced, or separated (Lim, Eres, et al., 2020; Office of National Statistics, 2018) is associated with increased loneliness.

selected based on previous research and entered into the models in order of their importance (i.e., hierarchical method) (as per Field, 2018). Because of the strong evidence based on previous literature on general population and systematic review on autistic adults regarding predictors of loneliness, I expected there would be a medium to large effect. Therefore, the sample size (n=203) was large enough for the numbers of predictors (n=8) to conduct regressions (as per Field, 2018). I entered predictors in both model 1 and 2 using forced entry, instead of stepwise because stepwise method is only beneficial in more exploratory analysis (without specific hypotheses from past work as in this case) (Field, 2018). Categorical predictors that contained more than two categories were dummy coded (as per Field, 2018). Prior to conducting regression, I confirmed that any assumptions were met for regression analysis by following the guidelines. on Field (2018) (e.g., outcome variable [i.e., loneliness] is linearly related to any predictors).

Note: Lim et al. (2020) was a literature review on factors associated with increased loneliness and solutions to loneliness and Office for National Statistics (2018) was

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my participants as migrants when they were grown up outside of the UK but lived in the UK at the time of the survey.

[15] In Lim et al. (2020), depression was reported as a factor associated with increased loneliness in three studies (Cacioppo et al., 2010; Peerenboom et al., 2015; Singh & Misra, 2009) all of which used self-report questionnaires to measure depression. In Lim et al. (2020), anxiety was reported as a factor associated with increased loneliness in two studies: one study used a self-report questionnaires to measure anxiety (Beutel et al., 2017) and another was a meta-analysis (Mahon et al., 2006). Unlike previous studies that measured depression and anxiety using psychometric measures, in this study, participants were asked whether they have any other diagnoses in addition to autism and specified their diagnoses in an open-text box if they chose to do so (e.g., depression, anxiety).

[16] In Lim et al. (2020), lower educational level was reported as a factor associated with increased loneliness in two studies: one study defined lower educational level based on numbers of years of schooling (Ausin et al., 2017) and another defined it based on the 1997 International Standard Classification of Education. In this study, I defined lower educational qualifications as not having university qualifications. This seemed reasonable since the majority of participants has gained higher educational qualifications.

a report on factors associated with increased loneliness based on the UK-based Community Life Survey study from 2016 to 2017.

Qualitative analysis

Qualitative data, gathered from participants' discussions of the strengths and weaknesses of the UCLA and SELSA scales, were analyzed using reflexive thematic analysis (Braun & Clarke, 2006, 2019; Clarke & Braun, 2013) to identify the patterns across the data regarding autistic adults' views on the scales. The analysis followed the recommended six steps: familiarization with the data; coding the data; identifying the themes; developing the themes; refining the themes; and producing a report (see Table 3.6 for full details; Braun & Clarke, 2006, 2021). Coding of the data and developing of the themes were concurrently done by an autistic (myself) and non-autistic researcher (a research assistant at CRAE). This was the first time that I conducted reflexive thematic analysis, and the involvement of the second researcher was due to me being a novice qualitative researcher at the time of the analysis. Their support enabled me to better follow the processes of reflexive thematic analysis. After developing the themes, I had conversations with my supervisor, Dr. Laura Crane, via email and video-calls to further refine the themes. After several discussions, my supervisor and I reached an agreement on the themes. For more details, Table 3.6 provides information on who contributed to what stages of the analysis and how. Data were analysed via inductive, semantic, and critical realist approaches (Braun & Clarke, 2006). Taking an inductive approach meant that codes and themes were grounded in the data without using any existing coding framework. A semantic approach meant that codes and themes reflected the meaning of the data rather than coders' assumptions. Taking a constructionist approach meant that

codes and themes were developed to report autistic adults' views on the existing

loneliness measures as reality without assumptions.

Reflexivity means that the analysis is influenced by the researchers' views

and experiences, emphasizing the importance of researchers continuously

interrogating their influence on the analysis (Braun & Clark, 2019). For example, it is

necessary to note the positionality of those who involved in the thematic analysis

(Braun & Clarke, 2019; Clarke & Braun, 2013). In this regard, I have been involved in

the autism community as a self-advocate (see Chapter One for further details), and

my supervisor and a research assistant at CRAE who supported with aspects of the

design and analysis have all been involved in the autism community as allies. We all

view autism from a social (as opposed to a medical) model of disability within a

broader neurodiversity paradigm (i.e., autism is a difference in how one views and

experiences the world and autistic people do not require 'curing' or 'fixing').

In addition to clarifying and reflection on my positionality, my reflexive practice

included many dialogues with other people who were involved in the analysis

process (i.e., the research assistant and my supervisors). These have been

described in detail in Table 3.6. As an autistic researcher, the narratives in the data

were very similar to my perspectives. Involvement of other non-autistic researchers

in the analysis enabled me to keep reflecting on the influence of my views in the

interpretations of the data, through reflective questioning. Furthermore, to ensure

that the qualitative analysis acknowledges differing perspectives from the majority

voice, I conducted a negative case analysis and purposefully looked for any data that

contradicts the themes following the thematic analysis. Where there were differing

perspectives, I reported them at the end of describing each theme. This negative

case analysis was also an opportunity for me to draw out any competing themes that

aligned with my personal perspectives.

Table 3.6. Six steps in thematic analysis

Step	Description
Step 1: familiarization with data	I exported the participants' responses from Qualtrics, and copied and pasted them on a Word document for myself and a research assistant. Each of us familiarized ourselves with the data by repeatedly reading and listening to the data several times and immersing ourselves in the data. ("Us" indicates a research assistant and I who were involved in the analysis.)
Step 2: coding data	Each of us added codes to the data by using the comment function on Word. Both of us considered codes as something that capture a single idea of a piece of data.
Step 3: identifying themes	Each of us then independently organized the codes into possible themes. Both of us considered themes as something that cluster several or more codes and demonstrate patterns in the data.
Step 4: developing themes	In developing themes, we exchanged the Word documents with codes and what we thought as possible themes via email (the possible themes were either in a form of bullet points or a table). I met my supervisor to report back our analyses (orally) and to further discuss possible themes and agreed that our initial themes were similar; therefore, we chose the wordings of themes that best represented the participants' views.
Step 5: refining themes	Steps 5 and 6 were an iterative process of writing up the results (including thematic map) and seeking feedback from my supervisors. This approach was taken to share more context into the analyses with my supervisors and to further refine themes (e.g., narratives associated with possible themes). I met my supervisors several times to discuss their feedback and to refine/agree on the themes. The conversations were mainly to categorize the identified

	themes into main themes and sub-themes.
Step 6: producing a report	In writing up the results, I clearly explained each theme, presented example quotes, and narrated participants' accounts. My supervisors provided me with feedback and we met several times to discuss the feedback.

3.3 Results

The data included two groups: formally diagnosed and self-identified autistic adults. I therefore began my analysis by determining whether there were any differences in loneliness scores between these groups. Data in each group met most of the assumptions to perform an independent samples t-test (as per Field, 2018), however normality in the distribution could only be met for both groups on SELSA, not on the UCLA or direct measure. Independent samples t-test and its equivalent nonparametric test were performed accordingly. Reported levels of loneliness on the UCLA scale were not significantly different between the formally diagnosed group (Mdn^{17}=61.00) and the self-identified group (Mdn=65.00), U=2311.00, z=-1.18, p=.24. On average, reported levels of loneliness on the SELSA were also very similar between formally diagnosed (M=149.00, SE=44.61) and self-identified (M=148.39, SD=38.01) autistic adults, t(201)=.07, p= .94. Likewise, reported levels of loneliness on the direct measure in the formally diagnosed group (Mdn=2.00) did not significantly differ from the self-identified group (Mdn=2.00), U=3126.00, z=-.13, p=.90. Because there were no significant differences between the formally diagnosed and self-identified participants in reported levels of loneliness on all three measures, I report data on loneliness from both groups together.

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[17] The median, not mean for each group was reported as median is more appropriate for non-parametric tests (Field, 2018).

3.3.1 Quantitative data: Correlation between three loneliness measures

Correlational analyses were first used to examine the associations between the three measures used in the current study. As can be seen in Table 3.7, all measures were positively correlated with one other, suggesting that 1) they all index the same construct, and 2) the UCLA and SELSA scales align with autistic adults' subjective experiences of loneliness.

Table 3.7. Correlations among the three self-report loneliness measures

	SELSA	Direct measure
UCLA	$r = .79$	$r = -.53$
	$p < .001$	$p < .001$
SELSA	--	$r = -.50$
		$p < .001$

3.3.2 Quantitative data: Autistic adults' loneliness ratings

Participants' scores on the UCLA, SELSA and the direct measure of loneliness are presented in Tables 3.8 and 3.9. Since I did not collect my own comparison group data to confidently compare my data against, I gathered indicative data from the general population. From this, I can tentatively suggest that my autistic adult sample's loneliness rates seemed to be higher than those in the general population. However, because I cannot confidently show the comparability of the samples on a range of key variables (e.g., age, gender), these results should be treated with caution.

Table 3.8. Descriptive statistics of the total scores of the loneliness measures

Population	Statistics	UCLA scale	SELSA	The direct measure of

			Total	Romantic subscale	Family subscale	Social subscale	loneliness
Autistic adults (current study)	M (SD)	60.1 (10.8)	148.9 (43.6)	47.9 (22.2)	37.1 (16.8)	63.8 (19.0)	2.2 (1.1)
	Range	26-80	51-247 total	12-84	11-77	23-98	1-5
Adults in the general population [18]	M (SD)	39.1 (9.0)	N/A	42.6 (20.7)	20.5 (11.0)	31.1 (13.5)	N/A

Table 3.9. Frequencies in the direct measure of loneliness for autistic adults in the current sample and adults in the general population

	Often/always	Some of the time	Occasionally	Hardly ever	Never
Autistic adults	35.5%	30.1%	19.7%	10.8%	3.9%
Adults in the general population [19]	6%	15%	24%	31%	23%

3.3.3 Quantitative data: Individual differences in the levels of loneliness

I began these analyses by considering age separately from other demographic variables because I hypothesized that there might be a U-shape relationship where I might see increased loneliness at two different time points – for younger adults and older adults (see Table 3.5). Each age group's loneliness scores on the UCLA, SELSA and direct measure of loneliness are presented in Table 3.10.

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[18] Statistics for the UCLA Loneliness Scale Version 3 among adults in the general population is based on the data from 56 non-autistic adults (16 years +) in the USA (Brooks, 2014). The statistics for the SELSA among adults in the general population is based on the data from 354 non-autistic university students in Canada. The total scores and ranges of the scores were not reported in either of the studies (NA indicates that the data were not available). The statistics for the direct measure of loneliness among adults in the general population could not be found.
[19] Data from the Community Life Survey 2017-2018; a survey of 10,217 adults (16 years +) in England.

Note that these results must be treated with caution as the sample only included four participants who were aged 66 and older. No clear U-shape relationship was observed between age and loneliness scores (see Table 3.10). While the most frequently answered response on the direct measure among younger age groups (i.e., 24 and younger, 25-34, and 35-44) was "some of the time", that of older groups (i.e., 45-54, 55-65, 66 and above) was "often or always" (see Figure 3.1), indicating that older age groups in my sample appeared to be lonely more often than younger groups in my sample. As these data suggest more of a linear relationship than a U-shaped relationship, age was entered into the regression analysis discussed later (as per Field, 2018).

Table 3.10 Descriptive statistics of the total loneliness scores in each age group

		<25	25-34	35-44	45-54	55-65	>65
N(%)		28 (13.8)	35 (17.2)	58 (28.6)	50 (24.6)	28 (13.8)	4 (2.0)
UCLA	M	57.8	58.5	57.9	62.6	65.0	58.5
	(SD)	(11.1)	(11.1)	(10.9)	(10.7)	(8.5)	(8.1)
	Range	26-78	36-77	33-73	37-80	50-77	49-67
SELSA	M	145.4	143.1	138.8	158.3	160.6	171.8
	(SD)	(38.2)	(38.9)	(42.8)	(48.6)	(42.1)	(47.4)
	Range	63-240	64-216	55-222	51-247	85-226	105-215
Direct measure	M	2.2	2.1	2.4	2.0	2.3	1.5
	(SD)	(.1)	(1.0)	(1.1)	(1.2)	(1.4)	(1.0)
	Range	1-5	1-5	1-5	1-5	1-5	1-3
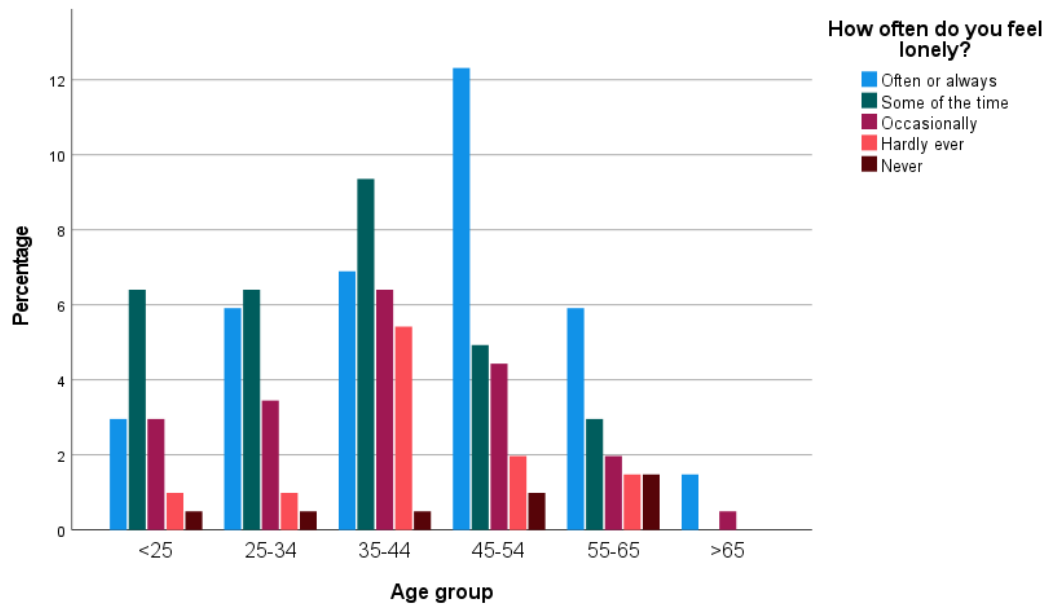
Figure 3.1. Reported frequency of loneliness by age group on the direct measure

To further examine the impact of individual differences on loneliness scores, multiple hierarchical regression was used. Since the three loneliness measures were correlated, total scores on any of three loneliness measures or a composite loneliness measure could have been used as the dependent variable. Instead, I selected the UCLA scale, for consistency across different analyses in my thesis (as this was the only measure on which I could look at reliable change over time, as will be discussed in Chapter Five, Section 5.2.5). For multiple hierarchical regression, I checked that my sample size was large enough given the numbers of predictors I entered into the models. Field (2018) recommended a sample size of 77 when entering up to 20 predictors and expecting a large effect, a sample size of 160 or more when entering up to 20 predictors and expecting a medium effect, and to avoid using regression analysis when expecting a small effect. As I expected a medium to large effect (based on my hypotheses, which were firmly grounded in previous research), my sample size (n=203) was large enough with the nine predictors I was entering into the model. Furthermore, key statistical tests (i.e., Durbin-Watson,

tolerance, VIF, plots of standardised residuals and predicted standardised values,

Cook's and Mahalanobis distances, standardized DFBetas, leverage, and

standardised residuals) were conducted to ensure that data met assumptions of

regression and that no cases had undue influence on analyses (see Appendix 3.2 for

a summary of the statistical checks for regression).

 First, I entered the predictors that previous research frequently reported as

factors associated with increased loneliness *both* in the general population and

autistic adults: anxiety (having anxiety versus not having anxiety) and, depression

(having depression versus not having depression). Second, I entered the following

variables, which previous research reported as factors associated with increased

loneliness *only* in the general population: gender (female versus other genders),

living arrangement (living alone versus living with others), relationship status (being

single, divorced/separated versus being married or in a relationship), employment

(not employed and not in education versus other employment status), highest

educational qualification (not having university qualifications versus having university

qualifications and above), location of growing up (having grown up in another country

[and living in the UK at the time of the survey] versus having grown up in the UK [and

living in the UK at the time of the survey]), and age[20]. As repeatedly trying different

groupings of continuous variables is best to be avoided (Harrison & Pius, 2021), age

was entered as a continuous variable. Age was entered in model 2 because entering

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[20] I did not enter age of diagnosis as a predictor 1) because it is actually how long one has been diagnosed as autistic that needs to be considered and 2) because previous research has not reported a clear association between how long one has been diagnosed as autistic and increased loneliness. Indeed, among autistic adults, those who were newly diagnosed as autistic reported the highest rates of suicidal ideation (Cassidy et al., 2014) and Chapter Two reported that suicidal ideation is associated with increased loneliness. This again shows that 1) it is the length of time that has passed since their autistic diagnosis that could potentially be associated with increased rates of suicidal ideation and loneliness, not age of diagnosis itself, and that 2) there is only a tenuous association between how long it has passed since one's autism diagnosis and increased loneliness.

age as a predictor could only be determined after looking at Figure 3.2 (i.e., not based on previous research).

Model 1 (including anxiety and depression) explained 6% of the variability in loneliness scores, $F(2, 200)$ =6.37, p=.002. Adding gender, living arrangement, relationship, employment, highest educational qualification and location of growing up in model 1, 20% of variance was explained, $F(9, 193) = 7.42$, $p<.001$. As seen in Table 3.11, being single, divorced or separated and being older statistically significantly predicted higher scores of loneliness on the UCLA scale ($p<.001$). Anxiety, depression, gender, living arrangement, employment, highest educational qualification, and location of growing up were not statistically significant predictors of loneliness in model 2.

Table 3.11. Linear model of predictors of loneliness in autistic adults

	b	SE B	B	P
Model 1				
Constant	58.20	.92		.00
Anxiety	1.51	2.09	.06	.47
Depression	4.59	2.01	.20	.02
Model 2				
Constant	45.64	3.00		.00
Anxiety	1.41	1.95	.06	.47
Depression	5.14	1.84	.22	.01
Gender	-1.05	1.38	-.05	.45
Living arrangement	-.70	1.91	-.03	.72
Relationship	8.13	1.93	.38	.00
Employment	1.21	1.77	.05	.49
Highest educational qualification	-.75	1.9	-.03	.61
Location of growing up	1.29	2.18	.04	.55
Age	.22	.06	.25	.00

3.3.4 Qualitative data: Autistic adults' views on the loneliness measures

As a general point, some respondents noted the uncomfortable nature of loneliness questionnaires: "It might be upsetting to answer for someone who doesn't have a partner or a good relationship with their family" (P18). More specifically, however, if participants *had to* complete loneliness scales, they tended to prefer the UCLA scale: "it [UCLA scale] was more specific and I could understand the questions better [than SELSA]" (Participant 10; henceforth P10). There was, however, a clear need for adjustments to make either questionnaire suitable for use with the autistic population. Taking comments across both loneliness measures, six themes were identified (see Figure 3.3). Next, I will present each theme in details (sub-themes are in bold italics). Quotes are presented verbatim, including any spelling/typographic errors, and where necessary, I provided supplementary explanations in brackets.

Theme 1: Failing to distinguish between the characteristics/experiences of loneliness and the characteristics/experiences of autism

Theme 2: What about camouflaging?

Theme 3: Underlying assumptions on views and experiences of loneliness

- *Being alone was a negative experience that contributes to feelings of loneliness*
- *The desire for social relationships and its association to loneliness*
- *Limited representation of relationships*

Theme 4: Failing to reflect the contextual and time-dependent nature of loneliness

Theme 5: Unclear wording made it difficult to respond

Theme 6: Formatting/user-experience issues

- *The response options themselves were not adequate*
- *Compound questions were difficult for respondents to answer accurately*

Figure 3.2. Thematic map of autistic adults' views on the loneliness measures

Theme 1: Failing to distinguish between the characteristics/experiences of loneliness and the characteristics/experiences of autism

In the UCLA scale, participants felt some items were associated with being autistic rather than being lonely. For example, in relation to question 9 (how often do you feel outgoing and friendly?) one participant explained: "I feel this highlighted more issues due to my autism and how that linked to my social relationships" (P110); in relation to question 6 (how often do you feel that you have a lot in common with the people around you?) a participant explained: "I never have a lot in common with people around me because they aren't ND [neurodivergent] and don't share my way of looking at the world. That doesn't mean that I'm lonely, it's just a statement of fact!" (P61); and in relation to question 13 (how often do you feel that no one really knows you wel1?), another participant detailed: "Answering 'often' to q.13 might look like I'm lonely, but I've never felt like anyone understands me and I have no expectation that anyone will" (P66). In relation to a particular item on the SELSA, many participants pointed out that not feeling "in tune" with others is what they recognize as a natural status from being autistic, and many autistic adults did not associate not being "in tune" with others with loneliness: "Not feeling "in tune" with others is more of an autistic thing than a loneliness thing for me" (P125).

Theme 2: What about camouflaging?

In the UCLA scale, some respondents explained that the questionnaire does not consider the fact that autistic adults may use camouflaging as a way to "fit in" with the neurotypical population, therefore skewing some of the results. For example, one participant explained: "I can find companionship by not being me and bending to others passions and interests; it's comfortable but doesn't remove loneliness" (P210); another participant explained "It really difficult because I am able to do a lot

of those things, however I don't enjoy them, I don't want to do them but feel as though I have to so that I am considered 'normal' Its draining" (P40). Likewise, on the SELSA, participants explained how difficulties in distinguishing between their real feelings and masking made it difficult for them to answer questions. A participant explained: "I also struggled with some of these questions because it's hard to unpick how I feel and how I perform "feeling". I'd struggle to say I don't feel part of my family because being part of my family [is] how society expects me to feel" (P140).

Theme 3: Underlying assumptions on views and experiences of loneliness

Both on the UCLA and SELSA questionnaires, autistic adults reported that there was an underlying assumption that ***being alone was a negative experience that contributes to feelings of loneliness***. In relation to the UCLA scale, participants explained how this assumption was not always the case and lamented how there was no way to reflect that this was a personal choice in the questionnaire. For example, one participant explained: "It assumes that everyone wants to be sociable and that they derive pleasure from the company of others. Some of us don't. Or don't all the time" (P100). Some participants noted that such assumptions could lead to inaccurate results. A participant explained: "where it says "How often do you feel isolated from others?", I've said "Often", but for me that's the goal. Managing to avoid other people is success to me, but I think someone reading this survey would possibly read my answer as a negative instead of the positive I see it as" (P46). Further, in relation to the SELSA, participants indicated that being alone is not necessarily the same as being lonely, and many respondents were happy to have no friends/one good quality relationship. For example, a participant explained: "It assumes that aloneness is loneliness. They're not the same thing" (P101).

In both questionnaires, participants also commented on underlying assumptions made about ***the desire for social relationships and its association to loneliness***. In the UCLA scale, the participants expressed that response options should be able to capture the fact that one may not have a desire to have lots of friends/partners or want to engage in such relationships. As such, a lack of this does not affect them in the same way that it would for those who desire such relationships. For example, a participant explained: "The questions appear to be completely ignoring the fact that I may be taking steps to actively avoid people" (P171). Likewise, on the SELSA, participants explained how many questions assumed that the respondent wanted to have friends/groups of friends/romantic partners and there was the underlying assumption that somebody who does not have these things is therefore lonely. A participant explained: "they referred to a group of friends and although I have several friends they are not a group together but I am happy with this" (P62).

Participants noted that the questionnaires presented a ***limited representation of relationships***, reflecting an assumption that loneliness is associated with certain types of social relationships. In the UCLA scale, for example, it was highlighted that the questionnaire did not consider relationships that were not in close physical proximity (i.e., online friendships) but which may still play an important role in reducing feelings of loneliness. For example, a participant detailed: "it's hard to answer this because my best friends are online friends" (P89). In addition to online relationships with others, autistic adults mentioned that the questionnaire did not consider non-human relationships. A participant explained: "I think pets can help reduce loneliness" (P23). In relation to the SELSA, participants also commented on the limited representation of relationships linked to loneliness in the

questionnaire. For example, in relation to formal support networks, one participant explained: "Some of my contact with supportive others is from professionals and not informal social networks" (P85); in relation to long-distant relationships, a participant explained: "I feel that this section doesn't account long distance friendships" (P105); in relation to relationships with non-human agents, another participant described "I also am less lonely because I'm around my pets, and that isn't considered here" (P23).

Theme 4: Failing to reflect the contextual and time-dependent nature of loneliness

In the UCLA scale, specifically, participants felt that the questionnaire did not consider more contextual relationships (e.g., work colleagues) and the role they play in loneliness. Participant explained that loneliness can change depending on who they are with. For example, one participant explained: "At work (both my paid work and my voluntary work) I tend to feel supported by those around with and we have a common interest but they are not my friends" (P36). Further, the UCLA scale was not felt to account for how feelings of loneliness can change depending on the context. A participant explained: "A lot depends on the mood or situation of others at the time when I'd like their support" (P63). Participants also explained how loneliness will change over time. For example, one participant explained: "My experience of loneliness is very different now to when I was a child. Now I am happily married although I have few friends other than my wife. In my childhood I mostly had no friends at all" (P18). In relation to the SELSA, respondents also reported that the questionnaire did not consider the contextual time-dependent nature of loneliness, as these factors can contribute to feeling less lonely. For example, a participant

explained: "feelings can vary according to life experiences, and day to day ups and downs" (P135).

Theme 5: Unclear wording made it difficult to respond

In the UCLA scale, participants noted a lack of clarity around the undefined term "people". Whilst some participants liked how the questionnaire referred to "people" as opposed to specific relationships (e.g., family/friends/romantic relationships), many felt that this led to a loss of nuance regarding individual relationships. For example, one participant explained: "I am being asked to judge all people as the same. I feel in tune with other autistic activists. I am not in tune with the general population." (P85). Respondents also highlighted that putting all relationships together may skew the results of the survey (i.e., they may score very highly as they have one particularly good relationship but still feel lonely as they lack other relationships). A participant described: "I have an amazing husband who supports me in all of the above which is why I've put sometimes. Outside of him I would have answered most of the questions more negatively." (P98).

Participants noted that they generally preferred the fewer response options found on the UCLA measure (compared to the SELSA), but pointed out some unclear wording. For example, in relation to some items that used the term, "around you", one participant explained: "what does "around me" mean? With my mum? At the shops? On the Internet? I don't understand this questionnaire and feel like it could fail to capture my experience" (P60); in relation to question 1 (how often do you feel that you are "in tune" with the people around you?), a participant explained: "Firstly, some autistic people might have issues with 'in tune' - this isn't a questionnaire about group music-making" (P91). It should be noted, however, that one participant felt that the questionnaires were "worded well" (P45).

In relation to the SELSA, autistic adults pointed out that to whom the term "family" applies is unclear. Respondents highlighted that experiences with different specific people vary massively and it was therefore unhelpful to put them all under the same category (e.g., grouping children, parents, cousins, grandparents under the broad term "family"). For example, one participant explained: "When it talks about family, for me that's my mother. As an adult man this probably isn't what the questionnaire means to ask about. I wish I had a family - a wife and kids, but this isn't captured by the questionnaire" (P60). Instead, participants felt that questions should target specific members (e.g., give a clear explanation who family is referring to) or give the option for free text. A participant detailed: "all questions should be worded absolutely as clearly as possible so there is as little room for multiple interpretations of the question as possible and answer options should also be as clear as possible" (P171).

In relation to the SELSA, participants also mentioned that to whom the term "friends" refers to is unclear. A participant described: "would appreciate it if the terms used were defined more clearly, for example should I be including my girlfriend as a friend?" (P183). Respondents felt that the questionnaire failed to capture their overall experiences of friendships and its association to loneliness. For example, one participant explained: "Having a good friend group but feeling misunderstood in social or support groups. I often feel like an odd one out in autism support groups but feel like I can share more personal experiences with friends who share my demographics" (P118)

Theme 6: Formatting/user-experience issues

In the UCLA scale, whilst respondents generally preferred the fewer response options of this questionnaire (compared to the SELSA), many noted that ***the***

response options themselves were not adequate. For example, one participant detailed: "what exactly is the difference between often and rarely? Does never really mean never? Or is it a fuzzy never?" (P60). Further, participants felt that there were situations where their real experiences could not be explained using the four terms that were provided. To solve this, respondents suggested using a 10-point scale (1-10) or even just providing clearer definitions (i.e., sometimes = happens 50% of the time). Further, participants felt some items were not applicable to them and expressed a need for a 'not applicable' option. For example, in relation to the questions about friendships, one described: "I had to answer a few questions As If I didn't have a close friend... I sort of wished for a 'Not Applicable' option for the questions!" (P137); in relation to question about romantic relationships, another participant illustrated: "Some of the questions were not applicable to me as I do not have a partner. A n/a option might be helpful" (P178).

In the SELSA, **compound questions were difficult for respondents to answer accurately**. This was particularly salient with questions concerning romantic partners, whereby those without a romantic partner were unsure how to appropriately answer the question as their answer could be perceived in two ways: either that they were dissatisfied with their relationship or that they did not have a romantic partner. For example, one participant described: "I had to put strongly disagree for all of the romantic relationships ones as I am not in a relationship. This should not have been asked for single people" (P32). Further, participants felt compounds questions were also problematic for questions regarding friendships. For example, a participant explained: "These are two separate statements that I felt I'd like to comment on separately 1) not having friends I felt close to 2) wishing I did.

Though I don't think it affected my scoring I didn't like having to give a single answer to two statements at once" (P140).

3.4 Discussion

To the best of my knowledge, this is the first study that has investigated the appropriateness of existing loneliness measures for autistic adults both quantitatively and qualitatively. Confirming previous findings, autistic adults in the current study were found to experience increased loneliness when their scores were compared to loneliness scores reported by the general population (in previous studies). Further, several factors were found to be associated with increased loneliness in my sample. For example, autistic adults who experienced increased loneliness tended to be older in age, and not with a romantic partner. The UCLA scale and SELSA corelated with the direct measure of loneliness, suggesting that they align with autistic adults' subjective experiences of loneliness. However, qualitative data reported that autistic adults felt both measures were difficult for them to complete in multiple ways. These findings suggest further investigation may be needed to potentially adapt measures of loneliness to make them more acceptable for autistic adults.

The findings from this study appeared to corroborate existing studies suggesting higher levels of loneliness in autistic adults compared to the general population as reported in my systematic review (i.e., Chapter Two). Another systematic review and meta-analysis investigating loneliness in autistic adults and children (published after mine, Umagami et al., 2022), also reported higher levels of loneliness in autistic people compared with non-autistic people (Hymas et al., 2022). Furthermore, this study contributed to the studies showing what factors make autistic adults especially vulnerable to loneliness. Among autistic adults in this sample, being

single, divorced or separated and being older were predictors of increased

loneliness. While relationships or age has not been previously identified as factors

associated with increased loneliness in autistic adults (see Chapter Two , Section

2.3.4), they have been reported as factors associated with increased loneliness in

the general population (Lim, Eres, et al., 2020; Office of National Statistics, 2018).

Autistic adults in this study were largely employed or in education and had gained

higher educational qualifications. Such characteristics in individuals might have

made them appear "capable" (i.e., having fewer needs) and not likely candidates for

support. Indeed, autistic people could face various challenges in adulthood as a

result of being perceived as having fewer needs and receiving fewer support (Kapp,

2018). Therefore, for this sample of autistic adults, one could argue that support from

a partner and/or family members might have been increasingly highly valued and a

lack of such support led to increased loneliness. Support from others could be

considered particularly important with aging, since the parents of autistic adults will

age with their children and their capability for support may become less with aging.

This study reported a correlation among the UCLA scale, SELSA, and the

direct measure of loneliness, whereby the UCLA scale and SELSA aligned with

autistic adults' subjective experiences of loneliness. Yet autistic adults described the

nuance in how these loneliness measures might overlook their actual experiences of

loneliness. The key issues of the loneliness measures highlighted were: 1) not

reflecting autistic experiences, and 2) being unclear in how the questionnaires are

worded. Importantly, these key issues have also been identified in other

measurement studies outside of loneliness research (Cassidy, Bradley, et al., 2020;

Mason et al., 2022; Nicolaidis et al., 2020).

First, autistic adults in this study reported that the UCLA scale and SELSA did not reflect autistic experiences (i.e., themes 1, 2, and 3). This key issue has also been highlighted in other measurements outside of loneliness research. In their review of studies that adapted survey instruments for autistic adults, Nicolaidis et al. (2020) reported that the common issues with the existing measures included that they did not capture autism-specific aspects of the constructs (e.g., not considering sensory barriers in accessing healthcare). In the field of quality of life, Mason et al. (2022) reported that autistic adults interpret some items on the WHOQoL-BREF differently from the general population. In their discussion groups, autistic adults reported that the issues with the WHOQoL-BREF included that it did not consider their sensory experiences and that it did not consider they might have few or no friends. In the area of suicidality, Cassidy, Bradley, et al. (2020) reported that autistic adults interpret some items on the SBQ-R differently from the general population. In their cognitive interviews, autistic adults reported that the issues with the SBQ-R included that the response options did not reflect their experiences (e.g., the option, "very often (five or more times)" was confusing since "very often" meant more than five or more times for autistic adults), and that one item was not relevant to their experiences (e.g., the item asked whether they have communicated their suicidal thoughts to others, which was considered irrelevant in terms of their suicidality by autistic adults).

Second, autistic adults in this study reported several ways in which the UCLA scale and SELSA were unclear in how the questionnaires were worded (i.e., themes 4, 5, and 6). This was also not an exclusive concern identified in loneliness measures. In addition to not reflecting autistic experiences, another set of common measurement issues reported in Nicolaidis et al. (2020) was about the wordings in

the questionnaires. This included difficult terms/phrases/sentence structure, unclear response options, insufficient instructions/response options (which was the underlying causes of anxiety to answer accurately), and unspecific instructions about the item (which was the underlying cause of no room to reflect varying responses in different situations). In quality of life (Mason et al., 2022), autistic adults reported that some terms and phrases were unclear, which Mason et al. (2022) reported that the items did not consider autistic adults' literal interpretations (e.g., the term, "get around"). In suicidality Cassidy, Bradley, et al. (2020), autistic adults reported that some items and response options were unclear about their meanings (e.g., response options of "never" and "no chance at all" were difficult to distinguish).

To address the first key issue of not reflecting autistic experiences, previous studies have developed autism-specific items or adjusted wordings in the items and/or response options to adapt the measures for autistic adults (Cassidy et al., 2021; McConachie et al., 2018; Nicolaidis et al., 2020; Rodgers et al., 2020). To address the second key issue of being unclear in how the questionnaires are worded, previous studies have made the items and/or response options clearer and/or more specific to adapt the measures for autistic adults (Cassidy et al., 2021; McConachie et al., 2018; Nicolaidis et al., 2020; Rodgers et al., 2020). Sometimes, these changes included creative methods such as adding graphics and hotlinks (Nicolaidis et al., 2020).

Autistic adults in this study generally preferred the UCLA scale over SELSA, therefore, I recommend the UCLA scale as a potential measure to start adapting for autistic adults. Nonetheless, it is important to note that the UCLA scale and the SELSA are fundamentally different measures of loneliness. While the UCLA scale is a unidimensional measure assessing loneliness as a global construct, the SELSA is

a multidimensional measure assessing several dimensions of loneliness with three subscales: romantic subscale (i.e., assessing intimate loneliness in Cacioppo et al., 2015), family and social subscales (i.e., assessing relational loneliness in Cacioppo et al., 2015). Although the SELSA has subscales assessing different aspects of loneliness, autistic adults still felt their underlying experiences of loneliness were not reflected in the measure. The simplicity of the unidimensional measure (i.e., UCLA scale) appeared to have been preferred by autistic adults. Based on how previous studies addressed the key issues in the existing measures, Table 3.12 presents initial ideas about how the UCLA scale could be adapted for autistic adults. It is essential to note that the some of the concerns raised by autistic adults (i.e., identified themes 3, 4, 5, and 6) could also apply to non-autistic people (while more so for autistic adults) and the adaptations considered in this Chapter could also be helpful to adapt when using the measures with non-autistic people too. The suggested adaptations will need further discussion and development with the autistic community (as per Nicolaidis et al., 2020), but this will be a goal for future work.

Table 3.12. Suggested adaptations for the UCLA scale

Themes identified in this study (see Figure 3.2)	Adaptation	Example		Was there a specific reference point for the suggested adaptation?
		Concern	Suggested adaptation	
Failing to distinguish between the characteristics/experiences of loneliness and the characteristics/experiences of autism	To add a follow-up question in every item to ask whether the items are indexing their experiences of loneliness.	Autistic adults felt that some items were more about being autistic rather than being lonely.	"Is your response to this question related to your experiences of loneliness? (yes or no) If no, please explain why."	Referred to the adaptation made in Cassidy et al. (2021) to address the issue that an item did not consider that autistic people may not routinely share their suicidal thoughts to others but still experience them
What about camouflaging?	To add an instruction in the preface that specifies the condition under which autistic adults should consider the items.	No instruction specified the conditions in which the respondents should consider the items.	"Please consider the following items when you are being yourself without conscious efforts to 'fit in' with others"	Referred to the adaptations made in Cassidy et al. (2021) and Nicolaidis et al. (2020) to address the issue that the time-scale was not clear
Underlying assumptions on views and experiences of loneliness	To add the conditions in the items to specify the situations to	There was an assumption that being alone was a negative	Question 4 will ask "how often do you feel alone when you do not	Referred to the adaptations made in Cassidy et al. (2021) and

consider in responding to the items.	experience that contributes to feelings of loneliness. This was particularly about question 4 (How often do you feel alone?) and question 14 (How often do you feel isolated from others?)	want to?", question 14 will ask "how often do you feel isolated from others when you do not want to?"	Nicolaidis et al. (2020), but none was a specific reference to the suggested change
To add a follow-up question in every item to ask whether the items are indexing their experiences of loneliness.	Autistic adults felt that there was an assumption that the desire for social relationships and its association to loneliness	"Is your response to this question related to your experiences of loneliness? (yes or no) If no, please explain why."	Referred to the adaptation made in Cassidy et al. (2021) to address the issue that an item did not consider that autistic people may not routinely share their suicidal thoughts to others but still experience them
To explain in the instruction that the relationships could be online or with non-humans.	Autistic adults felt that limited variations of relationships were represented in the original measure. (online	"In considering the questions, feel free to consider any kinds of relationships you may have in your life. They could be	Referred to the adaptations made in Cassidy et al. (2021) and Nicolaidis et al. (2020), but none was a specific

		relationships were not considered)	those that are close in proximity, online, or with non-humans."	reference to the suggested change
	To add an open-box to allow respondents to explain what they felt were not captured in the measure		"If you are not sure about how to answer a question, please make your best guess and move on to the next question. If you would like to, you can write comments in the comment box below. (Note: information you choose to provide in the comment box will be read, but it will not be considered an answer to the survey questions.)"	Retrieved from the adaptation made in Nicolaidis et al. (2020) to address the issue that autistic adults felt anxious about whether they could accurately answer the questions
Failing to reflect the contextual and time-dependent nature of loneliness	To add an instruction in the preface to specify the context and time-scale to consider.	No instruction in the original measure was about the context and timescale to consider.	"Please consider your experiences during the last month."	Referred to the adaptations made in Cassidy et al. (2021) and Nicolaidis et al. (2020) to address

				the issue that the time-scale was not clear
Unclear wording made it difficult to respond	To add an open-box to allow respondents to explain what they felt were not captured in the measure.	The term, "People" in questions 1, 6, 10, 16, 18, 19, 20	"If you are not sure about how to answer a question, please make your best guess and move on to the next question. If you would like to, you can write comments in the comment box below. (Note: information you choose to provide in the comment box will be read, but it will not be considered an answer to the survey questions.)"	Retrieved from the adaptation made in Nicolaidis et al. (2020) to address the issue that autistic adults felt anxious about whether they could accurately answer the questions
	To replace and clarify the phrase.	The phrase, "around you" and "in tune" in questions 1 (how often do you feel that you are "in tune" with the	Question 1 (how often do you feel that you understand and are understood by the people in your life), question 6	Referred to Merriam-Webster (n.d.) about the meaning of "in tune": "in a state in which people agree with or

		people around you), "around you" in 6 (How often do you feel that you have a lot in common with the people around you), 8 (how often do you feel that your interests and ideas are not shared by those around you), 18 (how often do you feel that people are around you but not with you)	(how often do you feel that you have a lot in common with the people in your life), question 8 (how often do you feel that your interests and ideas are not shared by the people in your life), question 18 (how often do you feel that people are close in proximity but that you are alone)	understand one another" (no definition of "around you" could be obtained from trustworthy resources)
Formatting/user-experience issues	To add explanation of each response option to the preface of the measure in parenthesis	Response options: "never", "rarely", "sometimes", "always"	("never" means around 0% of the time, "rarely" means around 10% of the time, "sometimes" means around 50% of the time, "always" means around 100% of the time.)	Referred to the adaptation made in Nicolaidis et al. (2020) to address the unclear/undefined response options
	To add an additional response option and open-	No "not applicable" option was in the original measure.	To add additional response option of "not applicable	Participants suggested this

text box for respondents to further explain their response	(please explain why)" and open-text box to explain why the item was not applicable to the respondents.	change in the current study

Limitations

There are some limitations to this study that need to be acknowledged. First, autistic adults in this study were likely to be a non-representative sample. For example, this study has a high rate of White participants (i.e., 90.1%) and this is higher than the proportion of the White ethnic group in the UK's whole population (i.e., 78.4%) (Office for National Statistics, 2021b). While there is a lack of evidence in how ethnicity is associated with the prevalence of autism (Elsabbagh et al., 2012), generalization of the findings may be limited. Nonetheless, I made efforts to include diverse autistic adults where possible by reaching out to BAME and LGBTQ+ groups. Further, participants in this study were predominantly female and this may also limit the generalization of the findings since autism is more commonly diagnosed in males (Loomes et al., 2017). Also, most participants (69%) had gained university qualifications, and they would not be the representative of all autistic adults given that autistic people often struggle to complete university (Gurbuz et al., 2019; Newman et al., 2011). Finally, most participants (93.1%) used spoken language to communicate and thus this study may not represent the experiences of loneliness felt by autistic adults who use alternative communicative tools (e.g., sign language, communication devices). Despite the aforementioned limitations, the participants I had in my sample were an important group to explore loneliness within because research has shown that autistic individuals without intellectual disability who can communicate verbally are likely to be seen as "too 'normal' to be different and, equally, too 'different' to be 'normal'" and their support need is often underrecognized (Crane, Adams, et al., 2019, p. 484). Furthermore, it is equally important to note that this issue of sample representation is also common in many other studies on autism, as reported in Chapter Two.

Second, I acknowledge that using online surveys might have excluded some autistic adults. For example, autistic adults who did not have access to the Internet were likely not to be able to take part in this study. Also, people tend to participate in survey studies on the topics of their interests (Groves et al., 2004) and my participants might have been those who were more aware of their experiences of loneliness and/or were lonelier compared to the broader autistic population. Rubenstein and Furnier (2020) described the challenges in autism research studies where participants are recruited online as in this study, and reported that aforementioned selection biases are common in autism research using online methods (Rubenstein & Furnier, 2020). Nonetheless, on this sensitive topic of loneliness, online surveys might have worked well for those who would find it difficult to share their underlying experiences of loneliness otherwise (e.g., in interviews). Indeed, previous studies reported some benefits of online survey studies as opposed to other qualitative methods (e.g., no need to travel or communicate in person) (Braun et al., 2021) and these are particularly salient in autism research (Crane, Sesterka, et al., 2020).

Third, while the results of this study appeared to corroborate existing studies that suggested higher levels of loneliness in autistic adults compared to the general population, my sample was without a comparison group. Therefore, the general population groups that I compared my sample against were not well matched on key variables and the results need to be treated with a caution. However, the data from the general population could be used as a benchmark.

Fourth, the results from this study have to be taken with caution because one of the response options in the UCLA scale (i.e., "often") was worded differently from the wording in the original paper (i.e., "always") (Russell, 1996). This was not the

change I made myself, but instead of how the scale was presented in other existing resources for use in research (Fetzer Institute, n.d.). Nonetheless, this change in response options from the original paper might have had some influence on how autistic adults scored and commented on the scale. In hindsight, however, some participants in this study confirmed that the response option, "always" would be appropriate to include. For example, one participant explained: "Needs to be a descriptor beyond" often", i.e." always"" (P73). Future research should follow the scale presented in the original paper and have the response option of "always".

Fifth, it should be noted that I selected the loneliness measures (i.e., the UCLA scale and SELSA) in the online survey based on how frequently these had been used among autistic adults without consultation with autistic adults. Therefore, while autistic adults preferred the UCLA scale over SELSA, it is possible that autistic adults may prefer an entirely different loneliness measure from the UCLA scale when presented all existing options of loneliness scales. It should be noted that the paper by Nicolaidis et al. (2020) was published after the data in this study were collected, and therefore the process did not follow the exact steps recommended in Nicolaidis et al. (2020). Nevertheless, it is also worth noting that the process of measurement adaptation in this study mirrors the exact steps that the studies reviewed in Nicolaidis et al. (2020) took in adapting the measures (see Table 3.2).

3.5 Conclusion

To conclude, the research presented in Chapter Three examined 1) if and how accurately the existing measures of loneliness capture the experiences of loneliness in autistic adults, and 2) autistic adults' first-person accounts on their views/experiences of the frequently-used loneliness measures to identify whether

they need to be adapted for autistic adults and, if so, how. The UCLA scale and SELSA correlated with the direct measure of loneliness, suggesting that they align with autistic adults' subjective experiences of loneliness. However, qualitative data reported that autistic adults felt both measures were difficult for them to complete in multiple ways. The key concerns about the loneliness measures were 1) not reflecting autistic experiences (i.e., failing to distinguish between characteristics/experiences of loneliness and autism, not considering camouflaging, underlying assumptions on views and experiences of loneliness), and 2) being unclear in how the questionnaires are worded (e.g., not specifying the context/timescale, unclear terms/phrase, inadequate response options/sentence structure). These findings suggest the importance of further investigation to potentially adapt measures of loneliness to make them more acceptable for autistic adults. I have suggested some initial ideas in which these measures could be adapted for autistic adults, but they need further development in collaborative work with autistic adults. In the next Chapter (i.e., Chapter Four), I will report further data from the survey analysed in Chapter Three, more fully exploring autistic adults' first-hand experiences of loneliness.

Chapter Four

"Trapped in a no-win situation":

exploring the unique experiences of loneliness in autistic adults

4.1 Introduction

In Chapter Three, I evaluated existing loneliness measures for use with autistic adults. I identified that autistic adults feel that these measures do not fully capture their views and experiences of loneliness, despite the measures appearing to accurately measure their levels of loneliness. This finding suggests that there is a value in further qualitative investigations of the views and experiences of loneliness in autistic adults. Indeed, the latest tackling loneliness evidence review from the UK Department of Digital, Culture, Media and Sport (DCMS) (Qualter et al., 2022) identified the need to gain more understanding about the views and experiences of subgroups of people and specifically mentioned autistic people as a subgroup of people that require further exploration.

While there is a dearth of scientific evidence on the lived experiences of loneliness, they have been long described in autistic adults' autobiographies. Such autobiographical accounts explained loneliness as a distressful emotion arising from their unmet desire for social connections because of many social challenges they faced (e.g., sensory overwhelming environments and having to learn/conform to the social norm of non-autistic people; Bowman, 2021; Grandin & Scariano, 1986; Tammet, 2007). More recently, autistic adults have shared their experiences of loneliness through written blogs (e.g., Ambitious about Autism, n.d.), and more creatively through videos (e.g., Anja Melissa, 2017; Aspergers from the Inside, 2021) and arts (e.g., Farion, 2020). In addition to what autobiographical accounts already described, these accounts emphasized that some autistic adults desire social

connections while they also appreciate some alone time. There has been an emergence of qualitative research to understand autistic people's lived experiences of loneliness. As noted in Chapter Two, five existing studies have reported autistic adults' first-hand descriptions of loneliness (Ee et al., 2019; Elmose, 2020; Hickey et al., 2018; Smith & Sharp, 2013; Van Hees et al., 2015). These studies reported that some autistic adults desire social connection, though social interaction can be challenging. Further, these studies suggest that loneliness is a negative and persistent feeling for autistic adults, and not synonymous with being alone.

Despite five studies exploring the lived experiences of loneliness in autistic adults, only one study (Elmose, 2020) has exclusively investigated loneliness in autistic adults. Elmose (2020) investigated how autistic adults understand the concept of loneliness, specifically examining how an extensively used theoretical understanding of loneliness (Peplau & Perlman, 1982) makes sense for autistic adults. Elmose (2020) conducted four focus groups and confirmed their validity using four individual interviews. Participants were recruited from three informal and open networks via an organization for autistic adults in Denmark. In total, 25 autistic adults who self-reported their autistic diagnoses took part in the research. Introducing the research as a "shared investigation of loneliness" (Elmose, 2020, p. 7), the researcher presented autistic participants with a visual model of loneliness based on a definition of loneliness from Peplau and Perlman (1982) (i.e., loneliness is a negative feeling arising from the discrepancy between one's ideal and actual social relationships) and eight guiding questions as handouts. Elmose (2020) used the model of loneliness as a shared reference point, and guiding questions to ask about autistic adults' experiences of loneliness and social relationships, and how they might or might not be related to being autistic.

Using a thematic analysis approach inspired by Braun and Clarke (2006) and Miles et al. (2014), Elmose (2020) analyzed the data (assumably across focus groups and individual interviews though this was not clarified in the article) and identified four themes and nine sub-themes. Under the first theme of "experience of loneliness", Elmose (2020) reported that autistic adults' understanding of loneliness aligned with the loneliness definition of Peplau and Perlman (1982) and that autistic adults understand loneliness as a discrepancy between their desired and actual social relationships. Under the second theme of "being autistic as a frame of reference", Elmose (2020) reported that being autistic had a major influence on how autistic adults experienced loneliness and the underlying social relationships. Specifically, Elmose (2020) reported that autistic adults felt that it was challenging to socially interact with others, that they viewed and valued social interaction differently from non-autistic people, and that loneliness was inevitable due to the exhaustion from everyday activities (e.g., household chores, personal hygiene). Under the third theme of "discrepancies in relationships", Elmose (2020) reported that autistic adults felt that they were not being understood (or were being misunderstood) in social settings, were limiting the potential development of close relationships, and were masking in social interaction with others. Autistic adults reported that all of these factors caused their loneliness. Under the fourth theme of "ease of interaction", Elmose (2020) reported that autistic adults' experiences of loneliness were context-based. Specifically, Elmose (2020) reported that autistic adults felt lonely or not lonely depending on the opportunities available to access to social relationships. For example, living with a partner gave them social relationships in itself but also gave potential opportunities to interact with the partner's friends. Elmose (2020) also reported that shared interests and understanding made it easier for autistic adults to

make and maintain social relationships (e.g., being involved in interest groups, autistic communities). Likewise, being occupied with one's interests was a meaningful relationship for some autistic adults. Finally, Elmose found that some autistic adults used masking to 'fit in' and navigate the social relationships (to minimize feelings of loneliness) while others emphasized the importance of understanding and accepting oneself to feel less lonely.

The study reported in this Chapter differs from Elmose's (2020) study in two important ways: (1) methodology, and (2) positionality. In relation to methodology, I decided to use an online survey, while Elmose used focus groups and interviews. Online surveys were considered particularly useful for this study for two reasons. First, online surveys are especially suited when exploring sensitive topics which participants might feel reluctant to talk about in other qualitative study settings (e.g., individual interviews, focus groups) (Braun et al., 2021). Second, online surveys allow researchers to collect a wide variety of voices which could represent diverse perspectives or experiences on a given topic (Braun et al., 2021; Braun et al., 2017). Crane, Sesterka, et al. (2020) argued that using online surveys might enable autism research to include underrepresented voices (e.g., those who are not able to take part in social groups for autistic people, as in the study by Elmose, 2020). Investigating a range of voices is especially important when exploring an under-researched topic like loneliness in autism to provide a quality of data and appropriately inform practice (Braun et al., 2021). Online surveys remove some burdens which other qualitative methods (e.g., interview, focus groups) may impose on some participants (Braun et al., 2021) (e.g., no need to travel, no need to communicate in person), and this is especially the case in autism research (Crane,

Sesterka, et al., 2020). Such flexible and accessible nature of online surveys make the research more inclusive (Braun et al., 2021).

More importantly, to my knowledge, the current study is the first autistic-led study to qualitatively explore the experiences of loneliness in autistic adults. Not only was the researcher (i.e., myself) autistic, but six other autistic adults provided feedback on the final draft of the online survey to ensure the questionnaires were clear and meaningful for autistic adults (for details, see Chapter Three, Section 3.2.1). While Elmose's (2020) study was the first to exclusively investigate lived experiences of loneliness in autistic adults, the study reported no evidence of involving any autistic researchers in the research process. Grant and Kara (2021) recently argued that there are some advantages of including autistic researchers in qualitative research. Specifically, autistic researchers bring some helpful qualities including: long-term concentration (i.e., hyper-focus), creative thinking, attention to details, and depth of knowledge in one's area of interests (Grant & Kara, 2021).

In this Chapter, I aimed to explore the unique experiences of loneliness in autistic adults. More specifically, I investigated autistic adults' lived experiences of what loneliness feels like, how they deal with loneliness, what helps them with loneliness, and if and how their experiences of loneliness changes over time. Exploring these issues could be an important step 1) to consider and develop autism-specific items for loneliness measures (building on Chapter Three) and 2) to build autism-specific pathways to loneliness (Chapter Two identified no existing studies reporting them), both of which are necessary for identifying and taking actions in alleviating/preventing loneliness in autistic adults.

4.2 Methods

4.2.1 Design

In Chapter Three, I explained how I designed and used an online survey to collect data on autistic people's scores and views on widely-used measures of loneliness, as well as their definitions and experiences of loneliness (see Appendix 3.1 for the whole survey). Only data pertaining to definitions and experiences of loneliness are presented in this Chapter.

It is important to note that I designed my study throughout 2019 and the study by Elmose (2020) was published in June 2019. As such, this study was designed independently from that of Elmose (2020) and I was not aware of the work until my survey was already underway and I began working with the data. In the Table 4.1, I summarise key methodological differences between the current study and that of Elmose (2020). Since cultural backgrounds influence the experiences of loneliness (Barreto et al., 2021; Rokach et al., 2001), the difference in geographical locations is also important to be noted.

Table 4.1. Key differences between the current study and Elmose (2020)

	Current study	Elmose (2020)
Methodology	Online survey	Focus groups and interviews
Recruitment of participants	Widely via social media, and also via contacting UK-based organizations and social groups for autistic adults and the CRAE database	Via the Danish networks for autistic adults which organize biweekly meetings (which autistic adults self-enrolled themselves)
Positionality	The study was led by an autistic researcher and included/reflected autistic voices in finalizing the online survey.	There is no sign of autistic individuals' involvement in the study.
Geographic locations	The UK	Denmark

4.2.2 Participants

The sample in the current study is the same as that presented in Chapter Three. For participant demographics, please refer to Table 3.1.

4.2.3 Materials

From the online survey described in Chapter Three, the following questions are relevant to data presented in this Chapter.

Definition of loneliness

Participants were asked to provide their definitions of loneliness using an open-text box. Then, also using an open-text-box, they were asked to provide their opinions on a definition of loneliness often used by researchers: "loneliness is an unpleasant experience caused by reductions in the quality and quantity of social relationships and the discrepancy between one's ideal and existing social relationships" (Perlman & Peplau, 1981). While Elmose (2020) also explored definitions of loneliness in autistic adults with a reference to a widely-used definition of loneliness (Perlman & Peplau, 1981), this was considered important to explore again in a different sample. More importantly, the aim was for this definition to act as a reference point for the autistic adult participants, especially those who may have found it difficult to articulate their experiences of loneliness.

Views and experiences of loneliness

Participants were asked to respond to a series of questions about how loneliness affects them, how they deal with loneliness, what helps them with loneliness, and if and how their loneliness has changed over time. This initial development of the questions pre-dated the publication of Elmose (2020), and some questions overlapped with the guiding questions used in Elmose (2020) (i.e., how loneliness affects autistic adults, what helps them with loneliness). However, those questions were considered important to explore in a different sample using a different method. To further explore the management of loneliness in autistic adults, the survey also asked how participants currently deal with loneliness. Following the feedback from

autistic adults on the final draft of the survey, some questions were added (i.e., how their experiences of loneliness has changed over time [not explored in Elmose (2020)], if there was anything else they would like to add). The responses to the questions were optional and included[21]:

1) How does loneliness affect you? If you prefer, please feel free to describe a specific situation you have felt lonely

2) When you are feeling lonely, how do you usually deal with this (e.g., is there anything you do that makes you feel more/less lonely)?

3) If loneliness affects you, do you have any ideas about what might help you feeling less lonely?

4) Has your experience of loneliness changed over time? If so, how?

5) Is there anything else you want to mention regarding loneliness?

4.2.4 Procedure

The survey was administered as per the description provided in Chapter Three. As before, ethical approval was granted via the Department of Psychology and Human Development at IOE, UCL's Faculty of Education and Society. All participants gave informed consent before taking part.

4.2.5 Data analysis

As per the other Chapters of my thesis, data were analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2019; Clarke & Braun, 2013). My aim was to identify patterns across the data regarding autistic adults' unique autistic

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[21] There was an additional question asked to participants about what their priorities of future loneliness research are. The exact question was the following: if you think it's important to have more research on loneliness in autism, what should this focus on. The intention of this question was to guide subsequent studies of my thesis. However, because of the COVID-19 pandemic, the decision was made to do a follow-up COVID-related study as presented in Chapter Five. Nevertheless, the participants' responses to this question could be important and helpful for the future work on loneliness in autistic adults and will be discussed in Chapter Six.

experience of loneliness. Braun et al. (2021) recommend analysing participants'
responses to online qualitative surveys across the data, not question by question. I
completed the analysis independently following Braun and Clarke's six steps:
familiarizing myself with the data; coding the data; identifying the themes; developing
the themes, refining the themes; and producing a report (See Table 4.2 for full
details; Braun & Clarke, 2006, 2021). At the time of the analysis, a research
assistant at CRAE also independently coded the data to assist me as I was a novice
researcher in reflexive thematic analysis. However, among all reflexive thematic
analyses in my thesis (i.e., in Chapters Three, Four, and Five), this was the last
analysis I conducted and my confidence in this method of analysis grew to be able to
undertake this more independently. As a result, I completed this analysis on my own
without her assistance/inputs. After identifying themes, I met with my supervisors
(Dr. Laura Crane and Professor Anna Remington) several times to further develop
and refine themes. My supervisors have been involved in the autism community as
allies. I analysed the data from inductive, semantic, and critical realist approaches
(Braun & Clarke, 2021). Taking an inductive approach meant that codes and themes
were grounded in the data. A semantic approach meant that codes and themes
reflected the meaning of the data. Taking a critical realist approach meant that codes
and themes were developed to report participants' views and experiences as reality
without assumptions. Here, it is important to note that I am autistic myself and have
been involved in the autism community as a self-advocate, because of the analysis'
reflexive nature (Braun & Clarke, 2019; Clarke & Braun, 2013). Grant and Kara
(2021) argued that being autistic is a great asset in qualitative research and that their
creative thinking is particularly beneficial in the analysis. As an autistic self-advocate,
I view autism from a social model and within a broader neurodiversity perspective,

and think that autistic people simply experience the world differently from the majority of people. I explained more details on my positionality in Chapter One, Sections 1.1.1. and 1.2.1.

As part of my reflexive practice, I reflected very carefully on my assumptions about the data (Braun & Clarke, 2013). This bracketing exercise included my supervisor asking me about to what extent some themes came from the data to ensure they are not in the findings merely because they personally resonate with myself. While this analysis was conducted to identify the patterns in the data regarding autistic adults' unique experiences of loneliness, as an autistic researcher, participants' narratives seemed familiar to my views and experiences and I could have missed important themes due to their familiarity to my perspectives (i.e., not identifying them as particularly 'unique' to autistic adults). Thus, in hindsight, the bracketing exercise was also an opportunity to reflect on whether there were any important themes I might have overlooked. To ensure the trustworthiness of the analysis and to warrant that my autistic experiences of loneliness do not influence my interpretation of the data, the process followed the recommendations from Nowell et al. (2017). For example, themes and subthemes were vetted and agreed by all who were involved in the analysis process (myself and two of my supervisors). Moreover, peer debriefing was sought via presentation of the initial data analysis and quotes to autistic and non-autistic researchers at CRAE, who were familiar with autism research, in April 2021. The feedback was positive and confirmed that the themes were clear and appropriate, reflecting the participants' voices. Additionally, autistic researchers commented that the themes also well reflect their own experiences of loneliness.

Table 4.2. Six steps in the thematic analysis

Step	Description

Step 1: familiarizing myself with the data	I exported the participants' responses from the Qualtrics, copied and pasted on a Word document. I familiarized myself with the data by repeatedly listening to them (using the 'read aloud' function on my laptop) and immersing myself in the data.
Step 2: coding the data	I added codes to the data by using the comment function on Word. Codes were often combinations of words, rather than sentences, and captured a single idea associated with a fragment of the data.
Step 3: identifying themes	Using a Word document, codes were then organized into possible themes by recursively engaging with the codes and their associated data. This step included creating a hand-written mind map to visualize possible themes and their associations to possible sub-themes.
Step 4: developing themes	In developing themes, I took notes of the themes, their descriptions, and example quotes (in a form of tables or bullet points), shared them with and sought feedback from my supervisors several times.
Step 5: refining themes	I then met with my supervisors several times to refine the themes. Some conversations here were for me to reflect on my assumption about the data and to ensure it does not shape my analysis. Other conversations here were to discuss how one theme differs from another, whether some themes could be merged, and whether there could be sub-themes under overarching themes. Before finalizing the themes, I also conducted peer debriefing and ensured the themes were clear, appropriate and reflective of participants' accounts.
Step 6: producing a report	Finally, I wrote up the results. Writing up the results included clearly explaining each theme, presenting example quotes, and narrating participants' accounts. Revising the results was an integrative process of seeking feedback from my supervisors and meeting them to discuss the feedback.

4.3 Results

Quotes are presented verbatim, including any spelling/typographic errors.

Four themes were identified (see Figure 4.1).

1. Internal conflict between the desire for, and barriers to, social connection

2. Barriers to connection for autistic adults

- *Sensory environments*
- *Lack of societal understanding and acceptance of autism*
- *Lack of shared understanding and experiences*

3. The importance of meaningful relationships

- *Connecting with similar others*
- *Spending time with pets/animals*
- *Reliance on one person and fear of losing that person*

4. Connecting with oneself

- *Understanding and accepting of oneself*
- *Accepting loneliness*

Figure 4.1. Thematic map of autistic adults' unique autistic experience of loneliness

Theme 1: Internal conflict between the desire for, and barriers to, social connection

Many autistic adults described an internal conflict between wanting to connect with others and finding social situations challenging: "I don't want to spend more time with people in person than I already do, because social situations make me anxious and often take place in environments that are intolerable to me on a sensory level. But I want to feel as if I am part of society and belong in society, which currently I don't" (Participant 243; henceforth P243). One participant described struggles with social interactions as "mentally and physically exhausting: painful even" (P19). As a result, autistic adults reported that they often avoided social situations (in their attempt not to feel lonely) while acknowledging that successful social interactions could yield the connection they desired:

"If I go out and am around people sometimes that exacerbates my feelings of not belonging. It feels like being in a glass box looking out at everyone rushing around getting on with their lives when I'm stuck not knowing what to do or how to behave to fit in. It often makes me feel worse not better" (P170).

Participants described aloneness as a choice, whereas loneliness was described as an unwanted feeling: "loneliness should not be confused with wanting to be alone and enjoying it" (P62). One described the borderline between the two: "[loneliness is] When being alone becomes a burden" (P196). Sometimes, the desire for connection and desire for aloneness appeared to conflict. Participants reported that they enjoyed their own company but also liked to have some connection with others: "I am happy in my own company, but there are times I wish I had a friend or friend to share my interests with" (P164). Sometimes, aloneness was also felt to be necessary to recover from the exhaustion from socializing: "sometimes a "reduction" in quantity is a good thing. I need to be alone quite a lot to recharge" (P28). Autistic adults reported feeling stuck and hopelessness about the internal conflict they experienced: "need to socialise/have good friendships but also how social interactions exhaust us… this catch-22 can lead to loneliness" (P33).

Theme 2: Barriers to connection for autistic adults

Autistic adults reported a range of different ways in which their longing for connection was difficult to overcome. First, ***sensory environments*** in social situations made interactions difficult for autistic adults: "my severe sensory overload makes socialising stressful, tiring and physical draining" (P64). Some adults directly linked their challenges with social situations to loneliness: "it [loneliness] is the lifelong failures and difficulties that I have had with making and keeping and managing relationships" (P2). Second, a perceived ***lack of societal understanding***

and acceptance of autism made it difficult for autistic adults to feel connected with

others:

> "In my opinion, being Autistic is like being born in Autistic culture in a family (in
>
> my case) where everyone else experiences NT [neurotypical]culture. So you
>
> do have a culture, but its spread out and with no set land mass or country. So
>
> every day of my life is culture shock. And my culture isn't respected, its
>
> disregarded and seems as a negative medical condition that people would
>
> rather not be there. That's why I'm lonely" (P162).

Lack of societal understanding and acceptance of autism was not only felt to be a

barrier to social connection but was also perceived as a factor contributing to autistic

adults' feelings of loneliness: "it is the neurotypical expectations that cause much of

the loneliness and put up barriers. We need to feel accepted as we are and have the

'normal' expectations removed" (P168). Third, a perceived ***lack of shared***

understanding and experiences made it difficult for autistic adults to feel

connected with others. For some, this was described as feeling different from others:

"Not fitting in. Things not clicking emotionally. Being on the outside. Being left out"

(P160). For others, it was described as feeling not understood/misunderstood: "not

feeling able to make contact because you don't know how to make yourself or your

needs understood" (P100). Participants explained that they felt pressured to change

themselves to fit in to achieve connection with others, which was lonely for them: "[I

feel lonely when] I feel I have to hide who I am" (P85). They also described how they

felt tired of having to be someone they are not in attempting to achieve connections

with others: "The only way to eradicate loneliness is to change the world. I'm sick of

people telling me I need to change who I am" (P191). Due to a lack of shared

understanding, between autistic and non-autistic people, autistic adults in this study

reported a paradox, in that being with others could be a cause of loneliness:
"Sometimes I can feel lonelier in a group or a crowd, because I'm not fitting in" (P34),
"when I feel completely shunned from groups and misunderstood. When people
assume I am happy not fitting in, like it suits me to be shunned. I feel isolated when
there's a group of people. That's when I'm at my most lonely" (P98). Participants
reported that the lack of shared experiences made it challenging for them to feel
connected when you have "few people with whom to share your experience of the
world" (P67). Autistic adults reported that sharing experiences was the central part of
having connection and commented on the absence of this in their narratives: "having
no-one who would be there for me in times of joy or in times of difficulty" (P42).

Theme 3: The importance of meaningful relationships

The autistic adults in this study highlighted that having meaningful
relationships with others was important, giving a sense of emotional connectedness
and access to people that they can confide in when needed. Autistic adult
emphasized that the quality of relationships was more important than the quantity of
relationships. ***Connecting with similar others*** was felt to be particularly important:
"[to cope with loneliness, I] try to go to a club of similar people e.g., a book group,
political / environmental group, choir" (P124). Autistic adults reported that they often
sought similar others through their shared interests and shared autistic identity:
"have connected with local autism peer support groups and hoping to find some
likeminded people there" (P22), and this was sometimes via social media: "being on
social media and being parts of groups where people share experiences and I feel
like I'm not the only one who feels like that any more" (P103). Another way that
autistic adults reported building meaningful connections was ***spending time with
pets/animals***: "autistic people in particular often get on better with animals than

people so they aren't a second best choice for us" (P202). Participants told us making such meaningful relationships with pets/animals made them less lonely: "I hug my dog or cat, it makes me feel loved and less lonely" (P58). For some autistic adults, meaningful relationships were reported between them and one other person, emphasising their **reliance on one person and fear of losing that person**. While having quality relationships was reported to provide autistic adults with the connection they wanted, they also expressed concerns about what would happen when they lose their 'one person': "my mum is the only person I feel I can go to with a problem, but every day I worry about what I will do when she is no longer here" (P22). Autistic participants also reported that they felt lonely when their 'one person' was not available for them and not with them: "having problems with my husband i am lonely. Because he is to me the one and only. When he is not, then i have no one" (P109).

Theme 4: Connecting with oneself

Some participants reported that avoiding social situations was helpful to stay connected with themselves, not being affected by the world: "I will shut myself off from the rest of the world and keep my interaction to a minimum wherever possible as this helps me keep my baseline and balance" (P99). Autistic adults desired social connection but found it challenging to build and maintain the meaningful relationships with others (i.e., having the internal conflict), which often resulted in loneliness: "we are trapped in a no-win situation: our condition means we get overwhelmed by people and sensory overload, and so we avoid, but then it leads to loneliness, and becomes a vicious circle" (P35). Some autistic adults felt that coming to terms with the tensions between the desire for connection and challenges with social interaction alleviated their feelings of loneliness. This **understanding and**

accepting of oneself helped them to be "more secure in who I am…I feel less lonely, value alone time, and choose who I connect with more carefully" (P181). As another participant explained: "I'm not so bothered by loneliness now… I've tried for a long time to moderate my behaviours for others so not get rejected, and I'm a bit fed up of doing this as a strategy. I'd rather be alone but more accepting of my autism" (P211).

Other participants reported that they came to terms with their feelings of loneliness: "I am more immune to it, learnt to live with it" (P157). For some, ***accepting loneliness*** as a part of their experiences alleviated loneliness: "I have accepted it is part of life for everyone, just to different degrees of importance" (P63); even if this was attributed to their autism: "I have accepted that loneliness seems to be an unavoidable part of being autistic" (P186). Indeed, accepting loneliness as something they could not change, regardless of any attempts, was felt to lessen feelings of loneliness: "I've reconciled myself to it [loneliness]. I don't really see much prospect of my life getting any better or more fulfilling" (P55). Sometimes, this accepting of loneliness took time to develop, and was linked with maturity: "It doesn't make me as unhappy as it used to. I'm older and have less energy, so I'm much more content to be in my sofa on my own every Friday night!" (P7), "I care less about being lonely as I get older" (P40).

4.4 Discussion

The results of this study indicate that some autistic adults *do* desire social relationships with others but experience multiple barriers to build such relationships. Specifically, autistic adults described barriers such as intolerable sensory environments, a lack of societal understanding and acceptance of autism (i.e., being perceived negatively different from the 'norm'), and a lack of shared understanding

and experiences (i.e., not fitting in, not feeling understood). Autistic adults reported their appreciation of meaningful relationships that provide them with a sense of emotional connectedness and access to people who they can confide in when needed. Autistic adults also reported that they managed to achieve such relationships by connecting with similar others (e.g., via interest groups or autistic peer support groups), spending time with pets/animals, and relying on one person (although the latter coexisted a fear of losing that person, e.g., parent, partner). Additionally, autistic adults reported that taking a step back from social interaction and connecting with oneself were necessary in navigating the social world. However, since autistic adults desired social connections, they experienced a tension in wanting to connect, finding it challenging, and needing time/space for oneself. This internal conflict between the desire for and barriers to connection was identified as an important theme in this study, leading to autistic adults experiencing feelings of helplessness. However, autistic adults identified their internal conflict and loneliness could be overcome by understanding and accepting oneself. For example, this included understanding what feels socially comfortable for themselves (e.g., with whom they interact) and accepting the social differences associated with being autistic. For some, loneliness was accepted as part of their autistic experience. Next, I will reflect on how the findings from this study compare to that of a similar investigation on this topic (Elmose, 2020) and further explore the implications of the findings.

Some of the findings from this study were unique to this study and were not previously reported in Elmose (2020). First, autistic adults in this study reported sensory environments as a barrier to social connections while this was not reported in Elmose (2020). Differences in study methods might account for this: autistic adults

in Elmose (2020) were all able to access in person social groups and sensory environments might have been less of an issue for them compared to those who took part in this online survey study. Notably, previous studies also identified sensory environments as a factor associated with increased loneliness in autistic adults (Smith & Sharp, 2013; Syu & Lin, 2018), as discussed in Chapter Two, Section 2.3.4. Second, autistic adults in this study reported spending time with pets/animals as a way to alleviate loneliness while this was not reported in Elmose (2020). Differences in study recruitment might account for this: autistic adults in Elmose's (2020) research were all self-enrolled in one of three autism network groups, which held meetings every other week. As such, spending time with pets/animals might have been less valued by participants who could engage in such groups, as opposed to those recruited online in the current study. My finding does, however, align with results of previous studies, which reported that autistic adults tend to have a 'special connection' with non-human agents including animals. This 'special connection' was previously referred to as object personification or anthropomorphism, and findings suggest that such relationships could play an important role in autistic adults' social experiences (Caruana et al., 2021; White & Remington, 2019). It is, however, unknown whether autistic adults experience meaningful connections due to the anthropomorphism of pets/animals or simply regard pets/animals as they are (i.e., non-human) and yet experience meaningful relationships. While there were some differences between the studies, there were some key insights into loneliness in autistic adults from this study that were also corroborated by Elmose (2020). These commonalities were that 1) autistic adults experienced a dilemma when weighing their desire for social connections within their limited energy, noting that refraining from social interactions do not necessarily reflect their unwillingness in social

participation, 2) feelings of disconnection from others (e.g., feeling not fitting in, being not understood/misunderstood) and lack of societal understanding/acceptance of autism, underpin loneliness and 3) the ways to alleviate loneliness appeared to be by having/connecting with significant/similar others and through acceptance of autistic difference. Because these findings were found across two different studies with two different methodologies, they could be considered robust. Next, I will explain these key insights in turn.

The first key insight from my results was that autistic adults experienced a dilemma when weighing their desire for social connections with their limited energy and that refraining from social interactions do not necessarily reflect their unwillingness in social participation. Specifically, while both this study and Elmose (2020) identified that autistic adults *do* desire social connections with others, autistic adults reported that they need to avoid social interaction due to the exhaustion from social interactions in this study and due to the exhaustion from everyday activities (e.g., chores, personal hygiene) in Elmose (2020). These findings mirror a report from Crompton, Hallett, et al. (2020) that interacting with non-autistic friends and family members (but not with autistic counterparts) is tiring and negatively impacts autistic people's ability to do daily tasks (e.g., finding it more difficult to prepare a meal after interacting with non-autistic people). Importantly, it appears to be essential for autistic adults to find a balance or rhythm between socializing and not socializing to avoid social or everyday exhaustion and to alleviate loneliness.

Research has shown that autistic adults benefit from support provided online (Crane et al., submitted; Harris et al., 2021). Crucially, autistic adults reported support provided online reduced the exhaustion from the expenditure of their energy on the stressors associated with in-person support (e.g., travelling, small talks)

(Crane et al., submitted). Considering autistic adults' dilemma in weighing their desire for social connections within their limited energy, those who interact daily with autistic adults (e.g., family members, co-workers) are also encouraged to be vigilant to autistic adults' energy levels when trying to understand their reactions to social situations. For example, autistic people's reluctance to attend a social gathering at work may simply reflect their exhaustion from work, work environments (e.g., social/sensory aspects), or personal responsibilities (e.g., chores, caring family members) rather than their reluctance to meet their co-workers.

Autistic adults' exhaustion due to social interactions and/or daily tasks can be explained in several ways. One explanation is the monotropic allocation of attention in autistic people (i.e., narrow and focused attention to a few things) (Murray et al., 2005). As a result, autistic people may be more likely to struggle with balancing out their limited energy than non-autistic people. In social interactions, individuals are expected to process multiple social stimuli (e.g., spoken language, facial expressions), yet this can be difficult and tiring for autistic people who experience monotropism (Murray, 2019). This may be compounded by the fact that autistic people also have to deal with their daily life demands that may be linked to survival (e.g., work, chores, grocery shopping). Autistic adults may need to prioritize these daily life demands, consequently feeling too exhausted to seek social interactions.

Autistic adults' reported exhaustion from social interaction could also be explained by considering the mechanisms of loneliness. The findings from this study broadly align with a prominent mechanism of loneliness, by Cacioppo and Hawkley (2009). As explained in Chapter One, Section 1.3.2, this model of loneliness explains that individuals who are experiencing loneliness become hypervigilant to social threats, act negatively towards others, receive negative reactions from others, and

experience enhanced loneliness (Cacioppo & Hawkley, 2009). In doing so, a negative cycle of loneliness develops (Cacioppo & Hawkley, 2009; Qualter et al., 2015; Spithoven et al., 2017). Aspects associated with autism (e.g., monotropism) could make experiences of hypervigilance for social threats to be more intense and distressing for autistic people.

The aforementioned hypotheses regarding the mechanisms of loneliness (Cacioppo & Hawkley, 2009; Qualter et al., 2015) are based upon the core idea that lonely individuals have a negative cognitive bias towards social information. Using the social information processing (SIP) model, Spithoven et al. (2017) explained this negative cognitive bias towards social information. The SIP was initially developed to describe social disturbances in children and Spithoven et al. (2017) explained that the cognitive bias is developed via four stages of the SIP (i.e., encoding of cues, interpretation of cues, clarification of goals, and response access and decision). Importantly, being autistic is likely to have some influence on the SIP. For example, encoding of cues in the SIP (i.e., paying attention to social stimuli) initially involves broadly scanning the social environment and then narrowing down one's focus, and they are likely to be influenced by some autistic experiences of the world such as monotropic focus, which may lead to more intense focus on negative stimuli.

At the next stage of interpretation in SIP (i.e., interpreting others' intentions), the double-empathy problem (Milton, 2012) is likely to be at work when autistic adults are interacting with non-autistic people, making it challenging for autistic people to interpret others' intentions (Crompton, Ropar, et al., 2020). While the SIP constantly relies on one's memory of past social experiences (Spithoven et al., 2017), autistic individuals can have difficulties recalling specific past events (i.e., episodic memory; Crane & Goddard, 2008; Crane et al., 2013) as autistic people

tend to employ a strategic and effortful approach to recall past experiences, thereby using greater executive functioning capacity compared to non-autistic people (Maister et al., 2013). Executive functioning is also employed at the response action and decision stage of SIP (Spithoven et al., 2017). Due to the aforementioned exacerbated cognitive demands in the SIP, undoubtedly, autistic adults may experience increased feelings of exhaustion by the time they decide their actions/reactions in a given social situation.

The second key insight into loneliness in autistic adults generated from my results was that feelings of disconnection from others (e.g., feeling not fitting in, being not understood/misunderstood) and lack of societal understanding/acceptance of autism, underpin loneliness. Disconnection from others has been reported as a factor associated with increased loneliness in other marginalized populations such as immigrants (Albert, 2021) and disabled individuals (Tarvainen, 2021). Various studies have also identified a lack of understanding/acceptance of autism as a factor associated with increased loneliness in autistic adults (Elmose, 2020; Hwang et al., 2017; Milton & Sims, 2016). The finding that the barriers to social connections for autistic adults are not inherent within the autistic individual but are linked to their social environments corroborates the findings that autistic adults experience challenges in social interactions in specific context of interacting with non-autistic individuals (Crompton, Hallett, et al., 2020). These findings suggest that solutions to loneliness in autistic adults need non-autistic people's cooperation, which might include community-focused solutions (e.g., autistic peer groups, shared interest groups) and societal-focused solutions (e.g., increasing societal understanding/acceptance of autism), rather than (or as well as) individual-focused solutions (e.g., counselling) or relationship-focused solutions (e.g., increasing social

opportunities) (Lim, Eres, et al., 2020). It is important for autism professionals to remember that increasing social opportunities may not always be the solution for loneliness in autistic adults. This is particularly important for the autistic population since the social world is often built on non-autistic people's terms (Crompton, Hallett, et al., 2020). As previously explained, it can take significant energy for autistic adults to engage in social interactions and sometimes such energy is not left after completing necessary daily tasks (Elmose, 2020). Notably, the internal conflict between the desire for and barriers to connection could be a unique aspect of loneliness in autistic adults.

Figure 4.2 illustrates the paradoxical loneliness loop that I developed based on the current study to explain loneliness in autistic adults. The paradoxical loneliness loop model gives a holistic picture of loneliness in autistic adults by considering loneliness in relation to the individuals and their social experiences. There is still little research on the pathways into loneliness in different populations (Qualter et al., 2022) and future research could enhance knowledge of loneliness by evaluating my proposed loneliness model not only in the autistic population but also in other populations (e.g., other marginalized groups).
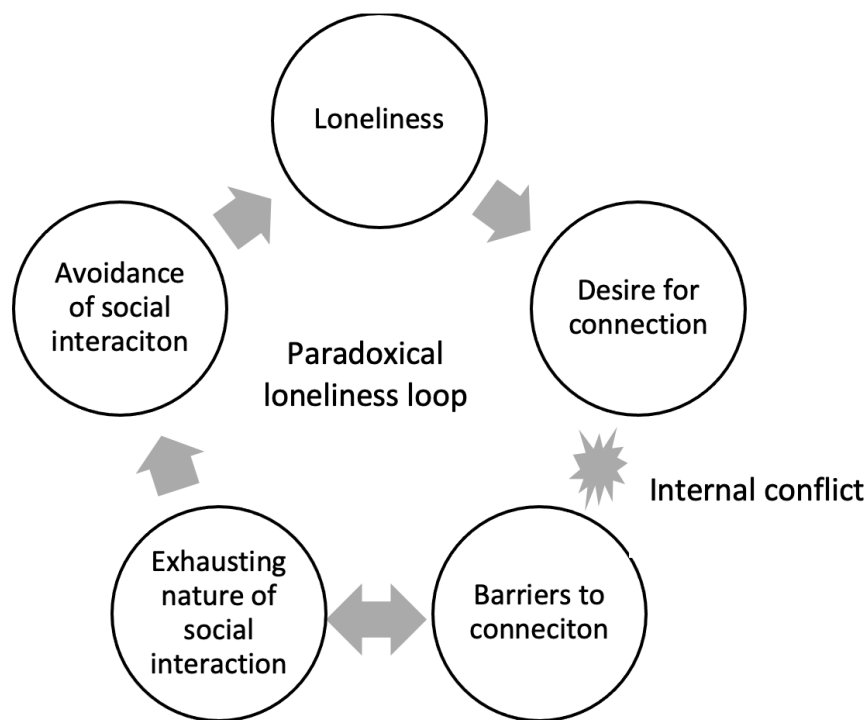
Figure 4.2. The paradoxical loneliness loop

The third key insight into loneliness in autistic adults identified from my results was that ways to alleviate loneliness appear to be: having/connecting with significant/similar others and through acceptance of autistic difference. Regarding connecting with similar others, some participants in this study described the importance of interacting with other autistic people and this is also evident in previous studies. Crompton, Hallett, et al. (2020), for example, conducted semi-structured interviews with 12 autistic adults to investigate whether there are any subjective differences between their experiences of interaction with autistic friends and family members and with non-autistic counterparts. Using thematic analysis, they reported that autistic adults felt more comfortable and understood when interacting with other autistic people compared to when interacting with non-autistic people. Autistic adults felt a sense of belonging with other autistic people and felt

they could be themselves with them. Crompton, Hallett, et al. (2020) also reported that autistic adults felt they were in a social minority and they had to conform to the expectations of non-autistic people when interacting with them. Connecting with other autistic individuals was identified as crucial for autistic adults in "building resilience to manage day-to-day life, improving well-being, and as a source of happiness" (Crompton, Hallett, et al., 2020, p. 1446). Relatedly, Crane, Hearst, et al. (2020) reported an initial evaluation of "Exploring Being Autistic", a ten-week autistic-led programme for newly diagnosed or identified autistic adults. The programme aimed to help the recently diagnosed/identified autistic adults to navigate the post-diagnosis/identification (e.g., learning about autism, processing their emotional responses). Sixteen autistic adults took part in the programme and participated in post-programme interviews upon completion (n=16) and again six months after completion (n=11) of the programme. Crane, Hearst, et al. (2020) reported that autistic adults had positive responses to the autistic-led nature of the programme, appreciated the diversities within the group and a sense of belonging it provided, and gained a more positive and practical understanding of autism (e.g., making sense of one's challenges). These findings align with those in Chapter Two, where research showed that accepting oneself, including one's autistic identity, could make autistic adults less lonely (Ee et al., 2019; Mazurek, 2014; Milton & Sims, 2016).

Strengths and limitations

It is important to consider the strengths and limitations of this study over and above those in Elmose (2020). A key strength of this study was the use of a different methodology (i.e., an online survey) from Elmose (2020) to explore autistic adults' experiences of loneliness, which may have been particularly helpful for those unable to engage in spoken discussions (who may have a very different lived experience of

loneliness). A further strength of this study was that the use of autistic voices in the research process (i.e., the study was led by an autistic researcher, myself, and six other autistic adults fed feedback to the final draft of the survey), unlike Elmose (2020) which did not appear to involve autistic people in the research process. In terms of limitations, since this study is based on the same online survey as that reported in Chapter Three, similar limitations apply: the study had a non-representative sample (e.g., most were White, highly educated, etc.), and the study was limited to those who had access to the Internet (See Chapter Three, Section 3.4 for more details). Additionally, there were some unique limitations to this study. First, the involvement of autistic individuals in the research process was limited. Although this study was led by an autistic researcher, the involvement of other autistic individuals was limited to providing feedback to the final draft of the survey. Nonetheless, the survey was developed with their feedback to ensure that the survey was clear to autistic people and the research could be meaningful for them. Second, the individuals who were involved in the peer debriefing were all involved in autism research and were familiar with autism. Therefore, it could have been easy for them to understand the themes from this study compared to those who may not be familiar with autism. Despite these limitations, this study strengthened the existing knowledge about the first-hand experiences of loneliness in autistic adults, in particular, to the preceding work by Elmose (2020), using different methodology, avenue of recruitment and positionality, and being based in a different country from Elmose (2020) (see Table 4.1 for details).

4.5 Conclusion

In conclusion, this study extended the work of Elmose (2020), providing a qualitative understanding of loneliness in autistic people. The findings from this study

that were corroborated by Elmose (2020) illuminate important aspects of loneliness in autistic adults: 1) a dilemma when weighing their desire for social connections within their limited energy, so refraining from social interactions does not necessarily reflect an unwillingness for social participation, 2) feelings of disconnection from others (e.g., feeling not fitting in, being not understood/misunderstood) and lack of societal understanding/acceptance of autism appear to underpin loneliness in autistic adults, and 3) connecting with similar others and accepting one's autistic differences appear to alleviate loneliness in autistic adults.

Following the study presented in this Chapter, I had intended to expand this PhD research by developing on the studies presented in Chapters Two, Three, and Four. However, the world was hit by the COVID-19 pandemic in early 2020, which created a unique social situation (e.g., physical distancing). I decided to use this situation to explore autistic adults' experiences of loneliness before and during the early stage of the pandemic in the UK using quantitative and qualitative methods. Therefore, in the next Chapter (i.e., Chapter Five), I will report if and how loneliness in autistic adults was impacted by the pandemic.

Chapter Five

Loneliness in autistic adults in the UK before, and in the early stages of,

the COVID-19 pandemic

5.1 Introduction

COVID-19 (Coronavirus disease) is an infectious disease caused by the SARS-CoV-2 virus, and was first reported in December 2019 in China (Johns Hopkins Medicine, 2022; World Health Organization, n.d.). Some infected individuals were reported to experience symptoms such as fever, cough or sore throat, while others were reported to have no symptoms at all (Johns Hopkins Medicine, 2022; World Health Organization, n.d.). In serious cases, the disease caused difficulties with breathing and even death (World Health Organization, n.d.). On March 11 in 2020, the World Health Organization (WHO) declared COVID-19 a pandemic (World Health Organization, 2020). As COVID-19 spread from person to person, reducing day-to-day contacts with others was considered essential in lowering the rates of disease's transmission, and was prioritized during early stages of the pandemic (GOV.UK, 2020). Consequently, in the UK, the government introduced social distancing measures, requiring people to stay home and away from other people (GOV.UK, 2020).

Prior to the pandemic, I had collected data on autistic adults' experiences of loneliness in the UK, as presented in Chapters Three and Four. When the pandemic occurred and social distancing was introduced, I decided to conduct a follow-up survey with participants who took part in the original survey to investigate their experiences of loneliness during the early stage of the pandemic in the UK. In the current study, I collected data between May 8th and May 22nd 2020. This was before

the introduction of the Covid-19 vaccination in the UK (BBC, 2020) and at a time when social distancing was the only preventative measure.

Despite protecting people from COVID-19, the introduction of social distancing posed a different public health concern: loneliness. During the early phase of COVID-19 (i.e., around the time that the study reported in this Chapter took place), some studies reported increased loneliness in the general population (Killgore et al., 2020; van Tilburg et al., 2021) while others reported no changes (Luchetti et al., 2020). In the UK, 530 out of 1964 adults (27%) reported that they felt lonely in March 2020 during the first national lockdown (Groarke et al., 2020). From late April to late May 2020 (under lockdown), 5,569 out of 15,530 adults (35.86%) in the UK reported that they were sometimes or often lonely (Li & Wang, 2020). A large longitudinal study on psychological and social impacts of the COVID-19 in the UK found that adults in the general population experienced increased loneliness during the early stage of the COVID-19 pandemic (late March to early May) compared to before the pandemic (Bu et al., 2020b). While 8,884 out of 31,064 adults (28.6%) reported being 'sometimes' lonely and 2,640 out of 31,064 adults (8.5%) reported being 'often' lonely before the pandemic, 19,610 out of 60,341 adults (32.5%) reported being 'sometimes' lonely and 11,042 out of 60,341 adults (18.3%) reported being 'often' lonely during the pandemic (Bu et al., 2020b).

During the early stages of the pandemic, many factors associated with *increased* loneliness were not specific to the time of the pandemic (Groarke et al., 2020) and included being a young adult (as opposed to being over 65 years of age) (Bu et al., 2020a; Groarke et al., 2020), being separated or divorced, having current symptoms of depression, having greater emotion regulation difficulties, having poor sleep quality (Groarke et al., 2020), living alone, having one or more chronic health

conditions (Bu et al., 2020a; Luchetti et al., 2020), and having low income (Bu et al., 2020a). Nonetheless, there were some additional COVID-19-specific factors that were associated with increased loneliness, which included social distancing restrictions (e.g., not leaving home except for necessities) (Killgore et al., 2020) and currently or previously having experienced symptoms of COVID-19 (Li & Wang, 2020). Research also reported on factors associated with *decreased* loneliness during the early stage of the pandemic, which included having greater levels of social support (Bu et al., 2020a; Groarke et al., 2020), being married or living with a partner (Groarke et al., 2020; Li & Wang, 2020), living with a greater number of other adults (Groarke et al., 2020), and having a job (Li & Wang, 2020).

At the time of writing, the experiences and/or management of loneliness in the general population were reported in just one study. McKenna-Plumley et al. (2021) conducted interviews (via telephone or video-call) with eight individuals in May 2020 to explore the first-hand experiences of loneliness in the general population during the first national lockdown in the UK. The researchers recruited participants by recontacting individuals who reported feeling lonely during lockdown in another (unpublished) study and analyzed the data using reflexive thematic analysis. The researchers identified four themes from the data: 1) loss of in-person interaction causing loneliness, 2) constrained freedom, 3) challenging emotions, and 4) coping with loneliness. Under the first theme, McKenna-Plumley et al. (2021) reported that their participants experienced loneliness due to the loss of in-person interaction and online interaction did not replace in-person experiences. Under the second theme, the researchers reported that their participants felt their freedom was constrained either by the government rules or fear of seeing others (and contracting the virus), which led to strained relationships or frustration as part of their experiences of

loneliness. Participants felt the frustration "because distancing measures acted as an uncontrollable block to seeing others" (McKenna-Plumley et al., 2021, p. 9). Under the third theme, the researchers reported that their participants experienced fluctuation in mood and challenging emotions (e.g., worry, fear) alongside with loneliness. Under the fourth theme, it was reported that participants attempted to cope with loneliness mainly via social interaction and distraction (e.g., spending time doing their hobbies).

Scheeren et al. (Submitted) recently conducted a scoping review to synthesize evidence on the impacts of the COVID-19 pandemic on autistic adults. A total of 55 studies were identified, mostly from European countries (n=31, 56%) and the USA (n=13, 24). Scheeren et al. (Submitted) found that autistic adults were significantly impacted by the virus, with higher rates of COVID-19 infections, and higher risk of developing serious illness and being hospitalized, compared to adults in the general population. Scheeren et al. (Submitted) also reported that autistic adults were impacted by the social distancing measures implemented during the pandemic. Regarding services and support, Scheeren et al. (Submitted) identified that some autistic adults found remote delivery of services and support in the pandemic as acceptable due to less barriers to care (e.g., no need to travel) while others found it as unhelpful and experienced a discontinuity of care (e.g., due to technological problems or difficulties with communication with their therapists). Scheeren et al. (Submitted) found that most of their included studies reported negative impacts on autistic adults' wellbeing (e.g., loss of social contacts and limited access to professional support) while some studies reported positive impacts (e.g., lower pressure from the external world and more quality time with family).

Importantly, some autistic adults were found to experience both positive and negative impacts on wellbeing at different points during the pandemic.

Scheeren et al. (Submitted) examined the factors associated with better mental health in autistic adults during the pandemic, which included being male, being older in age, having better pre-pandemic mental health, having lower stress in relation to the pandemic, having higher perceived social support, and having the ability to keep the routines or make new ones. Further factors associated with positive impacts on autistic adults' wellbeing or mental health included access to support, reduced pressure to conform to the non-autistic social rules, reduced sensory strain and greater control over sensory experiences, not being infected by COVID-19, social relationships (e.g., maintaining friends, online communication with family), clear/accessible COVID-19 related information, and societal inclusion and acceptance of autistic adults. Furthermore, Scheeren et al. (Submitted) reported that few of their included studies actively included autistic adults or their allies in their research process and recommended that future research should be underpinned by a participatory framework.

Some research conducted during the pandemic suggested that autistic adults may be impacted by loneliness. At the start of the pandemic, some researchers expressed concerns about the impacts of social distancing measures on social isolation, loneliness and consequent mental health issues among autistic adults (Cassidy, Nicolaidis, et al., 2020; den Houting, 2020). Subsequent work to investigate these hypotheses found some evidence to support this assertion. In a study primarily conducted in Australia, Pellicano et al. (2021), for example, conducted in-depth qualitative interviews with 44 autistic adults, 16 autistic young people (12-18 years of age), and 84 parents of autistic children about autistic

people's day-to-day experiences and experiences with their mental health during the early stage of the pandemic (i.e., spring 2020). Autistic people in their study reported that they missed meeting their friends, therapists or support workers in person, and some autistic people felt lonely. Autistic adults reported that the lack of in-person contact negatively impacted their mental health. Similarly, Maljaars et al. (2022) conducted an online survey with autistic and non-autistic adults from three European countries (Belgium, the Netherlands, and the UK) and investigated how the early stage of the pandemic impacted their daily life. Most autistic adult participants in Maljaars et al. (2022) reported that online interaction did not successfully replace in-person interaction and some felt lonely due to the limited in-person interactions.

Between the time of data collection of this study and time of finalizing the thesis, two studies were published on changes of experiences in loneliness among autistic adults during the early stages of the pandemic. Scheeren et al. (2022) collected data on the levels of loneliness and stress in the Netherlands at three time points via online surveys: pre-lockdown in March 2020 (T0), during the first lockdown in April 2020 (T1), and during the second lockdown in October 2020 (T2). Scheeren et al. (2022) recruited participants from the Netherlands Autism Register (NAR), a database of autistic and non-autistic adults and parents of autistic individuals (note: adults included those who were 16 years old and over). Participants included 512 autistic adults at T0, 685 autistic and 150 non-autistic adults at T1, 576 autistic and 130 non-autistic adults at T2. Scheeren et al. (2022) examined the changes in the levels of loneliness and stress on the overlapped samples between T1 and T2 which were 448 autistic adults and 70 non-autistic adults. In relation to loneliness, participants completed De Jong Gierveld Loneliness Scale (DG Loneliness Scale-6; Gierveld & Tilburg, 2006) at T0, T1, and T2. The DG Loneliness Scale-6 is a self-

report multidimensional scale developed for the general population to access the levels of intimate and relational aspects of loneliness (Cacioppo et al., 2015). Scheeren et al. (2022) examined changes in loneliness in autistic adults from pre-lockdown (T0) to lockdowns (T1 and T2), finding that autistic adults' levels of loneliness remained consistent over the three time points but were higher than those reported in non-autistic adults during lockdowns (T1 and T2). Scheeren et al. (2022) also examined the changes in loneliness from T1 and T2 in both autistic and non-autistic groups, and reported that they were stable over two time points in both groups. Finally, Scheeren et al. (2022) examined predictors of loneliness. The researchers found that predictors of increased loneliness at T1 were being autistic, and that predictors of increased loneliness during lockdowns (T1 and T2) were similar between autistic and non-autistic groups, which included low perceived social support and being more worried about COVID-19-related matters. A strength of Scheeren et al. (2022) study was that they collected data before and during the pandemic using the same measures and they had a non-autistic comparison group (though this was only during the pandemic). Despite such strengths, Scheeren et al. (2022) reported that their sample was likely not to be representative of all autistic adults (e.g., those with minority genders were underrepresented, those who received an autism diagnosis in adulthood were overrepresented). Further, Scheeren et al. (2022) only collected quantitative data, without any qualitative investigation to provide context to their results.

In a second study on loneliness in autistic adults during the pandemic, Capp et al. (2022) conducted an online survey between June 2020 and September 2020 in the UK when the national lockdown restrictions were starting to be eased (Institute for government, n.d.). This survey had two aims. First, they sought to examine

differences in current levels of loneliness, quality of life, depression, and anxiety across groups of autistic adults (n=73), autistic adults with additional neurodivergent identities (n=63), non-autistic but neurodivergent adults (n=53), and, adults who are not neurodivergent (predominant neurotype; PNT; Beardon, 2022) (n=98). Second, they wanted to investigate the perceived changes in the aforementioned psychological outcomes due to the pandemic. In relation to loneliness, participants completed the University of California, Los Angeles, 3-Item Loneliness Scale (UCLA-3; Hughes et al., 2004) which is a self-reported unidimensional scale developed for the general population to assess the levels of loneliness. After completing the UCLA-3, participants were asked whether their feelings of loneliness had changed due to the pandemic and answered on a five-point Likert scale (i.e., much better, a little better, no changes, a little worse, and much worse). Capp et al. (2022) showed that autistic adults with and without additional neurodivergent identities reported increased levels of loneliness compared to PNT adults. Capp et al. (2022) reported that there were no differences in the reported levels of loneliness between autistic adults with and without additional neurodivergent identities. Regarding the perception of changes, Capp et al. (2022) reported that participants across the groups tended to report that their perceptions loneliness had worsened due to the pandemic. Capp et al. (2022) reported that a strength of their study was that they used a unique comparison design: two autistic groups (one with additional neurodivergent identities and another without them) and two non-autistic comparison groups (one with neurodivergent identities and another without them). Additionally, another strength of their study was that they used measures that were validated for use in autistic adults, with one of the measures used in this study developed specifically for autistic adults. Despite these strengths, Capp et al. (2022) noted that

some of their limitations included that the sample was not likely to be representative of the target population. Capp et al. (2022) also reported that another limitation of their study was that they retrospectively asked their participants about their perceived changes in loneliness, quality of life, depression, and anxiety (i.e., no data collection prior to the pandemic), therefore they relied on participants' memories of their pre-pandemic experiences. This could mean that their perceived changes might have not accurately represented actual changes.

The aim of the current Chapter was to examine two key questions. First, if and how experiences of loneliness for autistic adults changed before and during the early stage of the COVID-19 pandemic; and second, how autistic adults managed and wanted to manage loneliness during the early stages of the COVID-19 pandemic. When I began to design the study presented in this Chapter, little evidence was available upon which to generate hypotheses (i.e., since the studies mentioned in this introduction were not yet published). As such, my hypotheses were tentative and were based on the background literature about what was known about loneliness in autistic adults (e.g., from Chapter Two). One potential hypothesis was that autistic adults might experience *increased* loneliness due to having fewer available support or social opportunities due to the social distancing. Indeed, autistic adults do desire social connection (e.g., Hickey et al., 2018; Van Hees et al., 2015). An alternative hypothesis was that autistic adults might experience *decreased* loneliness, due to more widespread use of online communication, which has been perceived as a helpful way of communicating by autistic people (Benford & Standen, 2009; Mazurek, 2013; Zisk & Dalton, 2019). Finally, it could be hypothesized that autistic adults may experience *no change* in their feelings and experiences of loneliness, due to them active avoiding social situations prior to the COVID-19 pandemic, with

consequent social distancing continuing to protect themselves from social exhaustion and negative experiences (Cacioppo & Hawkley, 2009). Given the heterogeneity of the autistic population, all three hypotheses could be plausible. Qualitative data were also collected on participants' experiences of loneliness at the time, to better understand the impact of the pandemic on loneliness among autistic adults.

5.2 Methods

5.2.1 Design

In this Chapter, data are presented from a subset of participants who took part in the research presented in Chapters Three and Four (Time 1). At the start of the COVID-19 pandemic, I recontacted them about the opportunity to complete a follow-up survey (Time 2). At this time, the UK was under its first national lockdown (Brown & Kirk-Wade, 2021), and residents in the UK were required to stay home except for very limited purposes (e.g., grocery shopping, one form of exercise a day, medical needs, traveling for work when unable to work from home). During this time, certain public places were closed (e.g., libraries, gyms, churches) and gatherings of more than two people in public were restricted (GOV.UK, 2020). In the Table 5.1, I presented the summary of key differences between the current study and recently published studies on changes of experiences in loneliness among autistic adults (Capp et al., 2022; Scheeren et al., 2022). Importantly, the current study used quantitative and qualitative data on loneliness in autistic adults before and during the early stages of the COVID-19 pandemic.

Table 5.1. Key differences between the current study and Scheeren et al. (2022)

	Current study	Scheeren et al. (2022)	Capp et al. (2022)

Aim	To examine if and how experiences of loneliness for autistic adults changed before and during the early stage of the COVID-19 pandemic; and to investigate how autistic adults managed and wanted to manage loneliness during the early stages of the COVID-19 pandemic	To examine the continuity and change in loneliness and stress among autistic and non-autistic adults during the early stage of the COVID-19 pandemic	To examine the differences of the levels of loneliness, quality of life, depression, and anxiety across groups of autistic adults, autistic adults with additional neurodivergent identities, non-autistic but neurodivergent adults, and PNT adults, and to explore the perceived changes in the levels of loneliness, quality of life, depression, and anxiety due to the pandemic.
Study design	Mixed methods	Quantitative	Quantitative
Measures of loneliness	The UCLA Loneliness Scale Version 3, the Social and Emotional Loneliness Scale for Adults, and a direct measure of loneliness	de Jong Gierveld Loneliness Scale	The UCLA-3
Participants	Autistic adults	Autistic and non-autistic adults	Autistic adults, autistic adults with additional neurodivergent identities, non-autistic but neurodivergent adults, and PNT adults
Data collection points in time	Data were collected at two points in time between November 2019 and January 2020, and during May, 2020	Data were collected at three points in time during March, 2020, during April, 2020, and during October, 2020	Data were collected at one point in time between June 2020 and September 2020

Geographic locations	The UK	The Netherlands	The UK

5.2.2 Participants

Time 1

As detailed in Chapter Three, Section 3.2.2, 203 participants completed an online survey on loneliness among autistic adults between November 2019 and January 2020. Participant demographics are presented in Chapter Three, Section 3.2.2.

Time 2

Of the 203 participants who completed the Time 1 survey, 128 expressed an interest in being invited to take part in further research. These participants were recontacted at Time 2: between May 8, 2020 to May 22, 2020 (two weeks), and all who were living in the UK were eligible to take part (due to international differences in COVID-19 responses). The participants were limited to those living in the UK at the time of the study, because of international differences in COVID-19 restrictions that could affect people's experiences of loneliness. A total of 94 participants engaged with this Time 2 survey. Time 2 responses were not considered for those who did not choose to complete the key loneliness questionnaire (described below) (n=10) or whose IDs did not match up to Time 1 survey (n=24). Therefore, the final sample comprised 60 respondents. As can be seen in Table 5.2, participants at Time 2 had similar profiles to those who took part in Time 1 survey: many autistic adults were formally diagnosed in adulthood, female gender, from White ethnic backgrounds, grew up in the UK, had co-occurring conditions (depression and anxiety being most common), used spoken language to communicate, were educated in mainstream school, had high levels of educational qualifications, were

single, and tended to share their autism diagnosis with those close to them (e.g., family, friends). Additional demographic information relevant to the time of the pandemic was also collected. These data showed that many adults in the sample had no changes in their living arrangement due to the COVID-19 pandemic (and felt their living arrangements were satisfactory), and just over a fifth lived alone (without a human or animal companion) during lockdown. The majority experienced changes in employment during the pandemic, such as working from home. No participants had definitely tested positive for the virus, and few had experienced the loss of family members due to COVID-19. The frequency of leaving the house each week varied among participants, but once or twice as well as five or more times per week were the most common responses.

Table 5.2. Participant demographics (n=60).

Variable	Category	N (%)
Autism diagnosis	Formally diagnosed	51 (85.0)
	Self-identified and in process of obtaining a diagnosis	6 (10.0)
	Self-identified but not seeking a diagnosis	3 (5.0)
Age of autism diagnosis (n=51)	M: years (SD)	34.4 (14.6)
	Range: years	1-58
Age	M: years (SD)	41.5 (12.2)
	Range: years	20-68
Gender	Male (including transgender male)	21 (35.0)
	Female (including transgender female)	31 (51.7)
	Non-binary	8 (13.3)
Ethnicity	White (including British, Irish or any other White background)	53 (88.3)
	Black or Black British Caribbean (including the Caribbean, African or any other Black background)	1 (1.7)
	Asian or Asian British (including Indian, Pakistan, Bangladesh or any other Asian Background)	2 (3.3)
	Mixed (e.g., White and Asian; or any other Mixed background)	2 (3.3)
	Other (Jewish, Mexican)	2 (3.3)
Location of growing up	In the UK	50 (83.3)
	In another country	10 (16.7)

Co-occurring conditions	Yes	48 (80.0)
	No	12 (20.0)
Co-occurring conditions (text-entry) *multiple answers were allowed (n=48)	Depression	27 (45.0)
	Anxiety	21 (35.3)
	Physical conditions	13 (21.7)
	AD(H)D	7 (11.7)
	Learning disabilities	6 (10.0)
	OCD	7 (11.7)
	Other mental health/neurological conditions (e.g., psychosis, pathological demand avoidance)	4 (6.7)
	PTSD	3 (5.0)
	Eating disorder	2 (3.3)
	Tourette's syndrome	1 (1.7)
Ways of communication	Spoken language	56 (93.3)
	Communication devices and apps	4 (6.7)
Educational history	Mainstream school	56 (93.3)
	Specialist school	3 (5.0)
	Other (combination of home school and mainstream)	1 (1.7)
Highest educational qualification[22]	GCSEs	3 (5.0)
	National Vocational Qualification	2 (3.3)
	A/AS Levels	7 (11.7)
	First degree (e.g., BA, BSc)	20 (33.3)
	Higher degree (e.g., MA, MSc, PhD)	28 (46.7)
Relationship status	Married	17 (28.3)
	Not married, but in a romantic relationship	11 (18.3)
	Divorced/separated	7 (11.7)
	Single	27 (41.7)
Disclosure of autism diagnosis	Tend to share with anyone I meet	9 (15.0)
	Tend to share with those close to me (family, friends, co-workers, etc.)	34 (56.7)
	Tend not to share with anyone I meet including those close to me	8 (13.3)
	Tend to share if needed/relevant	5 (8.3)
	Other (e.g., when people are knowledgeable about autism, feeling reluctant due to not having an official diagnosis)	4 (6.7)
Changes in the living arrangement due to the COVID-19 outbreak	Yes	18 (30.0)
	No	42 (70.0)
Living arrangement during lockdown	Living with partner and/or children	31 (51.7)
	Living alone	17 (28.3)

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[22] In the UK's educational system, students are often entered for GCSE (General Certificate of Secondary Education) at around the age of 14 to 16 and for A/AS levels at around the age of 16 to 18.

*multiple answers were allowed	Living with pet(s)/animal family member(s)	14 (23.3)
	Living with parents and/or siblings	11 (18.3)
	Living with flatmates (including living in university accommodation)	3 (5.0)
Living space	Too cramped	9 (15.0)
	Small	10 (16.7)
	Just right	28 (46.7)
	Spacious	11 (18.3)
	Very spacious	2 (3.3)
Changes in employment	Yes	41 (68.3)
	No	19 (31.7)
Employment status during lockdown	I am working from home	27 (45.0)
	I am unemployed	10 (16.7)
	I am a key-worker and have continued to go out to work	5 (8.3)
	I am in full/part-time education	4 (6.7)
	I am volunteering	3 (5.0)
	I am a carer	1 (1.7)
	I am retired	2 (3.3)
	I have been furloughed	2 (3.3)
	Other (combination of the above)	2 (3.3)
Times of having left the house per week during lockdown	Less than once per week	12 (20.0)
	Once or twice per week	19 (31.7)
	Three or four times per week	9 (15.0)
	Five or more times per week	20 (33.3)
Covid infection status	No, I haven't tested positive for the virus (and I don't think I have been infected)	49 (81.7)
	No, I haven't tested positive for the virus (but I think I may have been infected)	11 (18.3)
	Yes, but I have recovered	0 (0.0)
	Yes, I am still unwell	0 (0.0)
Loss of family members due to COVID-19	Yes	8 (13.3)
	No	52 (86.7)

5.2.3 Materials

The survey completed at Time 1 was described in Chapters Three and Four. Of relevance to the current chapter, participants completed background questionnaires and three loneliness measures including the UCLA Loneliness Scale Version 3 (henceforth UCLA scale; Russell, 1996), the Social and Emotional Loneliness Scale for Adults (SELSA; DiTommaso & Spinner, 1993), and a direct measure of loneliness (Office for National Statistics, 2018). The Time 2 survey

comprised three parts: 1) background, 2) measures of loneliness, and 3) experiences of loneliness during lockdown (see Appendix 5.1).

Part 1 – Background

To better understand participants' situations at the time of the survey, they were asked to complete multiple-choice questions regarding whether they experienced changes in the their living arrangements due to the COVID-19 pandemic, what their current living arrangements and living spaces were (i.e., too cramped, small, just right, spacious, and very spacious), whether they experienced changes in employment due to the COVID-19 pandemic, their current employment status, the number of times they left the house per week, information on whether they had experienced a COVID-19 infection, and whether they had lost any family members due to COVID-19.

Part 2 – Measures of loneliness

Participants re-completed the UCLA scale (Russell, 1996), SELSA (DiTommaso & Spinner, 1993), and direct measure of loneliness (Office for National Statistics, 2018). As per the Time 1 survey, the order of these measures was counterbalanced across participants. Further information on these measures is provided in Chapter Three, Section 3.2.3.

Part 3. Experiences of loneliness during lockdown

Participants were asked to respond to a series of questions about their experiences of loneliness during lockdown. These questions were:

1) Has loneliness affected you during the lockdown (yes/no/not sure) and how (open text box, optional)?

2) Has your experience of loneliness changed during lockdown (yes, it has

lessened; yes, it has increased; no, it has stayed about the same; not sure)

and how (open text box, optional)?

3) How have you tried to manage feelings of loneliness during lockdown (open

text box, optional)?

4) Is there anything that you would have found useful in managing any feelings

of loneliness during lockdown? If so, please explain (open text box, optional).

5.2.4 Procedure

Ethical approval for the original study was granted via the Department of

Psychology and Human Development at UCL IOE on October 30, 2019 (UCL Data

Protection Registration Number: Z6364106/2019/10/155). Broad ethical

considerations for the original study are presented in Chapter Three, Section 3.3.4.

For the research presented in this Chapter, I submitted an ethical amendment, which

was approved on May 7, 2020. Here, the primary additional consideration was that

participants might be experiencing heightened anxiety due to the pandemic. To

mitigate this, at the beginning of the survey participants were reminded that their

participation was voluntary and that they could withdraw from the study at any time.

A complete copy of the questions was provided to participants prior to them deciding

whether to take part. Also, at the bottom of every page in the survey, participants

were provided with details of support organizations they could contact in the case of

distress (e.g., Samaritans, who have a text and phone service).

Once participants accessed the survey, they proceeded to an information

sheet and then to a consent form. The information sheet included the link to a

document enabling them to see all the questionnaires before deciding whether to

take part in the study. After giving consent, participants proceeded to the

questionnaires.

5.2.5 Data analysis

Quantitative data

The analysis of quantitative data was completed using SPSS software.

Descriptive statistics were used to present autistic adults' perceptions of loneliness in

the early stages of the COVID-19 pandemic (via scores on the loneliness scales, as

well as direct questions on the topic). Paired samples *t*-tests were used to compare

scores on the loneliness measures at Time 1 and 2, at a group level.

This study was conceived of expeditiously given how quickly the COVID-19

situation was evolving at the time of study design. As such, this new survey included

the same questionnaires as in the Time 1 survey, with some additional pandemic-

specific questions added. However, in hindsight, the Reliable Change Index (RCI;

Jacobson & Truax, 1992; Zahra & Hedge, 2010) appeared to be valuable in

evaluating changes for individual participants over time, in addition to the changes in

overall group scores, and the RCI requires the test-retest reliability value, which the

UCLA scale (but not the SELSA or direct measure) provides. Therefore, I present the

results of the UCLA, SELSA and direct measure at a group level, but will examine

the results on the UCLA more in depth in this Chapter. RCI was calculated using the

equation below.

$$\text{RCI} = \frac{x_2 - x_1}{\sqrt{2\left(s_1\sqrt{1 - r_{xx}}\right)^2}} \quad \text{(Jacobson \& Truax, 1992)}$$

In this equation, x_1 indicates each participant's score on the UCLA scale at

Time 1, x_2 indicates their score at Time 2, s_1 indicates the standard deviation of the

scores at Time 1, and r_{xx} indicates test-retest reliability of the measure used. The

RCI shows how much change was seen in each individual, in which direction, and

whether the change was statistically reliable. When absolute values of RCI were greater than 1.96, this meant that the changes in the scores between the two points were unlikely to be due to the variability of the measure, thus were considered statistically reliable.

Qualitative data

Two different methods were used to analyse the qualitative data collected for this Chapter. First, reflexive thematic analysis was used to identify patterns in open-ended data on the *experiences* of loneliness among autistic adults during lockdown (Braun & Clarke, 2006, 2019; Clarke & Braun, 2013). The process was iterative in the sense that I worked through the six stages: familiarizing myself with the data; coding the data; identifying themes; developing the themes; refining the themes; producing a report (See Table 5.3 for full details; Braun & Clarke, 2006, 2021). Analysis was conducted from a critical realist approach, perceiving participants' accounts are true while acknowledging that their accounts are affected by factors in wider social contexts (Braun & Clarke, 2013). These data were initially open-coded without using any coding framework (Braun & Clarke, 2021). The analysis was approached using inductive (i.e., codes and themes were developed from the data) and semantic (i.e., codes and themes reflect the data) elements (Braun & Clarke, 2021).

As part of reflexive practice, it is essential to reflect on researchers' positionality. What was particularly strong about this analysis was that it was done concurrently by both an autistic (myself) and a non-autistic researcher (a research assistant at CRAE). This positionality is likely to have affected how the data were analyzed. There were conversations around the extent to which each of us felt the data fitted the themes. Although both of us independently coded the data, we

exchanged the summaries of our codes, and our initial themes and their descriptions, and we found many similarities in our analysis. After each of us coded and developed themes, we met with one of my supervisors, to further refine the themes. It is important to note that reflexive thematic analysis brings subjective perspectives of the researchers involved in the analysis (Braun & Clarke, 2019, 2021), and both researchers view autism from a social model and neurodiversity perspective. Importantly, this approach places the need to accommodate the environments for autistic people, instead of placing the responsibility of change solely on autistic people.

Table 5.3. Six steps in the thematic analysis

Step	Description
Step 1: familiarizing myself with the data	I exported the participants' responses from Qualtrics, and copied and pasted them on a Word document. A research assistant at CRAE and I individually familiarized ourselves with the data by repeatedly reading or listening to responses and immersing ourselves in these data.
Step 2: coding the data	Using the comment function on Word, both researchers coded the data by assigning the most appropriate code to each data. Codes described a single idea about a segment of the data. Subsequently, we exchanged our coding documents via email and agreed via email that there were many similarities in our codes and that our initial impression about the data was also similar.
Step 3: identifying themes	Both researchers exchanged summaries of our thoughts via email. Specifically, the research assistant wrote up her summary in an email with possible themes and their descriptions, and I wrote up a thematic map on a Word document with possible themes. Under each possible theme, I noted which codes were clustered into the theme.

Step 4: developing themes	Both researchers provided feedback on each other's possible themes and made suggestions to group some themes/sub-themes together. We then met with one of my supervisors to discuss our ideas on the themes. During the meeting, we discussed whether some themes could be clustered together or whether there could be better wordings to convey the meanings of possible themes.
Step 5: refining themes	After the meeting with the research assistant and my supervisor, I made a summary of the analysis including possible themes and the descriptions to share it with my other supervisor. We agreed on themes via email. Steps 5 and 6 were an iterative process of writing up the results and seeking feedback from my supervisors. This refinement and consultation process was to ensure the themes were clear and true to participants' accounts.
Step 6: producing a report	After refining and naming the themes, I wrote up the final draft of the results. In the results, I clearly explained the descriptions of each theme and presented selected quotes to give examples of the themes. Writing a report was a repetitive process involving receiving feedback from and meeting with my supervisors to discuss their comments.

Additional qualitative data on the *management* of loneliness among autistic adults during lockdown was analyzed using content analysis (Mayring, 2015). Content analysis is "a research method that provides a systematic and objective means to make valid inferences from verbal, visual, or written data in order to describe and quantify specific phenomena" (Downe-Wamboldt, 1992, p. 314), and is often used in reporting the focus of the attention in the investigated groups (Downe-Wamboldt, 1992). I used content analysis to report the most common, and the most desired, ways of managing loneliness among autistic adults during the pandemic. I

approached coding from an inductive approach (i.e., codes were grounded in the data) and condensed the codes into a smaller number of categories with support from my supervisors. Finally, I counted the numbers of times each category was mentioned by participants (as per Bengtsson, 2016). I completed the analysis largely independently. However, to ensure the rigor of the analysis, 20% of the data (12 out of 60 responses) were cross-checked by the same non-autistic researcher who assisted with the thematic analysis. Specifically, this process included the research assistant categorizing the data on a Microsoft Word document using a comment function with agreed categories. The document had the data (i.e., responses on management of loneliness from 12 participants) and blank comment boxes next to the data to blind my analysis. Regarding the question on how autistic adults managed loneliness during lockdown, we agreed on 91.7% of the data (i.e., agreement on 11 out of 12 responses). The one disagreement was resolved through discussion. Regarding the question on how autistic adults wanted to manage loneliness during lockdown, inter-rater agreement was originally 75% of the data (i.e., agreement on nine out of 12 responses). However, two of the disagreement were on the same matter (i.e., it was felt that participants' responses could not be best captured by existing categories). To address this, we agreed to add a new category (access to public places) and the agreement rate went up to 91.7% (11 out of 12 responses).

5.3 Results

5.3.1 Quantitative data: Autistic adults' loneliness ratings before and during lockdown

Participants' scores on the UCLA, SELSA and the direct measure of loneliness are presented in Tables 5.4 and 5.5. Overall, across all three measures, participant reported being less lonely during the pandemic compared to before the pandemic and this change was significant on the UCLA scale, $t(59) = 3.6$, $p=.001$, and direct measure, $t(59) = -5.7$, $p < .001$, but not on not the SELSA, $t(59) = 2.6$, $p = .01$. I also examined participants' scores across the three subscales of the SELSA. Here, participants reported being less lonely during the pandemic compared to before the pandemic, yet none of these changes was statistically significant.

Table 5.4. Comparison of the descriptive statistics of the loneliness measures before and during the pandemic

	Statistics	UCLA scale	SELSA				The direct measure of loneliness
			Total	Romantic subscale	Family subscale	Social subscale	
Before the pandemic	M (SD)	63.1 (11.1)	158.3 (46.7)	50.1 (23.5)	43.2 (19.0)	67.0 (19.2)	1.9 (1.0)
	Range	33-80	64-247	12-84	11-77	26-98	1-5
During the pandemic	M (SD)	59.5 (11.2)	150.0 (43.8)	46.4 (21.5)	38.9 (17.7)	64.7 (18.8)	2.6 (1.2)
	Range	37-80	53-234	12-83	11-77	27-98	1-5
Paired samples t-test	T	3.6	2.6	2.3	2.8	1.2	-5.7
	Df	59	59	59	59	59	59
	P	.001	.01	.02	.007	.24	<.001

Table 5.5. Comparison of the frequencies in the direct measure of loneliness before and during the pandemic

	Often/always N(%)	Some of the time	Occasionally	Hardly ever	Never
Before the pandemic	29 (48.3)	18 (30.0)	7 (11.7)	5 (8.3)	1 (1.7)
During the pandemic	13 (21.7)	19 (31.7)	9 (15.0)	17 (28.3)	2 (3.3)

At an individual level, Reliable Change Index (RCI) was used in relation to the UCLA scale and are presented in Figure 5.1 and Appendix 5.2. This analysis revealed that scores on the UCLA scale decreased in 39 participants (65.0%), increased in 19 participants (31.7%), and stayed the same in two participants (3.3%) (see Appendix 5.2). Six participants showed a clinically significant and statistically reliable change in loneliness scores (indicated in red in Figure 5.1). Of these, five showed significant decreases in loneliness (P11, 24, 30, 31, 35) and one showed a significant increase in loneliness (P33).
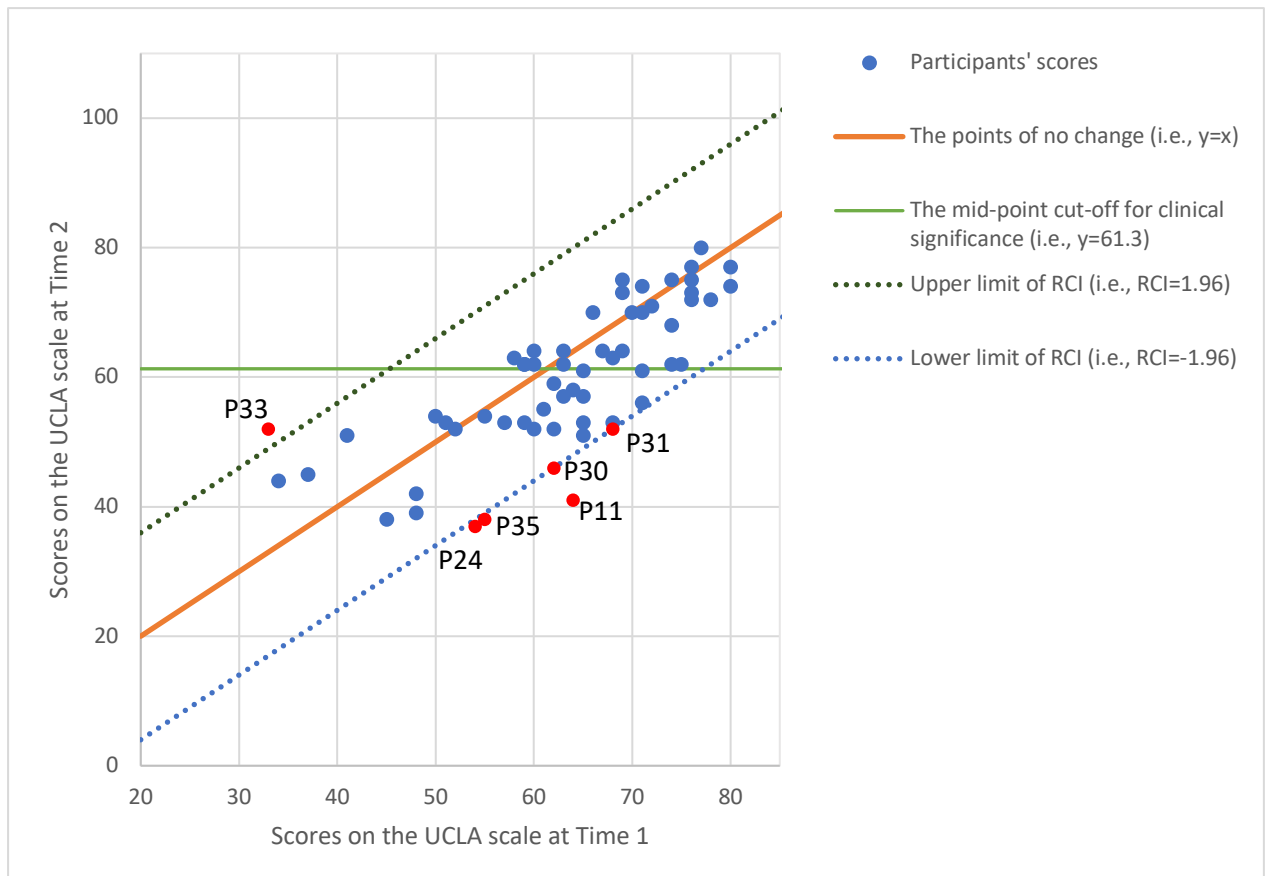
Figure 5.1. Scatterplot showing Time 1 and 2 scores
Note: In Figure 5.1, the participants above the y=x diagonal line showed an increase in scores and those below the y=x diagonal line showed a decrease in scores. The mid-point cut-off was calculated by taking the midpoint of the means of participants' scores at Time 1 and 2 (Zahra & Hedge, 2010). The scores below this horizontal line indicate clinically significant changes while those above it indicate not clinically significant. The scores between the line of upper limit of RCI and line of lower limit of RCI show unreliable changes. The scores below or above those lines indicate reliable changes.

In addition to completing the UCLA scale, participants were directly asked about any changes in loneliness due to the pandemic. As seen in Table 5.6, around half of the participants reported feeling affected by loneliness during lockdown. Further, around half felt their experiences of loneliness had changed during lockdown: 21.7% reported that their loneliness had lessened and 36.7% reported that their loneliness had increased. The remainder felt that their experience of loneliness had stayed the same, or were unsure.

Table 5.6. Perceptions of loneliness during lockdown

Questions	Responses	N (%)
Has loneliness affected you during lockdown?	Yes	31 (51.7)
	No	22 (36.7)
	Not sure	7 (11.7)
Has your experience of loneliness changed during lockdown?	Yes - it has lessened	13 (21.7)
	Yes - it has increased	22 (36.7)
	No - it has stayed about the same	16 (26.7)
	Not sure	9 (15.0)

5.3.2 Qualitative data: Experiences of loneliness among autistic adults during lockdown

Qualitative data were collected in relation to two areas: experiences of loneliness during lockdown (analyzed using thematic analysis) and management of loneliness during lockdown (analyzed using content analysis). Quotes are presented verbatim including any spelling and typographic errors.

Regarding participants' experiences of loneliness during lockdown, three themes and seven sub-themes were identified (see Figure 5.2).

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┌─────────────────┐     ┌─────────────────┐     ┌─────────────────┐
│  The impacts of │     │  Exaggeration of│     │  A "new" normal │
│ prescribed social│     │existing difficulties│  │                 │
│  circumstances  │     │                 │     │                 │
└────────┬────────┘     └─────────────────┘     └────────┬────────┘
```
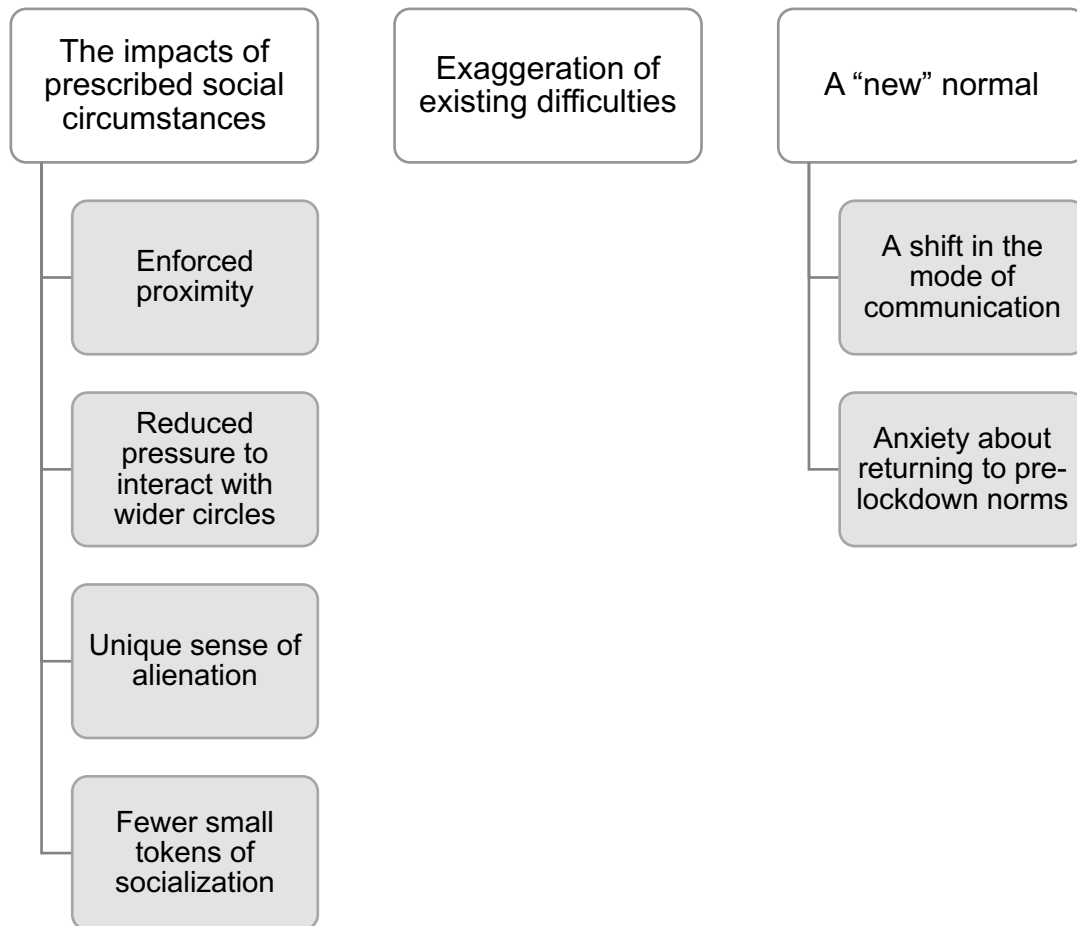
Figure 5.2. Thematic map of autistic adults' experiences of loneliness during lockdown

Theme 1: The impact of prescribed social circumstances

Autistic adults in this study reflected on the way in which their social situation had been determined by the pandemic restrictions. Autistic adults highlighted the effects of ***enforced proximity*** during lockdown. The constant close proximity to specific others was overwhelming and tiring for some, who reported that the lack of choice in who you spend time with could cause loneliness: "never alone but lonely (Participant 1; henceforth P1). For others, this made them less lonely: "I'm at home with my partner who is also my best friend and the person who understands me most and I communicate with most" (P3), "I am happy living with my husband and cat" (P24). For those who were living alone, lockdown often meant more isolation:

"[loneliness has increased during lockdown because] I live on my own so I am always alone" (P34).

Autistic adults emphasized the **reduced pressure to interact with wider circles**. This was described as comforting and reduced the sense of alienation they reported feeling when with others: "[loneliness has decreased during lockdown because] I always feel more alien when there are other people about because I realise how much I don't fit in" (P23). Some participants explained how they were already in somewhat of a lockdown by choice before COVID-19, so lockdown was felt to have no impact on their experiences of loneliness: "I've been isolated at home for years, the lockdown didn't change [loneliness] much really" (P10). Autistic adults reported feeling more equipped to deal with lockdown due to their prior experiences: "I have been alone and largely self-sufficient all my life. It's prepared me for lockdown… being autistic has in many ways prepared me for this situation" (P39).

Autistic adults highlighted that lockdown brought a **unique sense of alienation**. Some participants reported that the sense of togetherness during lockdown in the society reminded them that they were alone: "[loneliness has increased because] I'm more aware nobody cares about me. I'm more aware of being alone while everyone else seems to have someone to go through all this with" (P44). Some felt excluded from others (e.g., colleagues, friends): "I feel left out of the video calls that my coworkers have been doing each week, because I don't feel comfortable with group video calls and find them too difficult to understand" (P28). Others felt they had a different response to lockdown from non-autistic people and felt that non-autistic people did not understand their unique sense of loneliness: "[loneliness affected me during lockdown] because when i complain the loneliness,

instead of validating my feelings people tend to answer 'it's the same for everyone'" (P1).

Autistic adults reported that they had *fewer small tokens of socialization* that were deemed as important to them and were hard/impossible to do online. Participants spoke of valuing casual social interactions: "I miss going for a cup of tea with my colleagues and the office dogs as I have no pets of my own" (P31). Further, they discussed the impact of having fewer surface level conversations with strangers and acquaintances: "if the gym had been opened I really don't think it [loneliness] would have been as big a problem - definitely!!! The gym was my one social activity (well, I did it on my own, but it felt like a social activity to me)" (P47).

Theme 2: Exaggeration of existing difficulties

The autistic adults in this study described a magnification of the difficulties that they had already experienced prior to lockdown: "I have few friends but can't meet up with them now, and we don't have the sort of relationship where we call each other up, so they actually don't feel like they are friends anymore" (P20). They also reported they had more time for reflection during lockdown, which "…caused me to ruminate too much which has not been good for mental health" (P51). Some reported that lockdown exacerbated the conflict between the desire for, and struggles with, social interaction:

> "I think that now most people feel like I feel every day - but they feel it because Covid 19 threatens their life, I felt it because I feel so invaded by [humans] in normal day to day situations. I realise that this may seem to contradict my desire to not feel lonely - and to be near people that I feel close to - but they are so very rare - there are so few people that i can connect with - that is why it is lonely" (P54).

Theme 3: A "new" normal

The autistic adults in this study reflected on the way in which lockdown brought changes to their life and the impact this had on them. Participants highlighted ***a shift in the mode of communication*** with more online interaction and more pressure to interact online (e.g., online social events). Some found this overwhelming with too many things to attend to: "I've found the constant bombardment of texts and whatsapps a bit much sometimes, feeling like I have to respond" (P30). Others noted that it was just different from the traditional in-person interaction: "electronic communications like Twitter, Facebook messenger and zoom have helped to limit the degree of loneliness, but only with the right people and when it doesn't feel forced or dutiful" (P52).

Many autistic adults found themselves ***adapting to the lockdown routine*** and liked some cultural changes the lockdown brought. For example, social distancing was reported to suit their needs in social situations (e.g., less small talk, working from home): "I like my own company and find being with too many others difficult so lockdown suits me fine" (P49), "Now I am used to the lock down and can appreciate the positive aspects, such as less noise and increase in the visibility of nature" (P60).

Autistic adults in this sample also reported ***anxiety about returning to pre-lockdown norms***. Now that many were beginning to adapt to the lockdown routine, changing the routine again to return to pre-lockdown norms appeared to be anxiety-provoking: "everyone seems to feel things will go back to normal after lockdown is lifted. Normal was bad for me too. Worse in many ways" (P44), "I feel like i am going into my shell more, the longer it goes on the harder i find it to get out of the house" (P20).

5.3.3 Qualitative data: Management of loneliness during lockdown[23]

Management of loneliness during lockdown was analyzed using content analysis, examining the strategies autistic adults used to manage loneliness as well as any support they would have liked. Quotes are presented verbatim including any spelling and typographic errors.

How autistic adults managed loneliness during lockdown

Responses from 60 participants who answered this question were analysed (see Table 5.7). About a quarter of the participants (n=16, 26.7%) reported that they did not feel lonely or did not attempt to manage any feelings of loneliness. There was one instance where the response did not align with the question and this was categorized as miscellaneous. For the remainder of the participants, management of loneliness commonly centred around seeking social interaction, followed by distraction/keeping busy.

Table 5.7. How autistic adults managed loneliness during lockdown

Category	N (%)	Example quotes
Social interaction (e.g., talking with others on the phone/in person where possible, using social media)	21 (35.0)	"I have been calling and messaging family more often and arranging video calls" (P31), "I try and reach out to people, speak to the people I would see in person and I join groups on Zoom" (P54)
Distraction/keeping busy (e.g., working more, walking/walking dogs, increased use of media)	15 (25.0)	"I distract myself by walking the dogs, playing games or reading" (P2), "I have worked more and tried to help people" (P59)
Mental health support (e.g., Seeing therapist/counsellor, "support staff", chaplain)	6 (10.0)	"I have a counsellor" (P29), "Talking to support staff over video call" (P43)
Routine (e.g., making a new routine for	4 (6.7)	"We've made a routine to better replicate his previous routine of 'coming

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[23] In the questionnaires on management of loneliness, autistic adults were advised to respond with NA if the question was not applicable to them (e.g., not having felt lonely). In hindsight, however, the intentions behind their responses of NA could have been either they did not feel lonely or did not attempt to/did not know how to manage any feelings of loneliness.

lockdown, sticking to the same old routine)		home from work'" (P3), "I try to keep to the same routine" (P6)
Resting	3 (5.0)	"Lying in my room a little while when my son is busy doing something or playing a video game" (P15), "Iv slept a lot" (P57)
Interacting with nature	2 (3.3)	"I have nature sound/scene videos running a lot to try and soothe me and take my mind somewhere less awful" (P44), "By spending energy with the sun and the moon. That has REALLY helped" (P47)
Crying	2 (3.3)	"I cry a lot" (P44), "When I feel bad about feelimg lonely (sometimes I just accept it) I allow myself to cry" (P54)
Space/time for oneself	2 (3.3)	"I've tried to get out and find somewhere quiet to sit by myself for a little bit" (P23), "Reflecting on how i feel" (P43)
Hugging a dog	1 (1.7)	"I've hugged my dog a lot" (P45)
Miscellaneous	1 (1.7)	"There is no one to talk to" (P50)

Note: as categories were not mutually exclusive, some percentages equal more than 100%.

How autistic adults wanted to manage loneliness during lockdown

Responses from the 60 participants who answered this question were analysed (see Table 5.8). Over a half of the participants (n=33, 55.0%) reported that they did not feel lonely or did not know what would have helped them alleviate their feelings of loneliness. There were also instances where the response did not align with the question and this was categorized as miscellaneous (i.e., participants either described their experiences of loneliness during lockdown or how they managed loneliness during lockdown instead of how they wanted to manage loneliness). Suggestions from the remainder of the participants centred on social interaction, highlighting that arranged, regular interaction would have been particularly helpful. A few participants mentioned access to public places but did not specify the purpose of their desire to access public places. This could be for small tokens of social interaction and this was indeed mentioned by autistic adults (see Section 5.3.2);

however, it could also be for other purposes such as a change of scenery and I could not determine why they wanted to access based on the data alone. Thus, a category of access to public places was added upon a discussion in the cross-check process (see Section 5.2.5 for how the cross-check was conducted).

Table 5.8. What autistic adults wanted to manage loneliness during lockdown

Category	N (%)[24]	Example quotes
Social interaction (e.g., regular phone calls from friends, arranged online meetings with colleagues, small tokens of socialization)	15 (25.0)	"More online social events with societies from uni, frequent video chats with people I used to be around at uni" (P1), "More people reaching out to me. Friends saying they'll call me regularly every week on a Friday at 10, for example" (P8), "I would have like zoom meetups but don't have anyone to have them with" (P38)
Miscellaneous	9 (15.0)	"The lockdown actually made things better, because I'm less expected to socialize (which I don't like)…" (P10), "I feel thatstructures " (P58), "I have turned to sweets and biscuits" (P15)
Support (e.g., having someone non-judgemental to talk to, having practical support)	5 (8.3)	"More support to do practical things like shopping" (P21), "Support given at start instead of when I started really struggling" (P43), "Having someone to talk to who understands me would have been good" (P44)
Access to public places	2 (3.3)	"Access to librairies" (P16), "For librairies and cafes to remain open" (P50)

5.4 Discussion

This study used quantitative and qualitative measures to consider autistic adults' levels of loneliness before, and in the early stages of, the COVID-19 pandemic. When considered on a group level, autistic adults' loneliness scores were lower during the early stage of the pandemic, compared to before the restrictions were imposed. This decrease, however, appeared to be driven by a small number of

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[24] Note: as categories were not mutually exclusive, some percentages equal more than 100%.

participants. RCI analysis revealed that only five out of 60 participants showed significant decreases in loneliness. A further 34 showed a decrease in absolute terms, while nearly a third of participants showed an *increase* in loneliness scores (though only one of these was significant). These data align with scores on the direct measure of loneliness that I used, where participants were asked to report on any perceived change in their experiences of loneliness during lockdown. On this measure, the findings showed more than one third of the autistic adults felt their loneliness had increased during lockdown, while only a little over a fifth felt it had lessened.

The qualitative data from this study confirmed these variable experiences, with autistic adults reporting on the nuanced ways in which lockdown had affected their level of loneliness. In particular, participants discussed the impacts (both positive and negative) of enforced proximity. For example, they discussed an appreciation of the reduced pressure to interact with wider circles of people, yet missing the small tokens of socialization that were now absent from daily life. Autistic adults also reported an exaggeration of existing difficulties and talked about both the ups and downs of a 'new' normal. Regarding the management of loneliness in the early stages of the COVID-19 pandemic, social interaction (albeit remote) and distraction were most commonly mentioned, however most participants struggled to identify what could have been helpful to manage loneliness during lockdown. Participants also reflected that they experienced a unique sense of alienation during lockdown compared to non-autistic people. In some cases, they felt that they had a different response to lockdown, one which was not understood by non-autistic people. In other cases, they felt that the rest of society were displaying a sense of togetherness that they were excluded from. The latter appears to be linked to

collective loneliness (perceived lack of belonging in society; Cacioppo et al., 2015) which autistic adults have tended to report frequently but little research has investigated (as reported in Chapter Two).

In summary, this study reported a mixed picture of autistic adults' experiences of loneliness before and during the early stages of the pandemic (i.e., increased, decreased and no change in, loneliness). This finding differed from what has been reported about experiences of loneliness in the general population. In the general population, previous studies tended to report increased levels of loneliness during the early stages of the pandemic compared to before the pandemic (Bu et al., 2020b; Killgore et al., 2020; van Tilburg et al., 2021) while one study reported no change in loneliness during this time (Luchetti et al., 2020). Differences in the study design might account for this: the aforementioned studies on the general population were all quantitative and reported the changes/no changes in loneliness by only using standardized measures of loneliness without qualitative exploration of experiences. While studies on loneliness in the general population during the early stages of the pandemic have tended to be quantitative, one study has reported the experiences and management of loneliness in the general population in the UK during the early stages of the pandemic (McKenna-Plumley et al., 2021). McKenna-Plumley et al. (2021) exclusively reported negative impacts of the pandemic, whereas the autistic adults in the current survey reported more mixed experiences. For example, autistic adults appreciated reduced pressure to interact with wider circles while this was not described by participants in McKenna-Plumley et al. (2021). In terms of management of loneliness during lockdown, autistic adults in this study most commonly reported using social interaction or distraction. The same tendency in the management of loneliness was reported in the general population (McKenna-Plumley et al., 2021).

This suggests some commonalities, but potentially also some important differences, in the experiences of autistic and non-autistic adults during the pandemic.

As noted in the introduction, there have been two other studies that explored the experiences of loneliness in autistic adults before and during the pandemic (Capp et al., 2022; Scheeren et al., 2022). Using mixed methods, the current study reported variability in the experiences of loneliness among autistic adults in the early stages of the pandemic (including increases, decreases, and no changes in, loneliness). This finding differed from the finding in Scheeren et al. (2022) which reported that autistic adults' levels of loneliness were overall consistent before and during the early stages of the pandemic, and also differed from the finding in Capp et al. (2022) which reported perceived experiences of loneliness had worsened in autistic adults. Differences in the study design and analysis might account for this. Notably, the study presented in this Chapter used mixed methods. A recent scoping review on the impacts of the COVID-19 pandemic on autistic adults (Scheeren et al., Submitted) reported that most of their included studies retrospectively examined the impacts of COVID-19 pandemic on wellbeing in autistic adults by asking them to estimate the impacts of the pandemic based on their memory on pre-pandemic experiences while a small number of studies (10 out of 55 studies, 31%) examined the wellbeing in autistic adults over more than one time period. Scheeren et al. (Submitted) reported that it was the latter prospective studies that used in-depth qualitative approaches and yielded mixed experiences.

A key finding from the current study was the variability in the experiences of loneliness among autistic adults during the early stage of the COVID-19 pandemic. While conclusions could be drawn from the group-level loneliness scores (i.e., that autistic adults felt less lonely during lockdown than before lockdown), autistic adults'

subjective ratings of the change in their experiences of loneliness and further qualitative data revealed that these group scores may have masked many different experiences. Most existing literature on the pre-pandemic experiences of loneliness in autistic adults has tended to look at loneliness at group level rather than paying attention to the experiences of autistic adults on an individual level (see Chapter Two, Section 2.3.2). These studies report that autistic adults are lonelier than non-autistic adults, because the mean group scores on the existing loneliness scales were higher in autistic adults than non-autistic adults (see Chapter Two, Section 2.3.2). It is problematic to come to the conclusions solely based on the mean group scores because the group difference could be based on a small number of participants in the same way the significant group change was based on a small number of autistic adults in the current study. It is critical for researchers and practitioners to remember that autistic experiences of loneliness can be varied. Indeed, variability in the experiences of autistic individuals is not limited to loneliness, but has also been reported in other areas of autism research spanning many aspects of daily life, such as employment (Scott et al., 2019), quality of life (Oakley et al., 2020), sensory processing (Uljarević et al., 2017), and restricted and repetitive behaviours (Park et al., 2020). Such heterogeneity in autistic experiences makes autism research more challenging (Hens et al., 2019; Lombardo et al., 2019; Uljarević et al., 2017). The present study emphasises the importance of future work taking individual differences into account to avoid drawing misleading conclusions.

While this study showed that autistic adults reported various experiences of loneliness during the early stages of pandemic, this finding was drawn by including the RCI analysis and exploration of autistic adults' first-hand experiences of loneliness. This highlights not only the need to consider individual differences, but

also the value of using triangulation: the convergence of data from multiple measures to achieve reliable, meaningful results when studying loneliness in autistic adults. This aligns with recommendations from a report from Pellicano et al. (2019), which showed the importance of using both quantitative and qualitative reports to better understand autistic outcomes. This approach is particularly important when examining loneliness in autistic population, given that standard outcome measures have not been designed for the autistic population (as discussed in Chapter Three).

Regarding the management of loneliness, while many autistic adults did not know what could have helped their loneliness during lockdown, they most commonly reported wanting more social interaction. Autistic adults' desire for social connections despite the existing (pre-pandemic) and additional (pandemic-related) barriers confirms their desire for social connections reported throughout this thesis (i.e., Chapters Two, Three, and Four). However, it is notable that there were some patterns in the kind of social interaction autistic adults wanted during lockdown. As described in Table 5.8, autistic adults particularly wanted social interaction that was scheduled on a regular basis and/or initiated by others. This may reflect autistic individuals' difficulties with uncertainty (Rodgers et al., 2018; Tierney et al., 2016) and their need for predictability in social interaction (Brede et al., 2022).

Qualitative data from this study showed that many autistic adults who experienced loneliness during the early stages of the pandemic struggled to report on what could have been useful in managing their feelings of loneliness. This challenge of identifying the most appropriate support for themselves is not limited to the pandemic time nor to loneliness for autistic adults. For example, autistic adults have previously reported challenges in identifying the best adjustment/support for themselves, explaining that it was difficult when the responsibility was on them to

know the specific adjustment/support to request in the workplace (Davies et al.,

2022) or at university (Dexter et al., in review). Autistic adults in the current research

did, however, report how they actually managed their loneliness (i.e., by seeking

meaningful connections, by connecting with oneself).

It is crucial to evaluate what aspects of the early stage of the pandemic

benefitted autistic adults in alleviating loneliness. Among the themes identified in this

study, the following appeared to support autistic adults' social needs: enforced

proximity, reduced pressure to interact with wider circles, and adapting to lockdown

routines (particularly the consequences of social distancing). These findings align

with Heyworth et al. (2021) who conducted semi-structured interviews with 16

autistic young people (aged 12-18), as well as 32 autistic parents and 43 non-autistic

parents of autistic young people (aged 3-18) in Australia to examine their educational

experiences during the early stage of the pandemic (participants recruited in early

May 2020). Autistic young people in Heyworth et al. (2021) described fewer social

expectations when learning from home since most social interactions were with their

parents and much more predictable compared to those with their peers in school.

Autistic young people also reported less stress and better academic performance

because of fewer social expectations (Heyworth et al., 2021). This could be linked to

the finding in Chapter Four, that social interaction consumes much energy for autistic

adults. It is important to emphasize that these findings do not advocate for keeping

autistic adults away from others. Instead, these findings appear to describe the

importance of autistic adults having 'breathing space' from the social world in line

with the finding on autistic children's experiences of friendships (i.e., they sometimes

want to play by themselves) (Calder et al., 2013). While having minimal social

interaction for a while (e.g., interacting only with people who live together) may

benefit autistic adults to do well in other areas of life (e.g., academic or work performance), autistic adults in this study equally reported missing small tokens of socialization and described their desire for support during lockdown.

In adapting to lockdown routines, autistic adults in this study appreciated aspects of social distancing and government directives such as working from home. This finding aligns with two recent reports. First, the charity Autistica (2020) presented a collection of views on lessons learned from the pandemic, which were derived from autistic people, their families, and the professionals who work with them. This report highlighted: that remote working has made more job roles and meetings accessible for autistic people; that online therapy sessions using video calls reduced autistic people's distress with travelling and its associated unpredictability while still providing them with the meaningful therapeutic relationships; that virtual options increased accessibility to the events (e.g., conferences); and that remote learning options in educational settings could make education accessible to those who find the school settings difficult. Taken together with the results of the current study, it appears that remote options can benefit autistic individuals in various social settings (e.g., workplace, education, therapy, meetings). This is in line with how the arrival of the Internet in 1990s let autistic individuals to start connecting with each other and share their experiences with wider society, as outlined in Chapter One, Section 1.2.1 (e.g., Dekker, 2020). Moving out of the pandemic, online interactions could continue being beneficial for autistic adults to build and maintain meaningful relationships with others and to thrive more generally (e.g., vocationally). Given that loneliness leads to premature death (Holt-Lunstad et al., 2015) and autistic adults experience higher levels of loneliness than

the general population, the need to keep remote options open for autistic individuals even after the pandemic time should not be underestimated.

Limitations

The current study is not without its limitations. The study presented in this Chapter shared some common limitations with the studies reported in Chapters Three and Four: 1) participants were not representative of all autistic adults in the UK, and 2) using online surveys might have excluded autistic adults who had no access to or difficulties accessing the Internet (see Chapter Three, Section 3.4).

A further limitation of this study is that autistic adults reported that existing measures to assess loneliness did not fully capture their experiences (see Chapter Three) yet the study presented here used these same loneliness measures. Due to the rapidly changing situation with the COVID-19 pandemic at the time of this study, I had to design the study quickly and did not have enough time to adapt the measures as suggested in Chapter Three. Nonetheless, Chapter Three also reported the measures used in this Chapter aligned with autistic adults' subjective ratings of how lonely they were. Further, by incorporating qualitative data in addition to quantitative data, this study provided a detailed account of the experiences of loneliness in autistic adults during the early stage of the pandemic.

5.5 Conclusion

While this study was not in the initial plan for my PhD research, the implementation of lockdown in the early stage of the pandemic in the UK created an unprecedented social situation and a unique opportunity for research. Using mixed methods, this study reported the variable experiences of loneliness in autistic adults. While quantitative data (i.e., scores on loneliness measures) at a group level alone

showed decreased levels of loneliness in autistic adults, examination of individual differences (quantitatively and qualitatively) showed that autistic adults' experiences of loneliness during the pandemic were variable. The results highlight the value of examining loneliness in autistic adults from multiple angles and via multiple methods. Autistic adults' longing for social connections to alleviate loneliness during the pandemic confirmed their desire for social connections. Furthermore, this study showed that many autistic adults struggled with identifying what could have been helpful to alleviate loneliness during the pandemic, which was in line with previous reports that autistic adults tend to struggle with identifying the best support for themselves (e.g., at workplaces).

In next Chapter (i.e., General Discussion), I will discuss how my research findings – across all chapters - contribute to existing literature on loneliness in autistic adults and how they could be translated to real-life practice in reducing loneliness in autistic adults.

Chapter Six

General Discussion

6.1 Introduction

When I originally set out on this PhD journey, the aims of my thesis were: 1) to help non-autistic people learn about autistic adults' experiences of loneliness, and 2) to empower autistic people by sharing their views, experiences and perspectives. In the empirical chapters of my thesis, these aims were met through qualitative and quantitative investigations of autistic adults' experiences of loneliness. Importantly, throughout my research, I ensured that autistic adults could meaningfully input in two different ways: 1) by contributing to the design of the study (i.e., online survey materials), and 2) by sharing their views as participants within the studies.

To summarise the contribution of each Chapter of my thesis, in Chapter One, I provided background information on autism and loneliness, demonstrating the importance and urgency of addressing loneliness in autistic people. In Chapter Two, I conducted a systematic review to comprehensively synthesize quantitative and qualitative research on loneliness in autistic adults. One of the prominent findings from this review was that few empirical studies have used reliable and valid measures of loneliness developed specifically for autistic adults (which I addressed in Chapter Three). Another prominent finding was that there is a lack of research that explored autistic adults' lived experiences of loneliness (which I addressed in Chapters Four and Five). In Chapter Three, I conducted a mixed methods online survey to examine if and how accurately existing loneliness measures captured the experiences of loneliness in autistic adults. My key findings from this study were that 1) the widely-used measures of loneliness correlate with a direct measure of loneliness, indicating that they seem to accurately report the levels of loneliness in

autistic adults, 2) autistic adults reported several ways that the widely-used measures were difficult for them to complete, and 3) autistic adults in my sample reported feelings of loneliness, and several factors were associated with increased loneliness in autistic adults in this sample (i.e., being older in age, and being without a romantic partner). In Chapter Four, I conducted a qualitative study using an online survey to investigate autistic adults' lived experiences of what loneliness feels like, how they deal with loneliness, what helps them with loneliness, and if/how their experiences of loneliness change over time. My key findings were that 1) loneliness in autistic people is characterized by the internal conflict between the desire for and barriers to connections, 2) barriers to connections include sensory environments, a lack of societal understanding and acceptance of autism, and a lack of shared understanding and experiences, and 3) autistic adults can alleviate loneliness by connecting with similar and/or significant others, spending time with pets/animals, and understanding and accepting oneself. In Chapter Five, I conducted a mixed methods follow-up study using an online survey to examine if and how autistic adults' experiences of loneliness changed before and during the early stages of the COVID-19 pandemic in the UK. My main findings were that 1) autistic adults' experiences of loneliness varied during the early stages of the pandemic; and 2) autistic adults most commonly used social interaction to alleviate loneliness during the early stages of the pandemic.

In this Chapter, I will first demonstrate the contributions of this thesis to knowledge on autistic experiences of loneliness. I will then discuss the strengths and limitations of this research as well as the future directions in research and practice. Finally, I will present the conclusions of the thesis, along with my reflections of this PhD research.

6.2 Contributions of the thesis to knowledge on autistic experiences of loneliness

The studies included in my thesis helped to better understand the many facets of loneliness in autistic adults. In the next section, I outline some important questions about loneliness in autistic adults, demonstrating how my thesis has contributed to the field.

6.2.1 Question 1: Do autistic adults experience loneliness, and how does it relate to social interactions?

Throughout my research, loneliness has been shown to be a negative experience encountered by autistic adults. In studies reviewed as part of my systematic review (Chapter Two), autistic adults described their desire for social connections despite experiencing difficulties in social situations. Yet autistic adults also reported that loneliness was not synonymous with being alone. The latter finding was corroborated by the findings reported in Chapter Three, where autistic adults reported that frequently-used measures of loneliness were difficult to complete because they were based on some assumptions that did not apply to them. One such assumption was that being alone was a negative experience contributing to loneliness. In contrast, autistic adults explained that being alone was simply their choice and that they could be alone without feeling lonely. These findings were corroborated in Chapter Four, whereby autistic adults emphasized that they *do* want to have social connections but that it was not always possible to make connections with others due to experiencing barriers (e.g., sensory environments, lack of societal understanding/acceptance of autism). Because of such barriers, autistic adults explained that social interaction was tiring, which led to some avoiding social

interactions and others accepting loneliness as part of their experience. When considering how to manage feelings of loneliness during the early stages of the pandemic (in Chapter Five), autistic adults most frequently reported that they wanted social interaction.

The consistent finding that autistic adults *do* desire social connection of some forms adds to growing literature debunking the social motivation theory of autism (Chevallier et al., 2012), as discussed in Chapter One, Section 1.2.3. Conversely, the finding that autistic adults sometimes avoid social interactions and/or accept loneliness due to barriers to social connection fits well with the view of autism from the social model of disability (Oliver, 1990a): that difficulties in social interaction are not inherent in autistic people themselves but are contextual (i.e., depending on with whom, and in what circumstances, they interact).

In summary, the current research provided further evidence that autistic adults *do* want social connections of some forms, that autistic adults *do* experience loneliness in some circumstances/context, and that aloneness does not equate to loneliness.

6.2.2 Question 2: How can we determine how lonely autistic adults are?

Throughout my research, loneliness in autistic adults has been shown to be a complex feeling that cannot be sufficiently captured by standardized measures alone, especially when they are not developed for or validated in autistic adults.

The systematic review reported in Chapter Two demonstrated that few empirical studies had used reliable and valid measures of loneliness that were specifically developed for autistic adults. In just one study (Merkler, 2007), a measure of loneliness was developed for, and validated in, autistic adults. However, this measure had not been used or tested for reliability/validity outside of the original

thesis it was reported in. Further, existing literature had not established whether a new measure needed to be developed for autistic adults.

The results reported in Chapter Three showed that participants' scores on widely used measures of loneliness correlated with one another, and with a direct question about how lonely they feel. This finding suggested that the scores on the UCLA scale and SELSA aligned with autistic adults' subjective rating of their loneliness levels, potentially supporting their use with this population. However, qualitative data highlighted that autistic adults felt that these surveys were difficult to complete in multiple ways. More specifically, autistic adults felt that the measures did not fully reflect their autistic experiences and were also unclear in how they were worded. As such, while the UCLA scale and SELSA appear to accurately report autistic adults' subjective *levels* of loneliness, they could miss the underlying *experiences* of loneliness in autistic adults. Therefore, relying solely on standardized measures of loneliness may under/overestimate loneliness in autistic adults. Qualitative experiences of loneliness (as reported in Chapter Four) are, therefore, important to complement and explain scores on standardised measures.

As well as eliciting qualitative accounts from autistic adults, the research presented in this thesis highlighted the importance of taking individual differences into account when considering autistic experiences of loneliness. For example, the data presented in Chapter Five showed that loneliness levels *for the group* decreased during the early stages of the pandemic compared to before the pandemic. However, when looking at the data on an *individual level*, statistically significant and reliable decreases in loneliness were only seen in a small number of participants (five out of 60). Furthermore, autistic adults' perceptions of changes in loneliness during the early stages of the pandemic (compared to before the

pandemic) and their lives experiences during the pandemic were variable. Several studies outside the field of autism research have also emphasised the importance of examining the experiences of autistic people in multiple ways (e.g., Pellicano et al., , 2019).

Notably, the perspectives of autistic people have traditionally been overlooked in autism research. It is only relatively recently that researchers have started to conduct more qualitative research on autistic people, investigating autistic people's lived experiences (e.g., Gillespie-Lynch et al., 2017; Nicolaidis, 2012). This focus could be linked to increased recognition of autistic expertise. Milton (2014) argued that only autistic people themselves can fully represent their subjective experiences, and emphasized the need of including autistic researchers in research on autistic people (particularly concerning sociality). Indeed, Gillespie-Lynch et al. (2017) reported that autistic adults had more scientifically based knowledge of autism compared to non-autistic adults with or without an autistic family member, and suggested that autism research should involve autistic individuals as experts in autism. Likewise, Grant and Kara (2021) recently discussed the strengths of autistic researchers particularly in qualitative research including their detailed knowledge on their area of interests (i.e., respective topics on autism).

In summary, this research reported that it is important to complement standardized measures of loneliness with the first-hand accounts of autistic adults. Nonetheless, this research has also made some suggestions to adapt frequently-used loneliness measures for future research (although these adaptations have yet to be evaluated).

6.2.3 Question 3: What, if anything, is unique about autistic adults' experiences of loneliness?

Through my research, some unique aspects of loneliness in autistic adults were identified. First, my research presented in Chapter Four found that autistic adults' experiences of loneliness centre around the internal conflict between their desire for connections and difficulties in realizing their desire, which leads to loneliness. Autistic adults often experience multiple challenges in social settings that are built on the non-autistic majority's terms (e.g., difficulties with sensory environments) and they therefore experience exhaustion from social interactions (as discussed in Chapters Two and Four). As a result of such challenges and/or the need to rejuvenate from exhaustion, autistic adults sometimes avoid social interactions. Ironically, this avoidance may lead to loneliness, despite a desire for connection.

The research presented in Chapter Five, however, showed that autistic adults report some positive experiences in relation to loneliness during the early stages of the pandemic, due to reduced pressure to interact with wider circles (e.g., comforting, reduced sense of alienation. Yet autistic adults also reported missing small tokens of socialization). While the aforementioned findings from Chapter Five may seem contradictory, it is important to note that autistic adults appreciated the *general* sense of reduced social pressure while they also missed some *specific* forms of socialization such as chatting with colleagues at work and seeing strangers in public spaces.

Second, my research found that autistic adults experience meaningful relationships with significant others (e.g., parent, partner, pets/animals) and with similar others (e.g., other autistic people, others with same hobbies) (Chapters Three and Four). Although such relationships may be important for everybody regardless of their neurotypes, they might be particularly salient for autistic adults. For example,

autistic people often find changes and unpredictability difficult (e.g., Boulter et al., 2014), and while social interaction is unpredictable in nature (Riggs et al., 2006), meaningful relationships with significant others may provide continuity and constancy in relationships. Autistic individuals may also experience difficulties with starting and stopping activities (i.e., autistic inertia), and they tend to rely on external factors for their time management (Buckle et al., 2021), suggesting the significance of constancy regarding whom autistic adults interact with. Autistic people tend to be intensely gravitated towards their own interests (Murray et al., 2005), which may help them to comfortably and naturally cultivate meaningful relationships with similar others.

A third unique aspect of loneliness identified in my research was that loneliness in autistic adults appears to be underpinned by a lack of societal understanding and acceptance of autism (Chapters Two and Four), as well as a lack of shared understanding and experiences (Chapter Four). These factors often lead to autistic adults' use of camouflaging to 'fit in' which Chapter Two reported as a factor associated with increased loneliness in autistic adults. This could, therefore, be an important avenue for future research.

In summary, loneliness is a universal feeling shared by everybody, including autistic people, but there are some unique experiences of loneliness that only autistic individuals appear to experience; generally and in relation to the pandemic.

6.2.4 Question 4: What can be done to alleviate loneliness among autistic adults?

In my research, two key suggestions to alleviate loneliness in autistic adults were identified. First, I found (in Chapters Two and Four) that it is important for autistic adults to learn to accept autistic differences to help alleviate loneliness. This

acceptance can be gained by connecting with significant others and/or similar others. Such connections may be made/maintained with one person (e.g., parent, partner), pets/animals, or those online (as identified in Chapters Three and Four). I reported (in Chapter Five) that autistic adults who lived with significant others during the early stages of the pandemic (e.g., their partner) positively experienced enforced proximity, which gave them more time with their significant others and reduced loneliness.

Second, I found that society needs to make adaptations, adjustments, and be more understanding towards autistic adults to alleviate loneliness. My research provided some clues as to how this could be achieved. One way for society to support in alleviating autistic adults' loneliness is to remove sensory barriers in social environments. I reported (in Chapters Two, Four, and Five) that sensory environments can be barriers for autistic adults to engage in social interactions. This finding was corroborated by the finding reported in Crompton, Hallett, et al. (2020) where autistic adults reported that some social activities were not accessible to them due to the sensory uncomfortable environments (e.g., loud noise). Further, during the early stages of the pandemic, some autistic adults experienced decreased loneliness. More online social opportunities during lockdown (Chapter Five) might have removed the sensory barriers for autistic adults that they reported prior to the pandemic, decreasing loneliness (Chapter Four). Indeed, Crane et al. (submitted) evaluated the online version of a well-received autistic-led programme for newly diagnosed/identified autistic adults (Crane, Hearst, et al., 2020) and reported that autistic adults felt that online delivery of the program removed sensory barriers (e.g., in travelling, in-person interactions) and enabled them to fully engage in the programme. Another way that society could help alleviate loneliness in autistic adults

is by fostering a better understanding and acceptance of autism and by cultivating shared understanding and experiences between autistic and non-autistic people (as detailed in Chapters Two and Four). Indeed, in Chapter Four, Section 4.4, I reported that one of the key insights from Chapter Four and Elmose (2020) was that the feelings of disconnection from others and lack of societal understanding and acceptance of autism underpin loneliness in autistic adults.

While some autistic adults reported that they came to terms with their feelings of loneliness over time (see Chapter Four), it should be emphasised that accepting loneliness should be a last resort for autistic adults in such situations. As barriers in social interaction for autistic adults are often external to autistic people (e.g., sensory environments, lack of societal understanding and acceptance of autism), reducing the barriers in social interaction is impossible without the cooperation of non-autistic people. This idea relates to the concept of Autopia (autistic utopia), a term coined by Beardon to refer an ideal and inclusive world for autistic people (Beardon, 2020). Beardon (2020) explained that Autopia recognizes autism as a disadvantage, not a problem, and emphasized the need for the society to take initiatives to make accommodations for autistic people. Since little can be done by autistic people on their own to remove the barriers in social settings (except for choosing the 'right' social environment for themselves), some autistic adults may end up accepting their feelings of loneliness and grow to become comfortable with their decision. Nonetheless, there seems to be a fine line between being content with being on their own and being lonely. As autistic adults reported in Chapter Three, loneliness is time/context-dependent and those who may feel comfortable with being on their own at one point could feel lonely at another time and context in life.

In summary, autistic adults report trying different strategies to alleviate their feelings of loneliness. In alleviating loneliness, there are some strategies autistic adults may find helpful: accepting autistic differences and connecting with significant/similar others. There are also other strategies that society is encouraged to address: making adjustments/accommodations in sensory environments within social settings, improving societal understanding and acceptance of autism, and cultivating shared understanding and experiences between autistic and non-autistic people. Notably, the experiences of the pandemic showed that it was possible for society to make accommodations for autistic adults' social needs (e.g., making online options available for healthcare, learning, or conferences) (Autistica, 2020).

6.3 Strengths and Limitations

My thesis presented a robust and comprehensive investigation of loneliness in autistic adults, pre- and post-pandemic, and via qualitative and quantitative methods. Yet the research presented in this thesis is not without its limitations. To reiterate, there were some shared limitations across my studies. First, my sample was not representative of all autistic adults. For example, my participants were largely from a White ethnic background, female, had gained university qualifications or above, and used speech to communicate (see Chapter Three, Section 3.4 for further details). However, it is notable that my sample represented an important group to study loneliness within since the needs of the verbally/cognitively able autistic people are often overlooked (e.g., Crane, Adams, et al., 2019). Second, using online surveys might have excluded some autistic adults who were without access to the Internet. Yet, using online surveys might have enabled autistic adults to comfortably participate in the study on a sensitive topic of loneliness (e.g., compared to in-person

interviews). Online surveys are also beneficial in some ways and could particularly be helpful for autistic people (e.g., no need to travel) (Crane, Sesterka, et al., 2020).

There are additional limitations that might have impacted the findings of the thesis. First, recruiting participants mainly through social media and groups and organizations of autistic people might have meant that participants might have been largely self-advocates (Rødgaard et al., 2022) had more social model and neurodiversity-affirmative perspectives (i.e., viewing autism as a difference, not a disorder; see Chapter One, Section 1.2.1 for conceptualization of autism). For example, my research (in Chapters Two and Four) identified that autistic adults find it difficult to connect with others due to a lack of societal understanding and acceptance of autism (as described in 6.2.3 and 6.2.4). If participants had been recruited from different sources (e.g., a database for biological research on autism), they might have viewed autism differently from my participants. Second, my empirical studies focused on participants in the UK, as experiences of loneliness are different in different countries (Barreto et al., 2021). As such, the findings from my research must not be extrapolated beyond the UK. For example, higher individualism in certain cultures is associated with increased levels of self-reported loneliness (Barreto et al., 2021) and the UK is considered to be one of the most highly individualist countries (Hofstede et al., 2005). Further, there might be autism-specific differences related to loneliness across cultures. For example, people in Japan may view autism from more of a deficit-focused perspective compared to those in the UK and such difference in the societal view of autism will likely impact autistic adults' experiences of loneliness (Stegeman, 2020). Despite the focus on the UK, the approaches I have taken in this investigation of loneliness in autistic adults might be helpful for researchers in other countries to adapt. Third, my original plan was to

develop some aspects of my research further, such as taking forward some of the recommendations about measurement tools identified in Chapter Three. However, because of the pandemic, experiences of loneliness were thought to be impacted by the unprecedented social circumstances (e.g., social distancing measures) and a study on loneliness in the pandemic seemed like an important opportunity to provide a unique insight into loneliness in autistic adults. However, this change in plan meant that I was able to gather in-depth information about autistic experiences of loneliness during an unprecedented time. Importantly, across my entire thesis, I have laid important foundations for future work. Fourth, there are different ways to ensure reflexivity and I used some of these in my reflexive thematic analysis. For example, I used bracketing exercise in Chapter Four to reflect on my influence on the analysis. Further, I reflected on positionality in all Chapters where I used reflexive thematic analysis (i.e., Chapters Three, Four, and Five). However, this was the first time I conducted reflexive thematic analysis, and I subsequently learned more about different ways to be reflexive. I look forward to trying other techniques in the future and further develop my reflexive practice (e.g., using a reflexive journal where researchers reflect the progress of analysis throughout the process; Brown (2021)).

6.4 Future Directions

Following the important foundational work presented within my thesis, it is important to consider what could be done further so that autistic adults feel less lonely and those who seek connections experience connectedness. In this regard, my research participants identified a gap between autism research and practice. As part of the research presented in Chapter Four, I asked participants their priorities for future loneliness research. However, as previously noted, data on this question was

not included in Chapter Four, nor used to guide my research, because of the unprecedented social circumstances associated with the COVID-19 pandemic. While this is not a full analysis, it was interesting that participants (n=203) highlighted the importance of practicality in research: my sample of autistic adults emphasized that future research needs to investigate solutions to loneliness, including examining ways to improve societal understanding and acceptance of autism. For example, one participant explained that research needs to be "Helping us to be less lonely" (P18). Another participant added that research needs to investigate "How to meet social needs in an accessible way" (P68). Some autistic adults also expressed the urgency in addressing loneliness more practically: "What we need is action to remedy the situation" (P171). These sentiments are not unique to research on loneliness. For example, Pellicano et al. (2014) investigated the research priorities of autistic adults, their family members, practitioners, and researchers, using focus groups and interviews (n=72) and online surveys (n=1517). Pellicano et al. (2014) showed that despite more autism research than ever before, this research does not always have direct relevance to autistic individuals. Next, I will present different suggestions for future directions in research and practice to which efforts could be made to alleviate loneliness in autistic adults.

Cultivating acceptance of autistic differences in autistic adults

My research has identified that autistic adults could alleviate their feelings of loneliness by accepting their autistic differences. One autistic difference identified in my research was that autistic adults may experience meaningful relationships with one person (e.g., parent, partner), with pets/animals, and/or online. While these relationships may also be important for non-autistic people, they appear to be more salient for autistic adults as explained in Section 6.2.3. Cultivating acceptance of

autistic differences in autistic adults is not the same as forcing them to accept their differences nor leaving them to do so on their own. A good example of cultivating acceptance of autistic differences in autistic adults is found in a post-diagnostic support programme designed by and for autistic adults. Crane, Hearst, et al. (2020) reported an initial evaluation of "Exploring Being Autistic", a ten-week autistic led programme for newly diagnosed or identified autistic adults developed by an autistic consultant/trainer who was also one of the authors of the paper. Crane, Hearst, et al. (2020) found that autistic adults who completed the programme felt they could develop a positive view on autism. For example, Crane, Hearst, et al. (2020) reported that autistic adults felt they could better understand and deal with their daily challenges (e.g., anxiety) and better equipped to advocate for themselves. Importantly, autistic adults in Crane, Hearst, et al. (2020) reported that the comprehensive presentation of autism in the programme including autistic strengths had empowered them to accept their differences. Promoting self-compassion among autistic adults might help autistic adults to accept their autistic differences. Self-compassion involves kindness towards oneself, mindful awareness of one's feelings and thoughts, and recognition of common humanity (e.g., viewing pains or failures as part of human experiences instead of isolating experiences) (Neff, 2003). Cai et al. (2022) used online surveys to examine the relationships between self-compassion and mental health outcomes in autistic adults (n=153), and reported that increased self-compassion was positively associated with positive mental wellbeing and negatively associated with symptoms of anxiety and depression. Cai et al. (2022) also conducted interviews with autistic adults (n=11) to explore their experiences of self-compassion. Some autistic adults in Cai et al. (2022) reported that

understanding their experiences through the lenses of autism helped them to become more self-compassionate.

Social prescribing

My research has shown that connecting with similar others can help alleviate loneliness in autistic adults. Therefore, encouraging autistic adults to seek opportunities to connect with similar others and making such opportunities available is recommended, should they want to do so. A potential solution in this regard is social prescribing. Social prescribing (also known as community referral) refers to the way primary healthcare professionals refer their patients to non-medical services within the community (Chatterjee et al., 2018; GOV.UK, 2022). The National Health Service (NHS) England considers social prescribing as a key element of their Universal Personalized Care, which aims to give individuals choice and control over their care (NHS England, n.d.) and social prescribing is gaining more attention in the UK in recent years (Chatterjee et al., 2018; Husk et al., 2016; Kilgarriff-Foster & O'Cathain, 2015). Social prescribing is mainly used for people with long-term illnesses, complex social needs, mental ill health, and increased feelings of loneliness (NHS England, n.d.). In the UK, social prescribing often involves link workers who help the individuals referred by healthcare professionals to build a personalized strategy for their health/wellbeing and access appropriate support from local organizations or communities (GOV.UK, 2022; NHS England, n.d.). Social prescribing could involve a range of activities such as art, exercises, gardening, or cooking and practical support such as housing advice (GOV.UK, 2022; Thomson et al., 2015). There is yet little evidence to determine how beneficial social prescribing could be (Bickerdike et al., 2017; Pescheny et al., 2020), although a scoping review reported that social prescribing could increase self-esteem and mental health,

provide a sense of empowerment, and reduce symptoms of depression or anxiety (Thomson et al., 2015).

Due to the dearth of literature on social prescribing for autistic adults, Featherstone et al. (2022) conducted a systematic mapping review about a similar approach in supporting autistic adults (i.e., non-medical and/or community-based support). Featherstone et al. (2022) reported that 1) most evaluations have been on psychosocial support or vocational interventions and little evaluations have been on low intensity services that would be offered in social prescribing, 2) outcomes measures of non-medical/community-based support have focused on the characteristics of autism (e.g., communication) instead of autistic adults' health and wellbeing, and 3) non-medical/community-based support have some accessibility issues for autistic adults (e.g., group activities or having to travel to meet others can be difficult for some autistic people). The accessibility issues for such services were also highlighted in a commentary (Charlton et al., 2021) which provided an overview of potential barriers of and recommendations for social prescribing for autistic adults.

Charlton et al. (2021) noted that variability and complexity (e.g., co-occurring conditions and their impacts) in autistic people's daily challenges need to be taken into consideration when providing social prescribing for autistic adults. This recommendation that social prescribing needs to consider autistic people's variability and complexity was corroborated by the finding from Featherstone et al. (2022) that individual differences (e.g., age, motivation, cultural background) among autistic adults impact the enrolment, engagement, and retention in the non-medical/community-based services. Charlton et al. (2021) recommended that link workers need to be trained to have a good understanding of autism and that service providers might need to accommodate their services for autistic people's needs. This

is in line with the findings that autistic adults have less satisfying experiences with support and services when the service providers lack knowledge about autism (Brede et al., 2022; Featherstone et al., 2022). Charlton et al. (2021) suggested that the accessibility to the services/activities need to be considered when providing social prescribing for autistic people. For example, Charlton et al. (2021) recommended that service providers to provide clear information about what to expect in the activities before the initial attendance and to consider autistic people's different sensory experiences during their attendance. Additionally, Charlton et al. (2021) suggested the importance of making a goal with the link workers regarding what the individuals want to achieve through social prescribing, not assuming that discharge from services is equal to achieving the individuals' goals for their health and wellbeing (e.g., Dayson & Bennett, 2016). While more research is needed to build an evidence base for the efficacy of social prescribing for autistic adults, social prescribing could be one way to provide autistic adults with opportunities to connect with similar others and alleviate their loneliness.

Personally, I aimed to address this issue by setting up an autistic peer group at UCL, to give autistic students (both undergraduate and postgraduate) a safe space to meet other autistic students and build connections. From January 2019, once a week, the group met in person at UCL. To give structure to the meeting and promote meaningful conversations with each other, the group used topic cards that I prepared to help the group with conversations, where I described various topics such as family, hometown, and likes/dislikes of London. I put a pile of topic cards in the middle of the table around which the group sat, the members of the group took a topic card in turn, and everyone had the opportunity to discuss the topic as long as they felt comfortable doing so. The more time the group spent together, the deeper

and more sensitive conversations we had (e.g., on the topic of mental health). Since I left the UK, I passed on leadership of this group, which has now become UCL's Autism Society.

Such groups do not have to be exclusively for autistic people but based around interests. My research showed that autistic adults make meaningful relationships with similar others not only through autistic identity but also through shared interests (in Chapter Four). The latter was corroborated by the findings from Chapter Two: some included studies in the systematic review presented in Chapter Two (Elmose, 2020; Milton & Sims, 2016; Southby & Robinson, 2018) reported that connecting with like-minded people through shared interests is associated with decreased loneliness. Previous studies have reported that as many as 65% to 95% of autistic people have at least one "special interest" (i.e., intense interest) (Grove et al., 2018; Klin et al., 2007; Turner-Brown et al., 2011) in a wide range of areas (e.g., autism, gaming, or art; Grove et al., 2018). Many autistic adults in Grove et al. (2018) (363 out of 443 participants, 82%) reported having more than two special interests, suggesting that autistic people's interests may not be as narrow as previously described (Turner-Brown et al., 2011). Therefore, social prescribing to provide autistic adults with the opportunities to meet similar others could be through the veins of autism-related organizations, groups, or services and/or through interests' groups (e.g., art groups).

Accommodations in social settings

My research showed that sensory environments could be barriers for autistic adults to engage in social interactions, which added to the evidence from previous research that sensory avoidance is associated with increased levels of loneliness in autistic adults, as reported in the systematic review in Chapter Two (Smith & Sharp,

2013; Syu & Lin, 2018). One way to remove sensory barriers is to incorporate online interactions in various social settings (e.g., work). In Chapter Five, it was identified that some cultural changes during the early stages of the pandemic were beneficial for autistic adults, including remote work. This finding was corroborated by a report from Autistica (2020), which showed that online options during the pandemic were advantageous to autistic adults in multiple social settings including work and therapy sessions. Regarding social interactions that need to be in-person, accommodating sensory environments could more complex given the diversity and complexity in autistic adults' individual needs (Buckle, 2020). Nonetheless, it is important to learn from the environments that autistic adults consider to be accessible and inclusive, to consider how they could be emulated in other places. For example, Autscape is a well-received autism-related conference led by and for autistic people (although non-autistic people are also welcome to attend) (Autscape, 2022; Milton, 2013). Autscape is different from other autism conferences in that the "environment, schedule, social structure, behaviour expectations, and presentation topics are all designed to encourage full participation of autistic people" (Autscape, 2022). It is admittedly impossible to make *every* social situation akin to Autscape. However, it may be possible to make more social opportunities better suited for autistic individuals in small but significant ways.

To make accommodations in social settings for autistic adults, to alleviate their loneliness, society should strive to create inclusive social environments that could benefit *all* people and then consider making reasonable adjustments for autistic people if applicable. Striving for inclusive environments in workplaces for autistic adults has also been recommended in employment research on autism. For example, Romualdez, Walker, et al. (2021) reported that inclusive workplaces often

entail a good understanding of autism among employers and their willingness to make adjustments. Similarly, inclusive social environments may need a good understanding of autism in society and non-autistic people's willingness to make adaptations. The cooperation of non-autistic individuals is crucial in making accommodations in social settings. The autistic adults who participated in the study reported in Chapter Five described the challenges in identifying what could have helped their loneliness. This finding is corroborated by previous studies that reported autistic adults' struggles with identifying helpful accommodations for themselves in workplaces and feelings the pressure to actively ask for accommodations (Davies et al., 2022). Improving non-autistic people's understanding and acceptance of autism may encourage their cooperation in making simple and positive changes in social environments for autistic individuals. The onus is still placed disproportionately on autistic people in society to make adaptations, rather than on changes to enable autistic people to comfortably engage in various different situations (e.g., employment interviews; Scott et al., 2017). Within autism research itself, Botha (2021) reflected on their own experiences in academia as an autistic autism researcher and commented that the onus is placed on autistic autism researchers to challenge the traditional medical views of autism, instead of the responsibility rarely being shared with non-autistic autism researchers.

Creating resources for mental health professionals to learn about loneliness in autistic adults

My research has shown that lack of shared understanding and experiences underpins loneliness in autistic adults and that loneliness is uniquely experienced in autistic adults, suggesting that providing non-autistic people with the correct information on autistic adults' experiences of loneliness could be beneficial in

bridging the gap between autistic and non-autistic people's understanding and experiences of the social world. One way to implement this into practice is to create resources (e.g., training, information packet) to teach mental health professionals about loneliness in autistic adults based on my research findings.

Research has shown that mental health professionals tend to have little knowledge on autism and that autistic people often have negative experiences in mental health services as a consequence (Adams & Young, 2021; Brede et al., 2022). In a systematic review and meta-analysis which explored autistic adults' experiences with mental health services, Brede et al. (2022) identified that autistic adults often felt not understood by mental health professionals, and that many mental health professionals who work with autistic adults recognized their lack of knowledge on autism and wanted resources to better support autistic adults. The latter finding corroborated findings from Crane, Davidson, et al. (2019) that greater knowledge on autism was associated with higher levels of self-efficacy among psychiatrists who work with autistic people. It is crucial to equip mental health professionals who may encounter lonely autistic adults with the information about loneliness in autistic adults. Indeed, Crane, Davidson, et al. (2019) reported that many psychiatrists in the UK (120 out of 172, 69.8%) have at least one autistic adult under their care.

There are some strong examples of resources created for professionals that have been co-designed with autistic people and have been positively received (e.g., Nicolaidis et al., 2016). Importantly, to create such resources, meaningful involvement of autistic people is invaluable (e.g., Nicolaidis et al., 2020; Stark et al., 2020). Gillespie-Lynch et al. (2021) developed and examined two trainings to increase knowledge on autism among non-autistic people: one training co-created

with autistic people and another training created solely by non-autistic people. Gillespie-Lynch et al. (2021) reported that the training co-designed with autistic people improved non-autistic people's knowledge and acceptance of autism more than the training developed without autistic people's involvement.

Creating trainings for non-autistic people to learn about autism to improve the societal understanding and acceptance of autism

Although my research showed that autistic adults make meaningful connections (thereby alleviate loneliness) by connecting with similar others, it does not suggest that autistic people should be cut off from a wider social circle with non-autistic people. To encourage positive social experiences between autistic and non-autistic people, research has focused on whether autism diagnosis/identification disclosure could improve acceptance of autistic differences (Thompson-Hodgetts et al., 2020). Highlighting disclosure as a strategy of improving acceptance of autism puts the responsibility on autistic people. It is equally important for society to have better understanding and acceptance of autism and for research and practice to strive to achieve that goal. Indeed, Jones, DeBrabander, et al. (2021) reported that autistic adults who completed an autism acceptance training showed lower explicit biases (i.e., bias that is constructed within one's awareness) towards autistic adults regardless of diagnostic disclosure of autism. Importantly, my research also showed that lack of societal understanding and acceptance of autism underpins loneliness in autistic adults. However, achieving this change is a huge task because misconceptions about autism are deeply entrenched (Jensen et al., 2015; Sasson et al., 2017) and there is a lack of acceptance of differences in society generally, not unique to neurodiversity (Link & Phelan, 2001).

As one way to improve societal understanding and acceptance of autism, some studies examined the trainings designed to increase knowledge and decrease misconceptions about autism among non-autistic adults (e.g., using Microsoft PowerPoint presentations, videos) and reported successful outcomes of improving more acceptance towards autistic children (Dickter et al., 2021) and adults (Gillespie-Lynch et al., 2015; Jones, DeBrabander, et al., 2021; Jones, Morrison, et al., 2021). Such good quality autism trainings were 1) specifically designed for the targeted population (e.g., parents in Dickter et al., 2015, university students in Gillespie-Lynch et al., 2015 and Jones, DeBrabander, et al., 2021), and 2) developed with autistic people's inputs (Dickter et al., 2021; Gillespie-Lynch et al., 2015; Jones, DeBrabander, et al., 2021). By keeping in line with these key points, autism trainings could be implemented to increase acceptance of autism in non-autistic people to help alleviate loneliness in autistic adults. A practical question could be how to motivate non-autistic people to take autism trainings, especially when it is not a part of research. As researchers, it may be worth considering the possibility of working with policy makers to implement autism trainings as part of the education in various settings (e.g., medical schools, workplaces).

6.5 Conclusion

Loneliness in autistic adults is a difficult topic to examine because it is ultimately about what it means to be autistic and human. As social beings, autistic adults desire social connections of some forms as consistently reported by the participants in my studies. However, being autistic puts autistic adults in a social minority and they often struggle in social situations. The studies presented in this thesis contribute greatly to our understanding of loneliness in autistic adults. As well

as centring the autistic lived experience of loneliness and investigating ways to assess loneliness in autistic adults, this research has suggested a potential mechanism of loneliness in autistic adults and has provided some clues to solutions for loneliness in autistic adults. Loneliness is a serious issue that may have a significant impact on autistic adults' health, both physically and mentally. Future research should strive to use these findings to make practical changes to improve autistic adults' experiences of loneliness. Potential suggestions for this work include:

1) Providing opportunities (e.g., psychoeducation programmes) for autistic adults to foster an acceptance of autistic differences, and evaluating such schemes.

2) Providing accessible opportunities for autistic adults to connect with similar others (e.g., through social prescribing), and evaluating such schemes by asking autistic adults their views and experiences of the schemes.

3) Striving to make social environments more inclusive and making simple accommodations for autistic adults (e.g., to sensory environments) to enable them to fully participate in the social situations that they want to participate in.

4) Providing mental health professionals with resources to learn about loneliness in autistic adults.

5) Providing non-autistic people with opportunities to learn about autism to improve their understanding and acceptance of autism.

I hope that these ideas can be used to guide future work to alleviate loneliness in autistic adults.

6.6 Reflections

I started my PhD without much research experience. Therefore, I had to learn a number of new approaches and techniques such as conducting a systematic

review and using/interpreting different statistical tests. I have recognized myself developing into an independent researcher: having increasing confidence in my decisions in the research process and moving towards autonomy as a researcher. At the time of writing this final Chapter, I have prepared fewer drafts to complete final versions of the chapters, and have been able to solve problems with less supervisory input. Importantly, through this whole process, I developed a deep connection to my research. This process was akin to how I learned to ride a bike: at the start I had stabilizers and my mom was supporting the bike, but at some point the stabilizers came off and my mom stood back, and I was riding a bike on my own[25]. Notably, this growth as a researcher was only possible with the unceasing support from my supervisors.

I had been in higher education without any substantial breaks since Spring 2013, the year I graduated from high school. Like my peers in Japan, I took entrance exams for some Japanese universities and started my higher education journey in Tokyo, not expecting myself to drop out of the university, transfer to an American university, and even seek a PhD in the UK. Perhaps the most unexpected, but best, thing as part of this journey was discovering my autistic identity and my passion for advocating for autistic people. It was very challenging to find potential supervisors for my proposed PhD research and different challenges arose during my time as a PhD student. One of my favorite writers, Brene Brown (2015), explained that people have "the deeply held belief that we are inextricably connected to one another by a force greater than ourselves--a force grounded in love and compassion" (p.151). Some people call this nature or art, but I call this God. Throughout my PhD, I faced multiple challenges but every trial came to test and strengthen my faith, believing that God

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[25] I would like to thank my mentor, who pointed out this similarity to me.

will come through, even when I could not see any possible solutions to challenges I was facing (e.g., getting accepted to a PhD program, writing up a thesis). As I described in Chapter One (Section 1.1.1), I have greatly struggled with reading my whole life. Throughout my higher education journey, particularly during my PhD, I have developed many skills to support my readings such as listening to articles instead of reading them, changing the background color of my documents to pale pink, and writing down questions before reading (so that I do not get distracted when reading articles). No one who knew me in my youth expected me to be able to read numerous academic papers (e.g., at the time of writing, I have 717 references in my EndNote library), conduct original research, and write a PhD thesis on autism in a language I did not even understand back then. What seemed impossible to me and others only became possible because of my God and the help from others that He sent me. Throughout my journey, it was nothing but my faith that sustained me.

Prior to my sparked interest in autism, I was striving to become a mental health counselor, thereby completing a Master's degree in Counselling Psychology at Boston College. Back then, I was going through making sense of autistic diagnosis myself and not in a good position to support others. However, one thing was clear: I was intensely gravitated towards the topic of autism, so I changed my path from clinical practice to research while my desire to be a clinician did not disappear. Even though I started my research on loneliness in autistic adults thinking that it was all about connection and belonging, it was interesting to me that this research has led me back to the field of mental health more and more throughout my four years as a PhD student. For example, during my PhD, I became involved in the Loneliness and Social Isolation in Mental Health Network at UCL and the Mental Health Study Group at Autistica. Furthermore, one of the suggestions I made in

Section 6.4 based on my findings was about equipping mental health professionals with knowledge on loneliness in autistic adults. This is not merely a suggestion for someone else but one of the first things I would like to work on, post-PhD. Helping mental health professionals to learn about autism is exactly the kind of things my professor at Boston College encouraged me to do when I went to her office crying and told her that I could not complete a clinical degree even though I wanted to. Again, the frustration between the desire for something (whether it is for connection or something else) and not being able to fulfill the desire has been prevalent in my life and my research reported that such frustration/internal conflict characterizes loneliness in autistic adults.

To conclude, I stand by my words in Chapter One, Section 1.1.1: this thesis is not for me but for all autistic people, their families, and anyone who cares for them. I would like to end this thesis with a quote from my favorite children's book, "you are special". The quote is from Eli, the woodcarver (representing God) saying to Punchinello, one of the Wemmicks (small wooden people) carved by Eli and the main character whose differences have been poorly judged by other Wemmicks: "'Remember', Eli said as Punchinello was leaving, 'you are special because I made you. And I don't make mistakes'" (Lucado, 1997).

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Appendices

Appendix 2.1. Search strategy

Database	Terms	Search within	Results
ASSIA: Applied Social Sciences Index and Abstracts (ProQuest)	(autis* OR Asperger* OR Pervasive developmental disorder OR PDD OR ASD OR ASC) AND (lonel*OR social isolation) AND adult*	Abstract (search was limited to abstracts because searching anywhere brought 2,838 results with too many irrelevant papers)	29
	(autism AND loneliness AND adults)	Anywhere	638
BEI: British Education Index (EBSCO)	(autis* OR Asperger* OR Pervasive developmental disorder OR PDD OR ASD OR ASC) AND (lonel*OR social isolation) AND adult*	Not selected (all fields)	18
	(autism AND loneliness AND adults)	Not selected (all fields)	7
ERIC (ProQuest)	(autis* OR Asperger* OR Pervasive developmental disorder OR PDD OR ASD OR ASC) AND (lonel*OR social isolation) AND adult*	Anywhere	50
	(autism AND loneliness AND adults)	Anywhere	12

Medline (Ovid)	(autis* OR Asperger* OR Pervasive developmental disorder OR PDD OR ASD OR ASC) AND (lonel*OR social isolation) AND adult*	All fields	97
	(autism AND loneliness AND adults)	All fields	21
ProQuest Dissertations and Thesis Global (ProQuest)	(autis* OR Asperger* OR Pervasive developmental disorder OR PDD OR ASD OR ASC) AND (lonel*OR social isolation) AND adult*	Abstract (Search was limited to abstracts because searching anywhere brought 93,886 results with too many irrelevant papers. Search included both Master's theses and Doctoral dissertations.)	41
	(autism AND loneliness AND adults)	Abstract (Search was limited to abstracts because searching anywhere brought 8,392 results with too many irrelevant papers. Search included both Master's theses and Doctoral dissertations.)	8
PsycINFO	(autis* OR Asperger* OR Pervasive developmental disorder OR PDD OR ASD OR ASC) AND (lonel*OR social isolation) AND adult*	Abstracts (Search was limited to abstracts because searching anywhere brought 4,235 results with too many irrelevant papers.)	63

	(autism AND loneliness AND adults)	Abstracts (Search was limited to abstracts because searching anywhere brought 2,180 results with too many irrelevant papers)	24
Scopus	(autis* OR Asperger* OR Pervasive developmental disorder OR PDD OR ASD OR ASC) AND (lonel*OR social isolation) AND adult*	Abstract (Search was limited to abstracts because searching in all field brought 10,307 results with too many irrelevant papers)	89
	(autism AND loneliness AND adults)	Abstract (Search was limited to abstracts because searching in all field brought 3,300 results with too many irrelevant papers)	24
Web of Science Core Collection	(autis* OR Asperger* OR Pervasive developmental disorder OR PDD OR ASD OR ASC) AND (lonel*OR social isolation) AND adult*	All fields	218
	(autism AND loneliness AND adults)	All fields	117

Appendix 2.2. List of the excluded studies at full-text assessment

#	Study	Reasons for exclusion
1	Allely, 2015	It was a review.
2	Bailey et al., 2020	It did not report quantitative or qualitative data on loneliness.
3	Bal et al., 2021	It did not report quantitative or qualitative data on loneliness.
4	Brooks & Paterson, 2011	It did not report quantitative or qualitative data on loneliness.
5	Buonaguro & Bertelli, 2021	Full text not available
6	Cage et al., 2018	It did not report quantitative or qualitative data on loneliness.
7	Cai & Richdale, 2016	It did not report quantitative or qualitative data on loneliness.
8	Cassidy et al., 2014	It did not report quantitative or qualitative data on loneliness.
9	Causton-Theoharis et al., 2009	It included the autobiographies that had a "focus on childhood experiences" (p. 86).
10	Churchard et al., 2019	The participants did not have autism diagnosis.
11	Connor et al., 2020	It did not report quantitative or qualitative data on loneliness.
12	Feldhaus et al., 2015	The mean age of autistic participants was not reported though they included participants who were 15-27 years of age. The study referred to the participants as 'youth', 'young people' and 'adolescents'.
13	Friedman et al., 2019	It did not report quantitative or qualitative data on loneliness.
14	Furuhashi & Furuhashi, 2015	Full text not available
15	Gelbar et al., 2014	It was a review.
16	Happe & Charlton, 2012	It was a review.
17	Howlin et al., 2004	It was an editorial and did not constitute research.
18	Kapp et al., 2011	It did not constitute research.
19	Kirby, 2016	It did not report quantitative or qualitative data on loneliness.
20	Koegel et al., 2013	It did not report quantitative or qualitative data on loneliness.
21	Laugeson et al., 2015	It did not report quantitative or qualitative data on loneliness.
22	Lewis, 2016	It did not report quantitative or qualitative data on loneliness.
23	Lucas & James, 2018	It did not report quantitative or qualitative data on loneliness.
24	McConkey et al., 2021	It did not report quantitative or qualitative data on loneliness.
25	McVey, 2016	It is a thesis with the same study as MacVey et al. (2016).

26	Morrison et al., 2020	It did not report quantitative or qualitative data on loneliness.
27	Simmons, 2020	It did not constitute research.
28	Spain & Blainey, 2015	It was a review.
29	Stice & Lavner, 2019	Participants were not 'autistic' (not diagnosed or self-identified) and only had Broader Autism Phenotype.
30	Wendler, 2019	Mean age of the participants were 15.
31	Ya-Ching & Ling-Yi, 2018	It was a missed duplicate of Syu & Lin (2018).

Appendix 2.3. MMAT checklist table

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Ashbaugh et al., 2017	3. Quantitative non-randomized	S1.[26]	✓			
		S2.	✓			
		3.1.	✓			Clear descriptions of the target population and inclusion/exclusion criteria. (The sample does not appear to be the representation of the diverse autistic adults.)
		3.2.	✓			Interventions included engaging in social activities, social skill trainings, and peer mentoring by NT peer mentors. The numbers of such social engagements were self-reported every week during the intervention and the three-week follow-up.

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[26] The criteria numbers in the table (e.g., S1., 1.1.) correspond to those of the MMAT tool (Hong et al., 2018).

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
		3.3.	✓			
		3.4.		✓		It is hard to tell whether there were any other factors linked to the results without further qualitative exploration.
		3.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Baldwin & Costley, 2016	5. Mixed Methods	S1.	✓			
		S2.	✓			
		5.1.	✓			
		5.2.	✓			
		5.3.	✓			
		5.4.	✓			There is no divergence.
		5.5.	✓			Clear descriptions of the target population and inclusion/exclusion criteria. (The sample does not appear to be the representation of the diverse autistic adults.)
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Bourdeau, 2020 (Doctoral thesis)	3. Quantitative – non-randomized	S1.	✓			
		S2.	✓			
		3.1.		✓		The inclusion/exclusion criteria as well as the target population were not clear. (The sample does not appear to be the representation of the diverse autistic adults.)
		3.2.	✓			
		3.3.	✓			
		3.4.	✓			No confounding expected
		3.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Brooks, 2014 (Doctoral thesis)	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.	✓			Clear descriptions of the target population and inclusion/exclusion criteria. (The sample does not appear to be the representation of the

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
						diverse autistic adults.)
		4.3.	✓			
		4.4.			✓	Response rate was not reported.
		4.5.	✓			A clear explanation on analysis was not found, but the statistics were presented in the texts and tables.
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Caruana et al., 2021	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.	✓			Clear descriptions of the target population and inclusion/exclusion criteria. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			
		4.4.	✓			
		4.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments

Chen et al., 2016	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.	✓			Clear descriptions of the target population and inclusion/exclusion criteria. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			
		4.4.	✓			
		4.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Ee et al. 2019	5. Mixed methods	S1.	✓			
		S2.	✓			
		5.1.	✓			The rationale for using a mixed methods design was clear in the aim of this study.
		5.2.	✓			Both quantitative and qualitative data contributed to the whole picture of the results from this study.
		5.3.	✓			Social aspect relating to the experiences of

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
						loneliness were explored with both quantitative and qualitative data collection.
		5.4.	✓			There was no divergence between quantitative and qualitative results.
		5.5.	✓			The study was overall a high quality according to the criteria for both methods. (The sample does not appear to be the representation of the diverse autistic adults.)
Elmose 2020	1. Qualitative	S1.	✓			
		S2.	✓			
		1.1.	✓			Among the 25 participants, 24 of them involved in focus group interviews and four autistic adults also involved in individual interviews.
		1.2.	✓			Clear justification was made to explain why the study used both

Study	Category of study design	Screening questions and methodological quality criteria				
						focus group interviews and individual interviews.
		1.3.	✓			Phenomenological perspective using thematic analysis was rightfully used.
		1.4.	✓			
		1.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Gantman et al., 2012	2. Quantitative randomized controlled trials	S1.	✓			
		S2.	✓			
		2.1.	✓			They flipped a coin for randomization.
		2.2	✓			
		2.3.	✓			
		2.4	✓			
		2.5.	✓			All of their participants (N=17) continued the assigned intervention.
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Han et al. 2019	4. Quantitative descriptive studies	S1.	✓			
		S2.	✓			

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			4.1.	✓		They made sure that the participants were appropriately assigned to the three groups in the study: ASD, currently depressed and control groups. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.2.	✓			Clear descriptions of the target population and inclusion/exclusion criteria.
		4.3	✓			
		4.4.	✓			
		4.5.	✓			They provided reasons for each analysis.
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Hedley et al., 2018a	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.		✓		A clear justification of the sample frame used is not provided
		4.2.	✓			Clear description of inclusion criteria despite no clear descriptions of the

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
						target population. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			
		4.4.	✓			
		4.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Hedley et al., 2018b	4.Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.	✓			Clear inclusion criteria for participant despite no clear descriptions of the target population. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			
		4.4.	✓			
		4.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Hickey et al., 2018	1.Qualitative	S1.	✓			

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
		S2.	✓			
		1.1.	✓			Appropriate to investigate the experiences of older autistic adults.
		1.2.	✓			Semi-structured interviews were used.
		1.3.	✓			Thematic analysis was used.
		1.4.	✓			They provided quotes from the participants to justify each theme.
		1.5.	✓			
Hillier et al., 2018	5. Mixed methods	S1.	✓			
		S2.	✓			
		5.1.			✓	While the mixed method appears to be appropriate in this study, a clear rationale is not found in the text.
		5.2.		✓		Qualitative and quantitative results weren't effectively integrated.
		5.3.		✓		It is not clear how the authors attempted to draw the results across qualitative and

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
					✓	quantitative components.
		5.4.			✓	
		5.5.	✓			The study was overall a high quality according to the criteria for both methods. (The sample does not appear to be the representation of the diverse autistic adults.)
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Hull et al., 2017	1.Qualitative	S1.	✓			
		S2.	✓			
		1.1.	✓			
		1.2.	✓			
		1.3.	✓			Findings are derived from the data by thematic analysis using inductive approach.
		1.4.	✓			They provided quotes from the participants to justify each theme.
		1.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Hwang et al., 2017	1. Qualitative	S1.	✓			

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
		S2.	✓			
		1.1.	✓			
		1.2.	✓			
		1.3.	✓			
		1.4.	✓			
		1.5.	✓			
Jackson et al., 2018	4.Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.			✓	The inclusion/exclusion criteria were not clear, but the target population was clear. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			
		4.4.			✓	The information needed to judge this criterion is not reported in the study (i.e. response rate is not reported).
		4.5.	✓			
Study	Category of study design	Screening questions and	Responses			

		methodological quality criteria				
			Yes	No	Can't tell	Comments
Jantz, 2011	5. Mixed methods	S1.	✓			
		S2.	✓			
		5.1.		✓		The reasons for conducting a mixed methods study was not clearly explained.
		5.2.	✓			
		5.3.	✓			The findings were interpreted based on both quantitative and qualitative components.
		5.4.	✓			There were no divergences and inconsistencies between quantitative and qualitative result.
		5.5.	✓			The inclusion/exclusion criteria were not clear but the target population was clear. Overall, the study was a high quality according to the criteria for both methods. (The sample does not appear to be the representation of the diverse autistic adults.)
Study			Responses			

	Category of study design	Screening questions and methodological quality criteria	Yes	No	Can't tell	Comments
Levinson, 2020 (Doctoral thesis)	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.			✓	It was not clear where the study recruited the participants.
		4.2.		✓		No clear inclusion/exclusion criteria and no clear descriptions of the target population. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			Validated and reliable measures were used and the measurements were justified.
		4.4.	✓			
		4.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Lin & Huang, 2017	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
		4.2.	✓			Clear descriptions of the target population and inclusion/exclusion criteria. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			
		4.4.	✓			
		4.5.	✓			Clear justification for analyses was provided.
Mazurek, 2013	5. Mixed methods	S1.	✓			
		S2.	✓			
		5.1.	✓			
		5.2.	✓			
		5.3.	✓			
		5.4.	✓			There were no divergences and inconsistencies between quantitative and qualitative results.
		5.5.	✓			The inclusion/exclusion criteria were no clear, but overall the study was a high quality according to

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
						the criteria for both methods.
			Yes	No	Can't tell	Comments
Mazurek, 2014	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.	✓			Clear descriptions of the target population and inclusion/exclusion criteria. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			
		4.4.			✓	Response rate was not reported, and indicators of low nonresponse bias were also not presented.
		4.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
McVey et al., 2016	2. Quantitative randomised controlled trial	S1.	✓			
		S2.	✓			

Study	Category of study design	Screening questions and methodological quality criteria	2.1.		✓		It did not provide a description on how the randomization schedule was generated.
			2.2.	✓			
			2.3.	✓			
			2.4.	✓			
			2.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses				
			Yes	No	Can't tell	Comments	
Merkler, 2007 (Doctoral thesis)	4. Quantitative descriptive	S1.	✓				
		S2.	✓				
		4.1.	✓				
		4.2.		✓		Inclusion and exclusion criteria were not clearly stated.	
		4.3.	✓				
		4.4.	✓				
		4.5.	✓				
Study	Category of study design	Screening questions and methodological quality criteria	Responses				
			Yes	No	Can't tell	Comments	
Milton & Sims, 2016	1.Qualitative	S1.	✓				
		S2.	✓				
		1.1.	✓			The study explored the narratives of autistic adults within	

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
						the autism-related magazine.
		1.2.	✓			
		1.3.	✓			
		1.4.	✓			
		1.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Orsmond et al., 2013	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.			✓	The participants were recruited from a longitudinal study, the inclusion/exclusion criteria were not clear.
		4.3.	✓			Measures were not what were validated; however, the variables were clearly defined within their own quantitative questionnaires.
		4.4.	✓			The data were from a national study.
		4.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			

			Yes	No	Can't tell	Comments
Russell, 2020	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.	✓			Clear descriptions of the target population and inclusion/exclusion criteria. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			
		4.4.	✓			
		4.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Schiltz et al., 2020	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			The source of sample and sampling procedure appear to be adequate.
		4.2.	✓			Clear descriptions of the target population and inclusion criteria.
		4.3	✓			They used appropriate

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
						measures that were validated and reliable.
		4.4.	✓			
		4.5	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Smith & Sharp, 2013	1.Qualitative	S1.	✓			
		S2.	✓			
		1.1.	✓			The study explored the unique sensory experiences of autistic adults using the Ground Theory.
		1.2.	✓			
		1.3.	✓			
		1.4.	✓			
		1.5.	✓			
Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Southby & Robinson, 2018	1.Qualitative	S1.	✓			
		S2.	✓			
		1.1.	✓			The rationale was clearly stated.
		1.2.	✓			Semi-structured interviewed were conducted to collect the data.

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			1.3.	✓		
			1.4.	✓		
			1.5.	✓		

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Sundberg, 2018	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.	✓			Clear descriptions of the target population and inclusion/exclusion criteria. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3	✓			
		4.4.	✓			
		4.5.	✓			

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
Syu & Lin, 2018	4. Quantitative descriptive	S1.	✓			
		S2.	✓			
		4.1.	✓			
		4.2.	✓			Clear descriptions of the target population and

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
						inclusion/exclusion criteria. (The sample does not appear to be the representation of the diverse autistic adults.)
		4.3.	✓			
		4.4.			✓	Response rate was not reported, and indicators of low nonresponse bias were also not presented.
		4.5.	✓			
Van der Aa et al., 2016	5. Mixed methods	S1.	✓			
		S2.	✓			
		5.1.	✓			The reason for using this particular method was not clearly explained.
		5.2.	✓			
		5.3.	✓			
		5.4.	✓			No divergences and inconsistencies between quantitative and qualitative results were found.
		5.5	✓			Overall, the study was a high quality according to the

Study	Category of study design	Screening questions and methodological quality criteria	Responses			
			Yes	No	Can't tell	Comments
						criteria for both methods.
Van Hees et al., 2015	1.Qualitative	S1.	✓			
		S2.	✓			
		1.1.	✓			The study explored the higher education experiences of autistic students.
		1.2.	✓			Semi-structured interviews were used.
		1.3.	✓			
		1.4.	✓			
		1.5.	✓			

Appendix 2.4. Characteristics of 34 included studies

Study	Origin	Study Design	N (Male/Female/other)	Age (Range, M, SD)	Study Description	Key Outcomes
Ashbaugh et al., 2017	USA	Quantitative non-randomized (multiple case studies)	3 (2/1/NR)	19-24, NR, NR	Social intervention program with weekly meetings and peer mentoring.	Increased social integration, academic performance and satisfaction with university experience.
Baldwin & Costley, 2016	Australia	Mixed Methods (nation-wide survey)	82 (NA, 82, NA)	18-64, 32.7, 12.3	Self-report on health, work, education, social and community activities.	Poor mental health, unmet needs of support in education and employment, and social isolation were highlighted.
Bourdeau, 2020 (Doctoral thesis)	USA	Quantitative – non-randomized (quasi-experimental study)	Adults with ASD = 38, their caregivers = 38	Adults with ASD = 18-40, NR, NR	Quasi-experimental study to measure the impacts of social group participation on autism symptomology, social skills, and loneliness	Three-month engagement in social groups resulted in a significant decrease in the perceptions of ASD symptomology and social skills in both autistic adults and their caregivers, and a significant decrease in loneliness for autistic adults as a group.
Brooks, 2014 (Doctoral thesis)	USA	Quantitative descriptive (standardized questionnaires)	HFASD = 56 (28/28/NR), parent/caregiver = 56 (NR/NR/NR), typically-developing (TD) = 56 (28/28/NR)	HFASD = 18-40, 26.3, 6, TD = NR, 26.4, 4.6	Dissertation investigating gender differences in social skills, peer relationships, and emotional correlates.	Higher level of quality in friendship is associated with lower level of loneliness in both HFASD and TD groups.
Caruana et al., 2021	Australia, UK (Study 1 was conducted in both countries, Study 2 was with a	Quantitative descriptive (online survey)	Study 1 = full sample: 870 (261, 592, 15, 2 preferred not to say), no diagnosis: 484(111, 372, 1), autistic: 281(122, 147, 10, 2	Study 1 = full sample: 16-75+, no diagnosis: 16-75+, autistic: 16-somewhere between	Research based on two quantitative studies which explored the relationships between 1) autistic traits and anthropomorphism in the general population, and 2) loneliness and anthropomorphism in autistic adults.	More autistic traits, increased tendency to anthropomorphise non-human entities in the general population. More tendencies to anthropomorphism were associated with increased loneliness in autistic adults.

	smaller portion of participants who previously took part in the UK-based survey in Study 1)		preferred not to say) Study 2 = 89 (29, 51, 5, 4 preferred not to say)	65-74, Study 2 = 16-74		
Chen et al., 2016	Australia, Taiwan	Quantitative descriptive (experience sampling methodology (ESM))	30 (16/14/NR)	16-45, 24.8 (Australian participants: n=14), 9.0 (Australian participants: n=14), 27.8 (Taiwanese participants: n=16), 6.3 (Taiwanese participants: n=16)	ESM surveys of everday activity of "high-functioning" autistic individuals for 7 days, 7 times/day.	Highlighted the importance of considering in-the-moment experience in autism research. Level of loneliness did not depend on the types of activites.
Ee et al., 2019	Australia	Mixed methods Self-report (questionnaire and open-ended questionnaire)	Autistic = 220 (86/124/10), nonautistic = 146 (29/117/NR)	Autistic = 25-80, 41.9, 12.24, nonautistic = 25-79, 43.7, 13.49	Mixed method study of associated factors of loneliness and experiences of loneliness among autistic adults, collecting data from a longitudinal study.	Autistic adults were significantly lonelier than nonautistic adults. Social skills and dissatisfaction with social support were related to loneliness in both autistic and nonautistic adults. Thematic analysis showed variable experiences and perceptions of socialization.
Elmose, 2020	Denmark	Qualitative (focus groups and individual interviews)	25 (18/7/NR)	18-71, NR, NR	Qualitative study of the concept of loneliness among autistic adults.	Four themes were identified using a phenomenological thematic analysis: experience of loneliness, being autistic, discrepancies in social relationships, and ease of interaction.

Gantman et al., 2012	USA	Quantitative randomized controlled trials (randomized control trial)	17 (12/5/NR)	18-23, 20.4, 1.62	Social intervention Program using *The UCLA PEERS for Young Adults Program*.	PEERS social skill training improved caregiver-reported social skills of autistic young adults and it lessened social and emotional loneliness measured by SELSA.
Han et al., 2019	USA	Quantitative descriptive studies (self-report questionnaire)	Typically developing (TD) control = 28 (14/14/0), ASD = 49 (31/18/0), TD currently depressed = 30 (12/18/0)	TD control = NR, 25.32, 5.28, ASD = NR, 23.98 26.23, = TD currently depressed = NR, 26.23 4.67	Quantitative study of the relationships between self-reported pleasure in social and non-social rewards, severity of autism symptoms, loneliness and depressive symptoms in three groups: autistic adults, currently depressed adults and control group.	The less pleasure adults experienced, the higher loneliness they reported whether or not they were autistic. Autistic adults experienced high level of loneliness even when they reported high capacity for pleasure. Loneliness was the most reliable predictor of depression, compared to the capacity for pleasure and autism symptoms.
Hedley et al., 2018a	Australia	Quantitative descriptive (online survey)	71 (63/8/NR)	17-56, 26.14, 8.20	Online survey of loneliness, depression, and thoughts of self-harm.	Loneliness is a risk factor for depression and thoughts of self-harm. Depression is not the indicator for loneliness or thoughts of self-harm.
Hedley et al., 2018b	Australia	Quantitative descriptive (self-report questionnaire)	185 (93/92/NR)	14-80, 37.11, 15.41	Self-report of loneliness, social support and suicidal ideation and depression.	For depression and suicidal ideation, loneliness is a risk factor and social support is a protective factor.
Hickey et al., 2018	UK	Qualitative (semi-structured interview)	13 (10/3/NR)	51-71, NR, NR	Semi-structured interviews and thematic analysis of experiences of autistic adults in their late adulthood (pre- and post-diagnosis).	Highlighted difference in pre-diagnosis, life-review in post-diagnosis, and longing for connection throughout adulthood.
Hillier et al., 2018	UK	Mixed methods (self-report questionnaires and focus groups)	52 (51/1/NR)	18-28, 20.9, NR (all university students)	Self-report of self-esteem, loneliness and mental health and focus group on the 7-weeks social intervention program.	The social intervention program reduced loneliness and general anxiety and increased self-esteem. However, it did not have impacts on social anxiety, academic distress or depression.

Hull et al., 2017	UK	Qualitative (online survey)	92 (55/30/7)	Female = 18-68, 40.71, 14.14, Male = 22-79, 48.03, 16.62, Others = 27-69, 40.71, 14.29	Online survey of motivation, techniques and consequences of camouflaging.	Camouflaging is motivated by the desire to fit in and to have connections with others, presented as masking or compensation, and results in exhaustion, stress, anxiety followed by the need to be alone and identity crisis.
Hwang et al., 2017	Australia	Qualitative (semi-structured interviews)	Autistic adults = 15 (11/4/0), Carers = 9 (1/8/0)	Autistic adults = NR/50.3/17.11, Carers = NR/63.6/8.76	Semi-structured interviews with autistic adults and carers of autistic adults to explore the meaning of "age well" from their first point of views.	Thematic analysis identified eight themes: myself, being autistic, others, lifestyle and living well, being supported, relating to others, life environment, and societal attitudes and acceptance.
Jackson et al., 2018	USA	Quantitative descriptive (online survey)	56 (26/26/4)	18-57, 22.98, 6.01	Online survey of the experiences of autistic students in post-secondary education, specifically on the academic, social and mental health aspects.	Autistic students showed high level of academic comfort while they showed a high level of isolation, loneliness, anxiety and depression. About three-quarters of them expressed their lifetime suicidal behaviours.
Jantz, 2011	USA	Mixed methods (interviews and self-report questionnaire)	35 (24/11/NR)	24-77, NR, NR	Mixed method study on loneliness and the perception of support groups.	The participants showed a higher level of loneliness compared to their counterparts, and they perceived support groups as helpful due to social skills and support, information and advice, and structure.
Levinson, 2020 (Doctoral thesis)	USA	Quantitative descriptive (self-report questionnaire)	ASD = 123 (28/59/32/gender not reported n= 4), neurotypical = 115 (25/72/15 gender not reported n= 3)	ASD = NR, 23.13 (3.58), neurotypical = NR, 22.92 (3.37)	Quantitative study on the relationships among distress, emotion regulation and self-harm among autistic and neurotypical young adults.	Autistic and neurotypical young adults were similar in how they engaged in self-injurious behaviours (SIBs) and how they affected them. While lack of communication skills, anxiety and

						depression were associated with SIBs, lack of social skills, loneliness, emotional dysregulation and restricted and repetitive behaviours were not associated with SIBs.
Lin & Huang, 2019	Taiwan	Quantitative descriptive (interviews)	ASD (autism spectrum disorder) = 66 (43/23/NR), neuro-typical= 85 (52/33/NR)	ASD = 20-38, 27.8, 5.2, neurotypical = 20-38, 27.8, 4.3	Comparison of QoL and its association with anxiety, loneliness and sensory processing between ASD and neuro-typical groups.	Adults with ASD show lower quality of life, higher anxiety, higher loneliness and more difficulty with sensory processing than neuro-typical adults.
Mazurek, 2013	USA	Mixed methods (self-report questionnaire)	108 (52.8%/47.2%/NR)	18-62, 32.4, 12.5	Self-report of social media use, friendships and loneliness.	79.6% of the participants used SNS and the most popular reason for the SNS use was for social conneciton. Those who used SNS were more liekly to report having close frineds. However, decreased loneliness is associated with the friendship quality and quantity offline and not online.
Mazurek, 2014	USA	Quantitative descriptive (online self-report questionnaire)	108 (52.8%/47.2%/NR)	18-62, 32.4, 12.5	Self-report of loneliness, friendship and well-being (self-esteem, depression, life-satisfaction).	Loneliness is positively correlated with depression and anxiety, and it is negatively correlated with life-satisfaction and self-esteem. Friendships and autistic characteristics are also highly correlated with loneliness.
McVey et al., 2016	USA	Quantitative randomised controlled trial	Experimental = 24 (18/6/0), Waitlist control = 23 (20/3/0)	Experimental = NR/20.92/3.31, Waitlist control = NR/19.52/1.70	Replication and extension of the Gantman et al. (2012) by also examining the effects of PEERS on social anxiety in autistic young adults.	Improvements due to the PEERS were seen in social responsiveness, PEERS knowledge, empathy, and social anxiety.
Merkler, 2007 (Doctoral thesis)	USA	Quantitative descriptive (self-report questionnaire)	high functioning autism = 37 (30/7/NR), =	18-52, 29.65, 10.19	Self-report of social relationships, loneliness and mental health.	More social isolation was seen in the adults "with high-functioning autism" than their peers, and

			typically developing = 82 (26/56/NR)			isolation was associated with distress in the population.
Milton & Sims, 2016	UK	Qualitative (thematic analysis of issues of the magazine, *Asperger United* (AU))	NA	NA	Thematic analysis of issues of the magazine, *Asperger United* (AU).	Highlighted the importance of limiting social isolation of autistic adults.
Orsmond et al., 2013	USA	Quantitative descriptive (telephone interview)	620 (Wave 5 of the data from the National Longitudinal Transition Study 2)	21-25, NR, NR	Telephone interviews with young adults "with ASD" or their parents/guardians on social participation of young adults "with ASD" in the past 12 months.	Compared to the other disability groups (intellectual disability, emotional disturbance, learning disabilities), young adults "with ASD" are likely to never see friends, never get calls from friends, never be invited to activities and be socially isolated.
Russell, 2020 (Doctoral thesis)	USA	Quantitative descriptive (self-report questionnaire)	Autistic group = 22 (6 female), Insomnia group = 23 (11 female), 'NT' (typically developing) group = 21 (13 female)	Autistic group = NR, 25.26, 3.97, Insomnia group = NR, 24.95, 4,64, Neurotypical group = NR, 23.55, 4.88,	Quantitative study of the association of sleep quality and loneliness with perceived physical and mental health.	Lower sleep quality and higher levels of loneliness were positively associated with physical and mental ill health. More insomnia was positively associated physical ill health. Reduced sleep quality and greater loneliness were associated with mental ill health. More sleep problems were positively associated with mental ill health.
Schiltz et al., 2020	USA	Quantitative descriptive (self-report questionnaire)	69 (56/13/NR)	17-29, 20.24 (2.77)	Quantitative study of relationships among loneliness, mental health, autism features and social contact, using self-report questionnaire	The more autism features autistic adults reported, the more social and family loneliness, higher levels of anxiety and social depression.
Smith & Sharp, 2013	UK	Qualitative (instant messaging	HFA (high-functioning autism)/AS	25-49, NR, NR	Semi-structured interviews on sensory experiences.	Unique sensory experiences cause sensory stress, and they are positively associated with isolation.

		semi-structured interviews)	(Asperger syndrome) = 9 (NR/NR/NR)			
Southby & Robinson, 2018	UK	Qualitative (semi-structured interviews)	HFASD = 14 (12/2/NR), family members = 3, volunteer mentors = 2, professionals = 11	NR, NR, NR	Semi-structured interviews on the efficacy of "low-level" support.	Providing advocacy information and mentoring had significantly positive impacts on adults "with HFASD".
Sundberg, 2018	Hungary	Quantitative descriptive (self-report online questionnaire)	ASD = 85 (49/36/NR), control = (32/34/NR)	14-69, 26.68, 10.78	Self-report questionnaire on online gaming, loneliness and friendships.	Adult "with ASD" who play online games have more friends than those who do not, however, friendship quality or having a best/close friend is not associated with online gaming. Low to moderate use of online games is associated with less loneliness.
Syu & Lin, 2018	Taiwan	Quantitative descriptive (self-report questionnaire)	70 (46/24/NR)	20-39, 27.8, 5.0	Self-report questionnaire on sensory profile, anxiety and loneliness.	Sensory sensitivity was associated with higher level of anxiety and loneliness.
Van der Aa et al., 2016	Netherlands	Mixed methods (online survey)	ASC = 113 (62/49/NR), control = 72 (28/44/NR)	ASC = NR, 40.2, 12.3, control = NR, 40.5, 12.1	Online survey of computer-mediated communication (CMC) among people "with ASC".	People "with ASC" use CMC more frequently, and they report high-level of satisfaction in online social life and CMC use is negatively associated with life satisfaction.
Van Hees et al., 2015	Belgium	Qualitative (semi-structured interviews)	23 (17/6/NR)	18-25, NR, NR	Interviews on the experiences in higher education.	Students "with ASD" in higher education reported many challenges including social relationships, and they also reported the benefits because of their condition as well as their need for support.

Note: NR = not reported, NA = not applicable, terminology to describe autism corresponds to the exact terms in each article and it is not the intention of the review.

Appendix 2.5. Characteristics of the autistic participants

Study	Participants' autism diagnoses	Way of communication (verbal/non-verbal)[27]	IQ	Co-occurring diagnoses	Living situation	Employment	Highest level of education	Cultural background/ethnicity
Ashbaugh et al., 2017	Autism spectrum disorder (ASD)	Verbal	Average or above average	NR	All living at parent's home	NA	All are currently in university	NR
Baldwin & Costley, 2016	Autistic disorder (81%), Asperger's disorder (17%), PDD-NOS (2%)	NR	NR	NR	With parent(s) (47%), with partner (12%), alone (29%), other (12%)	NR	NR	Australian (68%), British/European (18%), other (14%)
Bourdeau, 2020 (Doctoral thesis)	NR (described as ASD)	NR	NR	NR	NR	NR	NR	NR (demographic variables were not collected due to institutional review board limitations)
Brooks, 2014 (Doctoral thesis)	High functioning autism spectrum disorder (HFASD)	NR	Female: WASI-II VCI score (SD) = 107.0 (14.8), WASI-II PRI score (SD) = 98 (18.8) Male: WASI-II VCI score (SD) = 105.7 (20.7), WASI-II PRI score (SD) = 102.5 (14.3)	Female: mood disorder (n=19), anxiety disorder (n=8), ADHD (n=11), other psychiatric	Female: independently/ with partner (n=14), with parents/family (n= 14) Male: independently/ with partner (n=7), with parents/family (n= 21)	NR	NR	NR

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[27] Almost all the entries are coded NR because the papers did not report participants' method of communication. Where information on communication cannot be inferred from what was written in the articles, the entries were coded NR. Whilst it could be assumed that the participants were verbal because the data were collected via interviews, interviews can be possible without verbal communication (e.g., text-based chat).

diagnoses (n=3)
Male: mood disorder (n=13), anxiety disorder (n=5), ADHD (n=10), other psychiatric diagnoses (n=0)

| Caruana et al., 2021 | NR (described as autism) | NR | NR | Study 1: NR
Study 2: Depression (n=14), anxiety (n=12), post-traumatic stress disorder (n=6), obsessive-compulsive disorder (n=4), bipolar disorder (n=4), dyslexia (n=2), | NR | NR | NR | NR |

				ADHD (n=2), Dyspraxia (n=1), other (n=6)				
Chen et al., 2016	"High-functioning" autism (HFA) (n=5), Asperger's syndrome (n=25)	NR	Minimum reading comprehension ability. (Australia sample: ≥ 85 on the reading comprehension subset of Woodcock Reading Mastery Test-3rd edition (WRMT-III, Woodock, 2011), Taiwan sample: verbal IQ ≥ 70 on the Wechsler Adult Intelligent Scale-IV (Wechsler, 2008).)	ADHD (n=3), depression (n=1), anxiety (n=1), OCD (n=2), depression and anxiety (n=3), depression, anxiety and OCD (n=1)	Alone (n=3), with partner/children (n=3), with parents/siblings (n=21), with others (n=3)	Student (n=11), unemployed (n=8), part-time (n=3), full-time (n=7), volunteer work (n=1)	High school (n=8), certificate (n=5), diploma (n=2), Associate's degree (n=1), Bachelor's degree (n=10), Master's degree (n=4)	Australian (n=14), Taiwan (n=16)
Ee et al. 2019	Autism or autism spectrum Disorder/condition (n=49), autistic disorder (n=1), Asperger's disorder (n=132), PDD-NOS (n=1), infantile autism (n=1), high functioning autism (n=33), missing (n=3)	NR	Basic proficiency in English	NR	Living alone (n=60, 27.5%), living with partner (n=100, 45.9%), living with parents (n=31, 14.2%), living with relatives (n=3, 1.4%), living with others (n=20, 9.2%), other arrangement	Employed (n=118, 44.3%) (They also reported 'missing' on which further details were not provided.)	Below year 12 (n=11, 5.1%), Year 12 (n=12, 5.6), further education (n=19, 89.2%), missing (n=6) (Many of their participants appeared not to have reported on this. The study was not clear what 'missing' meant and how it was	NR

					(n=4, 1.8%), missing (n=2)		different from participants' not reporting the information.)	
Elmose 2020	NR (described as autism)	NR	NR	NR	Living with no external support (n=8), living with some degree of external support (n=3), living at home (n=1), not disclosed (n=13)	Retired (n=1), early retirement (n=1), full-time (n=1), part-time (n=1), Work-testing, internship (n=2), sick-leave (n=1), unemployed (n=3), not disclosed (n=15)	Elementary schooling, grades 9–10 (n=1), secondary education (n=2), other youth education (n=3), higher education, short (n=2), higher education, long (n=4), currently in higher educational setting (n=3), not disclosed (n=10)	NR
Gantman et al., 2012	Autistic disorder (n=4), Asperger's Disorder (n=11), pervasive developmental disorder not otherwise specified (PDD-NOS) (n=2)	NR	Composite IQ score of greater than 70 on the Kaufman Brief Intelligence Test—Second Edition (KBIT-2; Kaufman and Kaufman 2005)	NR	With caregivers (including parents) (n=16)	NA	All are currently attending university at least part-time	Caucasian (n=10), Asian (n=5), Hispanic/Latino (n=2)
Han et al. 2019	NR (described as ASD)	Verbal IQ ≥80, verbal fluency based on Autism Diagnostic Observation	Reading level ≥5th grade	NR except that autistic participants did not have	NR	NR	NR	NR

		Schedule, 2nd edition		depression, psychotic or bipolar disorders and substance use disorders.				
Hedley et al., 2018a	ASD (n=11, 15.5%), Asperger's syndrome (n=54, 76.1%), HFA (n=5, 7.0%), not specified (n=1, 1.4%)	NR	NR	NR	With spouse or partner (n=7, 9.9%), independent (n=15, 21.1%), with family member, relative or carer (n=47, 66.2%), other (n=2, 2.8%)	Part-time or full-time (n=37, 52.1%), no employment (n=34, 47.9%)	Primary school (n=1, 1.4%), some secondary (n=3, 4.2%), completed secondary (n=24, 33.8%), certificate (n=13, 18.3%), diploma (n=8, 11.3%), Bachelor's degree (n=18, 25.4%), other (n=4, 5.6%)	Australian (n=60, 84.5%), Aboriginal or Torres Strait Islander (n=1, 1.4%), other (n=6, 8.5%), prefer not to say (n=4, 5.6%)
Hedley et al., 2018b	ASD (n=46, 24.9%), Asperger's syndrome (n=110, 59.5%), HFA (n=23, 12.4%), autistic disorder (n=4, 2.2%), PDD-NOS (n=2, 1.1%)	NR	NR	NR	With parents (n=59, 31.9%), with relatives (n=4, 2.2%), with others (n=12, 6.5%), alone (n=38, 20.5%), as a couple (n=63, 34.1%), other (n=9, 4.9%)	Part-time or full-time (n=92, 49.7%)	Current secondary (n=14, 7.6%), some secondary (n=7, 3.8%), completed secondary (n=17, 9.2%), certificate or diploma (n=39, 21.1%), Bachelor's degree (n=51, 27.6%), postgraduate degree (n=35, 18.9%), other/not reported (n=22, 11.9%)	NR

Hickey et al., 2018	Asperger's syndrome (n=8), HFA (n=5)	Verbal in English	NR	No diagnosis of intellectual disabilities	With spouse, children or partner (n=3), with family members (n=2), independent (n=4), supported housing (n=3), private house share (n=1)	Part-time or full-time (n=5), retired, unemployed (n=8)	Some secondary school (n=5), some university (n=1), Bachelor's degree (n=6), Master's degree (n=1)	NR
Hillier et al., 2018	NR (described as autism spectrum disorder)	NR	NR	NR	NR	NA	All are currently in university	NR
Hull et al., 2017	Autism/autistic disorder, Asperger Syndrome/Asperger's Disorder, Autism Spectrum Disorder, Atypical Autism or PDD-NOS	NR	NR	NR	NR	NR	NR	British (n=41), North American (n=16), Western European (=15), other (n=10)
Hwang et al., 2017	Asperger's syndrome (n=13), ASD (n=1), "High functioning" autism (n=1)	NR	NR	Mild intellectual disability (n=2), moderate intellectual disability (n=1)	NR	NR	NR	NR
Jackson et al., 2018	Asperger's (n=34, 60.7%), ASD (n=10, 17.9%), HFA (n=8, 14.3%), PDD-NOS (n=4, 7.1%)	NR	NR	NR	NR	NR	NR	White (n=45, 80.4%), Hispanic (n=2, 3.6%), Black (n=1, 1.8%), Asian (n=4, 7.1%), mixed/other (n=4, 7.1%)

Study	Diagnosis				Living situation	Employment	Education	Ethnicity
Jantz, 2011	Asperger syndrome	NR	NR	NR	Alone (n=17, 48.5%), with parents (n=10, 28.6%), with roommates or spouse (n=6, 17.1%), with a dependant (n=1, 2.9%), community home (n=1, 2.9)	Full-time (n=13, 37.1%), part-time or self-employed (n=6, 11.4%), receiving social security disability insurance (n=3, 5.7%), retired (n=2, 2.9%), unemployed (n=9, 25.7%)	Postgraduate degree (n=12, 34.3%), some postgraduate school (n=3, 8.6%), Bachelor's degree (n=7, 20.0%), Associate's degree (n=2, 5.7%), some university (n=8, 22.9%), high school diploma or GED (n=3, 8.6%)	NR
Levinson, 2020	NR (described as ASD)	NR	NR	NR	NR	NR	NR	White (n=101, 82%), Latinx (n=6, 5%), Asian (n=2, 2%), Black/African (n=2, 2%), Middle East/North Africa (n=1, 1%), Native American (n=1, 1%), multiracial (n=7, 6%), not reported (n=3, 2%)
Lin & Huang, 2017	NR (described as ASD)	NR	NR	Psychiatric disorders (n=15, 22.7%)	NR	Full-time or part-time (n=30, 45.5%)	High school and below (n=16, 24.2%), university and above (n=30, 45.5%)	NR
Mazurek, 2013	Autism or autistic disorder (29.6%),	NR	NR	NR	NR	Full-time or part-time	NR	Caucasian (88.0%)

	Asperger's Disorder (63.9%), PDD-NOS (6.5%)					(49.1%), unemployed (26.9%)		
Mazurek, 2014	Autism or autistic disorder (29.6%), Asperger's Disorder (63.9%), PDD-NOS (6.5%)	NR	NR	NR	Alone (19.4%), with parents (38.0%), with partner, spouse or roommate (28.7%), other (13.9%)	Full-time (24.1%), part-time (25.0%), student (24.1%), unemployed (26.9%)	NR	Caucasian (88.0%)
McVey et al., 2016	NR (described as ASD)	NR	M(SD) of Verbal IQ on the Kaufman Brief Intelligence Test – Second Edition (KBIT-2; Kaufman and Kaufman 2004): 93.38 (22.95)	NR	NR	NR	NR	Experimental group: Caucasian (n=20) Waitlist group: Caucasian (n=21)
Merkler, 2007	NR (described as young adults with "high-functioning" autism)	NR	69-118 (M=93.13, Sd=12.59) on BETA III (Kellogg & Morton, 1999)	NR	NR	NR	NR	Caucasian (n=33, 89%), African American (n=1, 3%), Asian (n=1, 3%), Indian (n=2, 5%)
Milton & Sims, 2016	NR (described as adults on the autism spectrum)	NR	NR	NR	NR	NR	NR	NR
Orsmond et al., 2013	NR (described as ASD)	NR	NR	NR	With a parent/guardian (82.0%), alone/with a roommate (7.8%), under supervision (10.2%)	Full-time or part-time (33.5%)	Currently attending postsecondary school (12.4%)	White (70.0%), African American (18.7%), Mixed/other (11.3%)

Study	Diagnosis				Living situation	Employment	Education	Ethnicity
Russell et al., 2020	NR (described as autism spectrum disorder)	NR	NR	NR	NR	NR	NR	NR
Schiltz et al., 2020	NR (described as Autism)	NR (they reported the participants were predominantly verbal)	M(SD)=96.56(17.79), ranging from 63-145 on Kaufman Brief Intelligence Test, Second Edition (KBIT-2) (Kaufman & Kaufman, 2004)	NR	NR	NR	NR	White (85.50%), Asian (5.80%), Black (4.40%), Middle Eastern (1.40%), American Indian (1.40%), not reported (1.40%)
Smith & Sharp, 2013	Asperger Syndrome	NR	NR	NR	Alone (n=4), with a spouse, partner and/or children (n=3), with parents (n=2)	Full-time or part-time (n=3), in training for employment (n=3), unemployed (n=3)	GCSEs (n=2), A-levels (n=4), Bachelor's degree (n=2), degree plus professional qualification (n=1)	White British (n=8), Ashkenzai Jewish (n=1)
Southby & Robinson, 2018	ASD or autism (56.3%), others are not speficied	NR	NR	NR	NR	NR	NR	NR
Sundberg, 2018	HFASD	NR	NR	NR	NR	NR	NR	NR
Syu & Lin, 2018	Pervasive developmental disorders, Asperger's disorder, or PDD-NOS	NR	IQ ≥ 70 (measure used to determine this was not reported), reading comprehension and writing skills in Mandarin Chinese	NR	NR	Employed (n=33, 47.1%)	High school and below (n=16, 22.9%), college and above (n=54, 77.1%)	NR
Van der Aa et al., 2016	NR (described as "high-functioning" autism spectrum disorders)	NR	NR	NR	Independent (n=93, 84.7%), non-independent (with parents,	Paid employment (n=42, 37.8%), retired	Primary school (n=1, 9%), lower vocational/intermediate secondary education (n=11,	NR

						sheltered etc.) (n=17, 15.3%)	(n=2, 1.8%), student (n=13, 11.7%), disability allowance (n=32, 28.8%), unemployed and actively seeking (n=6, 5.4%), not employed otherwise (n=16, 14.4%)	9.9%), intermediate vocational/higher secondary education (n=21, 18.9%), higher vocational education (n=35, 31.5%), university (n=43, 38.7%)
Van Hees et al., 2015	Autistic disorder, Asperger's syndrome, or PDD-NOS	NR	NR	NR	NR	NA	All are currently attending university	NR

Note: NA = not applicable, NR = not reported, the Table reports the description exclusively on autistic participants though some studies include both autistic and non-autistic participants.

Appendix 2.6. Characteristics of loneliness measures identified in the included studies

Measures	Aim of tool	Target population	Number of items (Subscales)	Response options	Format	Used in what references?	Validity and reliability
The UCLA Loneliness Scale, Version3 (Russell, 1996)	To measure loneliness and social isolation	General population	20 Note: Hillier et al. (2018) states they used the scale that is 10 questions, however, the other included studies and the original study suggest 20 items.	4-point Linkert scale	Self-report questionnaire	Brooks (2014)*, Hedley et al. (2018a), Hillier et al. (2018), Jantz (2011), Russel (2020)*	Validated and reliable in neuro-typical university students with Cronbach's alpha of .89-.94 (Russell, 1996). Test-retest reliability (r=.73) was reported in three studies (Brooks, 2014, Hillier et al., 2018, Jantz, 2011).
Social and Emotional Loneliness Scale for Adults (SELSA) (DiTommaso & Spiner, 1993)	To measure social, family and romantic loneliness	Adults in the general population	37 (social, family and romantic loneliness)	7-point scale Linkert scale	Self-report questionnaire	Bourdeau (2020), Gantman et al. (2012), McVey et al. (2016), Merkler (2007), Schiltz et al. (2020)	Validated and reliable with the Cronbach's alpha of .89 to .93 (DiTommaso & Spiner, 1993). Internal consistency within the study (0.71) was reported in one study (McVey et al., 2016).
The UCLA Loneliness Scale Short Form (ULS-8) (Hays & DiMatteo, 1987)	To measure loneliness and social isolation	General population	8	4-point Linkert scale	Self-report questionnaire	Ee et al. (2019)*, Hedley et al. (2018b), Lin & Huang (2017)*, Mazurek (2013), Mazurek (2014),	Validated and reliable with Cronbach's alpha of .84 (Hays & DiMatteo, 1987).

Scale	Purpose	Population	Items	Scale	Method	Studies	Reliability
Revised UCLA Loneliness Scale (Russell et al., 1980)	To measure loneliness	General population	20	4-point Linkert scale	Self-report questionnaire	Sundberg (2017)*, Syu & Lin (2018) Caruana et al. (2021), Levinson (2020)*	Cronbach's alpha ranged between .917-.930 among participants with ASD, Cronbach's alpha ranged between .930 - .944 among neurotypical participants (Levinson, 2020)
3 item UCLA Loneliness Scale (Hughes et al., 2004)	To measure loneliness in a telephone survey with a large numbers of sample	General population	3	3-point Linker scale	Self-report questionnaire	Jackson et al. (2018)	Validated and reliable with the good internal consistency despite the Cronbach's alpha being .72 (Hughes et al., 2004)
Isolation and Affect measure (Merkler, 2007) based on the Peer Network and Peer Dyadic Loneliness Scale (PNPDL) (Hoza, Bukowski, & Berry, 2000)	To measure loneliness	Adults "with high-functioning autism" and the neuro-typical university students	28 (social network isolation, dyadic isolation)	5-point Linkert scale	Self-report questionnaire	Merkler (2007)*	Reported as validated and reliable with Cronbach's alpha ranged from .97 and .98 in autistic adults (Merkler, 2007)
Loneliness Scale based on the Revised UCLA loneliness scale (Russell et al., 1980)	To scale loneliness as one of the aspects of life that affects life satisfaction in adults "with	Adults "with ASC"	6 *based on the 20 items used in the original scale (Russell, Peplau, &	5-point scale Linkert scale	Self-report questionnaire	Van der Aa et al. (2016)	NR, but the Revised UCLA Loneliness Scale was validated and reliable with Cronbach's alpha

| | high-functioning ASC" | | Cutrona, 1980) | | | | | of .94 (Russell et al., 1980). |
| Loneliness in context questionnaire (LiCQ) (Asher & Weeks, 2014) | To measure loneliness for adults in daily contexts | Adults in the general population | 10 | 5-point Linkert scale | Self-report questionnaire | Han et al. (2019)* | Cronbach's alpha of .90, .88, .87 for TD control, ASD, and TD currently depressed groups were reported in the study, validated and reliable (Asher & Weeks, 2014) |

Note: NR = not reported, neuro-typical = non-autistic, Cronbach's alpha is the measure of internal consistency and shows the reliability, close to 1.0 being more reliable.

Note: Asterisks indicate the studied that reported the scores in both autistic and non-autistic comparison groups.

Appendix 2.7. References for Appendices 2.1-2.6

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Appendix 3.1. Full copy of the survey used in Chapters Three and Four

Information sheet

Research: Views and experiences of loneliness among autistic adults in the UK

What are the aims of this research?
In this research, we want to find out how well widely-used questionnaires capture the experiences of loneliness among autistic adults. We also want to collect autistic adults' views and experiences of loneliness.

Who is carrying out this research?
This research is led by Kana Umagami, a PhD student at CRAE (the Centre for Research in Autism and Education). Kana is supervised by Dr Laura Crane and Dr Anna Remington. Kana is autistic herself, and hopes that lots of fellow autistic adults will use this opportunity to share their views and experiences of loneliness.

Why am I being invited to take part?
We would like autistic adults (over the age of 18 years), who are willing to share their views and experiences of loneliness, to take part in this research. Please note that you need to live in the UK to take part in this survey.

What will happen if I choose to take part?
If you decide to take part, you will be asked to complete a survey with three parts: (1) some questions about you; (2) some questionnaires measuring levels of loneliness; and (3) some questionnaires sharing your own experiences of autism. The survey will take approximately 20 minutes to complete. There are two lots of £25 (in Amazon gift voucher) for a prize draw for those doing the survey as a small token of gratitude. If you would like to enter the prize draw, you could leave your email address at the end of the survey.

Can I see the survey before I decide whether to take part?
Yes. The questions are available here.

Do I have to take part?
It is entirely up to you whether or not you choose to take part. If you decide to take part but change your mind, that's fine too.

Will my information be private and confidential?
Yes. If you choose to tell us your contact details (to receive a copy of the results, or to take part in our future research), these will be stored separately from the other information you provide. All information you provide will be stored safely, following the General Data Protection Regulation (GDPR). Information that could potentially identify you will not be included in any reports or publications.

Is there anything else I need to know?
If you choose to take part, we have some important information to tell you about the way we will use your data (the information you provide). Specifically, we have to tell you that the "data controller" for this project will be University College London (UCL). This is the university we work in. The UCL Data Protection Office (including the Data Protection Officer) oversees UCL activities involving the processing of personal data, and can be contacted by emailing data-protection@ucl.ac.uk. Further information on how UCL uses information collected from participants can be found here. The legal basis that would be used to process your personal data (e.g., your age, your gender identity) is performance of a task in the public interest. The legal basis used to process special category personal data (e.g., your ethnicity) is scientific or historical research or statistical purposes/explicit consent. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL by emailing data-protection@ucl.ac.uk

Could there be any problems for me if I take part?
If at any point you feel uncomfortable, you can end the survey at any time and do not need to give a reason. To stop the survey, you can simply close the browser.

What will happen to the results of the research?
The results will be written as an academic paper, and hopefully published in an academic journal. We will also do our best to share the results with the autistic community in the most accessible way we can.

Please contact Kana if you would like any further information: kana.umagami.18@ucl.ac.uk

This study has been approved by the Department of Psychology and Human Development at UCL Institute of Education.

Consent form

You need to give consent to take part. To do this, please click on the following statements if you agree with them. You need to click on every statement to take part.

1) I have read the information sheet about the research, I understand that participation is voluntary and that I am free to stop at any time, without needing to give a reason. ☐

2) I understand that all information provided is strictly confidential and will not be released by researcher in any form that would permit the identification of any of the participants. ☐

3) I agree to my data being collected, processed and stored according to the General Data Protection Regulation (GDPR) and to be destroyed after a minimum of 10 years. ☐

4) I agree to take part in the above study. ☐

Section 1: Questions about you
To start, we will ask some questions about you. This is for us to gain a clearer understanding on who is taking part in our research.

Are you autistic?
- o Yes (I have a formal diagnosis)
- o Yes (I self-identify as autistic and am on the waiting list to get a diagnosis)
- o Yes (I self-identify as autistic but am not seeking a diagnosis)
- o No (I am not autistic)

Do you live in the UK?
- o Yes
- o No

If you have a formal diagnosis of autism, how old were you when you received this (in years)?
- o Not applicable
- o 1-90 (dropdown choices)

How old are you now (years)?
- o 18-100 (dropdown choices)

Which of the following sentences best describe your attitude towards disclosing your autism diagnosis to others (official diagnosis or self-diagnosis)?
- o I tend to share my diagnosis with anyone I meet
- o I tend to share my diagnosis with those close to me (family, friends, co-workers, etc.)
- o I tend NOT to share my diagnosis with anyone I meet including those close to me
- o Other (please specify: _____)

Where did you grow up?
- o In the UK
- o In another country (please specify: _____)

What is your gender identity?
- o Male (including transgender male)
- o Female (including transgender female)
- o Non-binary
- o Other (please specify: _____)
- o Prefer not to say

What is your ethnicity?
- o White (including British, Irish or any other White background)
- o Black or Black British Caribbean (including the Caribbean, African or any other Black background)
- o Asian or Asian British (including Indian, Pakistan, Bangladesh or any other Asian Background)
- o Mixed (e.g., White and Asian; or any other Mixed background)
- o Chinese
- o Other (please specify: _____)

o   Prefer not to say

Do you have any other diagnoses? [These might be physical/genetic/developmental/learning/intellectual/behavioral challenges or mental health conditions, for example.]

o   Yes (Please specify your diagnosis/diagnoses:＿＿＿＿＿＿＿)

o   Yes, but I prefer not to disclose the diagnosis/diagnoses

o   No

How do you tend to communicate?
o   Spoken language

o   Sign language

o   Communication devices and apps

o   Other (please give details:＿＿＿＿＿＿＿)

What is your living situation?

o   Living with parents and/or siblings

o   Living with non-family members (including living in university accommodation)

o   Living with partner and/or children

o   Living alone

o   Living in a residential home

o   Other (please give details:＿＿＿＿＿＿＿)

o   Prefer not to say

What is your employment status?
o   Full-time paid job (over 35 hours per week)

o   Part-time paid job (less than 35 hours per week)

o   Not employed - in full/part-time education (student)

o   Not employed - not in education

o   In voluntary employment

o   Other (please specify:＿＿＿＿＿＿＿)

o   Prefer not to say

Where did you receive the majority of your education?
o   Mainstream school
o   Specialist unit within a mainstream school
o   Specialist school
o   Home school
o   Other (please specify:＿＿＿＿＿＿＿)
o   Prefer not to say

What is your highest level of education?
o   GCSEs

- NVQs
- A/AS Levels
- First degree (e.g. BA, BSc)
- Higher degree (e.g. MA, MSc, PhD)
- Other qualifications (please specify:_____)
- Prefer not to say

What is your relationship status?
- Married
- Not married, but in a romantic relationship
- Divorced/separated
- Single
- Other (please specify: _____)
- Prefer not to answer

Section 2: Loneliness definition

We would like to ask you how you define loneliness in this section.

We value your voices very much and your views will directly impact not only this research but also our on-going research on loneliness in autistic adults. However, for any reasons, if you would rather not answer any of the following questionnaires, please say so in the textbox below or say 'not applicable'.

How would you describe loneliness?

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Researchers often describe loneliness in this way:
Loneliness is often described as an unpleasant experience caused by reductions in the quality and quantity of social relationships and the discrepancy between one's ideal and existing social relationships.

What do you think of this definition of loneliness: do you think is it similar to/different from your definition of loneliness, and why?

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Section 3: Questionnaires about loneliness

We would like to ask you to complete **three loneliness questionnaires that are often used in research**.

These have been developed for the general population (not autistic adults specifically).

Also, there might be some overlap between questions on the different questionnaires.

After completing each questionnaire, you will have the opportunity to express your opinions on these loneliness questionnaires: please tell us what is good about them, what is not-so-good and anything that could be improved.

*We hope that you can complete the questionnaires with the answer that most closely matches your experience. However, if you find the questionnaires impossible to complete for any reasons, please tell us why it was impossible to complete the questionnaires in the open text-entry.

Questionnaire 1: The UCLA Loneliness Scale (Russell, 1996)
Indicate how often each of the statements below is descriptive of you.

Never	Rarely	Sometimes	Often
(1)	(2)	(3)	(4)

1. How often do you feel that you are "in tune" with the people around you?
2. How often do you feel that you lack companionship?
3. How often do you feel that there is no one you can turn to?
4 How often do you feel alone?
5. How often do you feel part of a group of friends?
6. How often do you feel that you have a lot in common with the people around you?
7. How often do you feel that you are no longer close to anyone?
8. How often do you feel that your interests and ideas are not shared by those around you?
9. How often do you feel outgoing and friendly?
10. How often do you feel close to people?
11. How often do you feel left out?
12. How often do you feel that your relationships with others are not meaningful?
13. How often do you feel that no one really knows you well?
14. How often do you feel isolated from others?
15. How often do you fee1 you can find companionship when you want it?
16. How often do you feel that there are people who really understand you?
17, How often do you feel shy?
18. How often do you feel that people are around you but not with you?
19. How often do you feel that there are people you can talk to?
20. How often do you feel that there are people you can turn to?

If you would like to, please tell us what you think about this loneliness questionnaire (e.g., what is good about it, what is not-so-good about it, and any improvements that could be made to better reflect your experiences of loneliness)

Questionnaire 2: The Social and Emotional Loneliness Scale for Adults (DiTommaso & Spinner, 1993)

Rate each item from 1 (disagree strongly) to 7 (agree strongly)

Disagree strongly						Agree strongly
(1)	(2)	(3)	(4)	(5)	(6)	(7)

1. I am an important part of someone else's life.
2. I feel alone when I'm with my family.
3. No one in my family really cares about me.
4. I have a romantic partner with whom I share my most intimate thoughts and feelings.
5. There is no one in my family I can depend upon for support and encouragement, but I wish there were.
6. I really care about my family.
7. There is someone who wants to share their life with me.
8. I have a romantic or marital partner who gives me the support and encouragement I need.
9. I really belong to my family.
10. I have an unmet need for a close romantic relationship.
11. I wish I could tell someone who I am in love with that I love them.
12. I find myself wishing for someone with whom to share my life.
13. I wish my family was more concerned about my welfare.
14. I'm in love with someone who is in love with me.
15. I wish I had a more satisfying romantic relationship.
16. I have someone who fulfills my needs for intimacy.
17. I feel a part of my family.
18. I have someone who fulfills my emotional needs.
19. My family really cares about me.
20. There is no one in my family I feel close to, but I wish there were.
21. I have a romantic partner to whose happiness I contribute.
22. My family is important to me.
23. I feel close to my family.
24. What's important to me doesn't seem important to the people I know.
25. I don't have a friend(s) who shares my views, but I wish I did.
26. I feel part of a group of friends.
27. My friends understand my motives and reasoning.
28. I feel "in tune" with others.
29. I have a lot in common with others.
30. I have friends that I can turn to for information.
31. I like the people I hang out with.
32. I can depend on my friends for help.
33. I have friends to whom I can talk about the pressures in my life.
34. I don't have a friend(s) who understands me, but I wish I did.
35. I do not feel satisfied with the friends that I have.
36. I have a friend(s) with whom I can share my views.
37. I'm not part of a group of friends and I wish I were.

If you would like to, please tell us what you think about this loneliness questionnaire (e.g., what is good about it, what is not-so-good about it, and any improvements that could be made to better reflect your experiences of loneliness)

[ ]

Questionnaire 3: Direct measure of loneliness (Office for National Statistics, 2018)
How often do you feel lonely?
- ○ Often or always
- ○ Some of the time
- ○ Occasionally
- ○ Hardly ever
- ○ Never

Section 4: Your views and experiences of loneliness

Now we want to find out what YOU think about loneliness.

We value your voices very much and your views will directly impact not only this research but also our on-going research on loneliness in autistic adults. However, for any reasons, if you would rather not answer any of the following questionnaires, please say so in the textbox below or say 'not applicable'.

How does loneliness affect you? If you prefer, please feel free to describe a specific situation you have felt lonely.

[ ]

When you are feeling lonely, how do you usually deal with this (e.g., is there anything you do that makes you feel more/less lonely)?

[ ]

If loneliness affects you, do you have any ideas about what might help you feeling less lonely?

[ ]

[ ]

Has your experience of loneliness changed over time? If so, how?

[ ]

If you think it's important to have more research on loneliness in autism, what should this focus on?

[ ]

Is there anything else you want to mention regarding loneliness?

[ ]

Please tick the relevant box to let us know whether you'd be interested in receiving an invitation to an interview for this project...

- An invitation will include more information about the interview, and you can then read it and decide whether or not to take part in an interview.
- Interviews could take place in person, via Skype, via email, via instant messenger - whatever you prefer.
- Contents of the interviews will yet to be confirmed based on the results of this survey, however, interviews will further ask you about your views and experiences of loneliness.

- Yes, I would like to be invited to take part in an interview. ☐
- No, I do not want to be invited to take part in an interview. ☐

Thank you for your interest in taking part in our future research!

If you would like to take part in an interview, we need to locate your data from the survey you just completed. For that reason, could you please provide us with the first two letters of your surname and the day you were born? This will be your unique ID code.

(E.g. 1) If your name is Kate Davies and you were born on the 1st of a month, then your code would be DA01.
(E.g. 2) If your name is Jesse Smith and you were born on the 10th of a month, then your code would be SM10.

[ ]

We need to know your email address to invite you to an interview

To leave your email address, please click **the link in the next page** to go to another survey. This is to avoid any association of your personal information and your answers on this survey.

<div align="center">End of the survey page</div>

Important - please read
If you would like to receive the results of the research and/or enter the prize draw, please **<u>click here</u>** to go to the page to leave your email address. This is to avoid any kinds of associations between your answers on this survey and your email address.

Thank you!
Thank you so much for taking the time to complete the survey. Your answers are greatly valued and appreciated. We will use this information to find out whether the existing questionnaires that measure loneliness really reflect the experiences of autistic adults. We will also begin to examine what loneliness in autistic people is like.

If you have any further questions after this survey, please do not hesitate to contact Kana (kana.umagami.18@ucl.ac.uk).

Appendix 3.2. Summary of statistical checks for regression (as per Field, 2018)

Statistical tests	What was assessed?	Assessment results
Durbin-Watson (i.e., Durbin-Watson tests whether the analysis meets the assumption of independent errors)	Assumption of independent errors (i.e., independent errors mean that the residual terms are uncorrelated to/independent from the dependent variable)	The assumption of independent errors was met because Durbin-Watson value was between 1 and 3 (i.e., 1.9).
Tolerance (i.e., Tolerance indicates whether there is a strong linear relationship between predictors)	Assumption of no perfect multicollinearity (i.e., no perfect multicollinearity means that no two or more predictors are perfectly correlated)	The assumption of no perfect multicollinearity was met because tolerance for any of the variables entered in either model 1 or 2 was over 0.2.
VIF (i.e., VIF is the variance inflation factor and indicates whether there is a strong linear relationship between predictors)	Assumption of no perfect multicollinearity	The assumption of no perfect multicollinearity was met because the average VIF was below 10 (i.e., 1.6 for model 1 and 1.3 for model 2).
Plots of standardised residuals and predicted standardised values (residuals mean the errors in the model)	Assumption of linearity and homoscedasticity (i.e., linearity means that the relationship between dependent and independent variables are linear (Field, 2018, p.230) and homoscedasticity means that the spread of outcome values is roughly equal at all independent variables)	The assumption of linearity and homoscedasticity was met because a random array of dots was observed.
Cook's distance (i.e., Cook's distance indicates the estimated changes in the analysis when a case was removed from the model)	Checking the cases that may have undue influence on the model.	No case appeared to have undue influence on the model because the values of Cook's distance were below 1.
Mahalanobis distance (i.e., Mahalanobis distance indicates the distance between cases and the mean(s) of the predictor variable(s))	Checking the cases that may have undue influence on the model.	No case appeared to have undue influence on the model. The critical values of the chi-square distribution (Field, 2018, p. 1005) with nine predictors

		are 16.9 (*p*=.05) or 21.7 (*p*=.01). Although one case (P55) would be deemed 'significant' (i.e., 22.7, *p*=.01), none of the cases should not exceed the criterion for Mahalanobis distance (as per Field, 2018[28]).
Standardized DFBetas (i.e., standardized DFBetas indicate the distance between an estimated parameter with all cases and with a case excluded)	Checking the cases that may have undue influence on the model.	No case appeared to have undue influence on the model because absolute values for standardized DFBetas were below 1.
Leverage (i.e., leverage indicates the influence of the observed predictor variable on the predicted values)	Checking the cases that may have undue influence on the model.	No case appeared to have undue influence on the model because leverage value is not greater than three times the average leverage value (i.e., 3 × (9 (i.e., number of predictors) + 1/203 (i.e., sample size] = .049) = .15 > .11 (i.e., maximum centered leverage value))
Standardised residuals	Checking the cases that may have undue influence on the model.	No case appeared to have undue influence on the model because the cases that had a standardized residual that was less than -2 or greater than 2 were eight cases (3.9%) and within the expectation in an ordinary sample (i.e., 5% of cases fall outside the limits on standardized residuals.

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[28] Field (2018, p. 421) explained that with a sample of 100 and three predictors, the critical values of the chi-square distribution is 7.81 (p<.05) while the criterion for Mahalanobis distance is 15, much greater than the critical value). It is reasonable to assume that the criterion for Mahalanobis distance with a sample of 203 with 9 predictors should be much greater than the critical value (i.e., 21.7). Please also note that I have checked the cases that might have undue influence on the model using some other statistical tests and identified that no case appeared to have undue influence on the model.

Appendix 5.1. Full copy of the survey used in Chapter Five

Information sheet

Research: Views and experiences of loneliness among autistic adults in the UK during the coronavirus lockdown

We hope you are keeping well in these strange times.
What are the aims of this research?
Earlier this year you kindly completed some questionnaires about loneliness as part of our research. Given the coronavirus lockdown in the UK, we're now re-contacting participants and asking them to complete some loneliness questionnaires again, to see if/how this has affected autistic adults' experiences of loneliness.

Who is carrying out this research?
This research is led by Kana Umagami, a PhD student at CRAE (the Centre for Research in Autism and Education). Kana is supervised by Dr Laura Crane and Dr Anna Remington. Kana is autistic herself, and hopes that lots of fellow autistic adults will use this opportunity to share their views and experiences of loneliness.

Why am I being invited to take part?
We are inviting autistic adults who completed the previous survey and expressed their interest in being invited to further research opporutnities on the topic.

What will happen if I choose to take part?
If you decide to take part, you will be asked to complete a survey with **three parts**: (1) some questions about you (multiple questions); (2) some questionnaires measuring levels of loneliness (multiple questions); and (3) some questionnaires asking about your experiences of loneliness during the coronavirus lockdown (open-text entry). The survey will take **approximately 15 minutes** to complete.

Can I see the survey before I decide whether to take part?
Yes. <u>The questions are available here.</u> (You see the duplicated loneliness measures in the PDF file, and it is due to their randomization and you will only get one set of the measures in the survey.)

Do I have to take part?
It is entirely up to you whether or not you choose to take part. If you decide to take part but change your mind, that's fine too.

Will my information be private and confidential?
Yes. If you choose to tell us your contact details (to receive a copy of the results, or to take part in our future research), these will be stored separately from the other information you provide. All information you provide will be stored safely, following the General Data Protection Regulation (GDPR). Information that could potentially identify you will not be included in any reports or publications.

Is there anything else I need to know? If you choose to take part, we have some

important information to tell you about the way we will use your data (the information you provide). Specifically, we have to tell you that the "data controller" for this project will be University College London (UCL). This is the university we work in. The UCL Data Protection Office (including the Data Protection Officer) oversees UCL activities involving the processing of personal data, and can be contacted by emailing data-protection@ucl.ac.uk. Further information on how UCL uses information collected from participants can be found here. The legal basis that would be used to process your personal data (e.g., your age, your gender identity) is performance of a task in the public interest. The legal basis used to process special category personal data (e.g., your ethnicity) is scientific or historical research or statistical purposes/explicit consent. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL by emailing data-protection@ucl.ac.uk

Could there be any problems for me if I take part?
If at any point you feel uncomfortable, you can end the survey at any time and do not need to give a reason. To stop the survey, you can simply close the browser.

What will happen to the results of the research?
The results will be written as an academic paper, and hopefully published in an academic journal. We will also do our best to share the results with the autistic community in the most accessible way we can.

Please contact Kana if you would like any further information: kana.umagami.18@ucl.ac.uk

This study has been approved by the Department of Psychology and Human Development at UCL Institute of Education.

Consent form

You need to give consent to take part. To do this, please click on the following statements if you agree with them. You need to click on every statement to take part.

1) I have read the information sheet about the research, I understand that participation is voluntary and that I am free to stop at any time, without needing to give a reason. ☐

2) I understand that all information provided is strictly confidential and will not be released by researcher in any form that would permit the identification of any of the participants. ☐

3) I agree to my data being collected, processed and stored according to the General Data Protection Regulation (GDPR) and to be destroyed after a minimum of 10 years. ☐

4) I agree to take part in the above study. ☐

Section 1: Questions about you

To start, we will ask some questions about you. This is for us to gain a clearer understanding on who is taking part in our research.

This part of the survey has 11 questions and should take a few minutes to complete.

Please enter the unique identifier you created at the end of the previous survey.

Note: this is the first two letters of your surname and the day you were born.
(E.g. 1) If your name is Kate Davies and you were born on the 1st of a month, then your code would be DA01.
(E.g. 2) If your name is Jesse Smith and you were born on the 10th of a month, then your code would be SM10.

Are you currently living in the UK?
- o   Yes
- o   No (please specify which country you are in:_____)

Were there any changes in your living situation due to the COVID-19 outbreak?
- o No
- o Yes (please explain:_____)

What is your current living situation in lockdown? Please select all that apply.
- o Living with parents and/or siblings
- o Living with flatmates (including living in university accommodation)
- o Living with partner and/or children
- o Living alone
- o Living in a residential home
- o Living with pet(s)/animal family member(s)
- o Other (please give details:_____)

Were there any changes in your employment status due to the COVID-19 outbreak?
- o No
- o Yes (please explain:_____)

Were there any changes in your employment status due to the COVID-19 outbreak?
- o I am a key-worker and have continued to go out to work
- o I am working from home
- o I have been furloughed
- o I am unemployed
- o I am in full/part-time education
- o I am retired
- o Other (please specify: _____)

How many times have you left your house since the UK was put under lockdown?
- o Less than once per week
- o Once or twice per week
- o Three or four times per week
- o Five or more times per week

Have you had access to professional mental health support when needed?
- o Yes, I've had a therapist/counselor/psychologist/psychiatrist.
- o Yes, I've had a mentor.
- o Yes, I've had a support worker.
- o No, I haven't had access to professional support and I wouldn't want this.
- o No, I haven't had access to professional support, but I would want this.
- o Not applicable
- o Other (please give details)

Which of the following do you think best describes your living space?
- o Too cramped
- o Small
- o Just right
- o Spacious
- o Very spacious

Have you tested positive for coronavirus?
- o   Yes, but I recovered.
- o   Yes, and I am still unwell.
- o   No, I haven't tested positive for the virus (and I don't think I have been infected).
- o   No, I haven't tested positive for the virus (but I think I may have been infected)
- o   Prefer not to answer

Has the coronavirus caused your family any loss?
- o   Yes
- o   No
- o   Prefer not to answer

Section 2: Questionnaires about loneliness

We would like to ask you to complete **three loneliness questionnaires that are often used in research**.

<u>These have been developed for the general population (not autistic adults specifically).</u>

Also, there might be some overlap between questions on the different questionnaires.

Questionnaire 1: The UCLA Loneliness Scale (Russell, 1996)

Indicate how often each of the statements below is descriptive of you.

 Please answer based on how you've felt **during lockdown (i.e., the past six weeks)**

If you find it difficult to complete, please try to choose the answers that are most close to your subjective experiences

Never	Rarely	Sometimes	Often
(1)	(2)	(3)	(4)

1. How often do you feel that you are "in tune" with the people around you?
2. How often do you feel that you lack companionship?
3. How often do you feel that there is no one you can turn to?
4 How often do you feel alone?
5. How often do you feel part of a group of friends?
6. How often do you feel that you have a lot in common with the people around you?
7. How often do you feel that you are no longer close to anyone?
8. How often do you feel that your interests and ideas are not shared by those around you?
9. How often do you feel outgoing and friendly?
10. How often do you feel close to people?
11. How often do you feel left out?
12. How often do you feel that your relationships with others are not meaningful?
13. How often do you feel that no one really knows you well?
14. How often do you feel isolated from others?
15. How often do you fee1 you can find companionship when you want it?
16. How often do you feel that there are people who really understand you?
17, How often do you feel shy?
18. How often do you feel that people are around you but not with you?
19. How often do you feel that there are people you can talk to?
20. How often do you feel that there are people you can turn to?

Questionnaire 2: The Social and Emotional Loneliness Scale for Adults (DiTommaso & Spinner, 1993)

Rate each item from 1 (disagree strongly) to 7 (agree strongly)

Please answer based on how you've felt during lockdown (i.e., the past six weeks)
 If you find it difficult to complete, please try to choose the answers that are most close to your subjective experiences

Disagree strongly						Agree strongly
(1)	(2)	(3)	(4)	(5)	(6)	(7)

1. I am an important part of someone else's life.
2. I feel alone when I'm with my family.
3. No one in my family really cares about me.
4. I have a romantic partner with whom I share my most intimate thoughts and feelings.
5. There is no one in my family I can depend upon for support and encouragement, but I wish there were.
6. I really care about my family.
7. There is someone who wants to share their life with me.
8. I have a romantic or marital partner who gives me the support and encouragement I need.
9. I really belong to my family.
10. I have an unmet need for a close romantic relationship.
11. I wish I could tell someone who I am in love with that I love them.
12. I find myself wishing for someone with whom to share my life.
13. I wish my family was more concerned about my welfare.
14. I'm in love with someone who is in love with me.
15. I wish I had a more satisfying romantic relationship.
16. I have someone who fulfills my needs for intimacy.
17. I feel a part of my family.
18. I have someone who fulfills my emotional needs.
19. My family really cares about me.
20. There is no one in my family I feel close to, but I wish there were.
21. I have a romantic partner to whose happiness I contribute.
22. My family is important to me.
23. I feel close to my family.
24. What's important to me doesn't seem important to the people I know.
25. I don't have a friend(s) who shares my views, but I wish I did.
26. I feel part of a group of friends.
27. My friends understand my motives and reasoning.
28. I feel "in tune" with others.
29. I have a lot in common with others.
30. I have friends that I can turn to for information.
31. I like the people I hang out with.
32. I can depend on my friends for help.
33. I have friends to whom I can talk about the pressures in my life.
34. I don't have a friend(s) who understands me, but I wish I did.

35. I do not feel satisfied with the friends that I have.
36. I have a friend(s) with whom I can share my views.
37. I'm not part of a group of friends and I wish I were.

Questionnaire 3: Direct measure of loneliness (Office for National Statistics, 2018)

How often do you feel lonely?

Please answer based on how you've felt **during lockdown (i.e., the past six weeks)**

- o   Often or always
- o   Some of the time
- o   Occasionally
- o   Hardly ever
- o   Never

Section 3: Your experiences of loneliness during lockdown

Now we want to find out your subjective experiences of loneliness during lockdown. This is your opportunity to explain in your words if and how loneliness has affected you and how you have managed it.

Has loneliness affected you during the lockdown?
- o   Yes
- o   No
- o   Not sure

Regarding your answer to the question above, please explain why

Has your experience of loneliness changed during lockdown?
- o   Yes - it has lessened
- o   Yes - it has increased
- o   No - it has stayed about the same
- o   Not sure

Regarding your answer to the question above, please explain how it has changed or why it hasn't changed.

How have you tried to manage feelings of loneliness during lockdown? Please explain in the textbox below. If this question is not applicable to you (e.g., you haven't felt lonely), then put NA to proceed.

Is there anything that you would have found useful in managing any feelings of loneliness during the coronavirus lockdown? If so, please explain. If this question is not applicable to you (e.g., you haven't felt lonely), then put NA to proceed.

Is there anything else you want to mention regarding loneliness during lockdown?

End of the survey page

Thank you!
Thank you so much for taking the time to complete the follow-up survey. Your answers are protected, valued, and greatly appreciated.

If you have any further questions after this survey, please do not hesitate to contact Kana (kana.umagami.18@ucl.ac.uk).

We hope you stay safe and well.
Have a lovely day.

Appendix 5.2. Scores on UCLA Loneliness Scale Version 3

at Time 1 and 2 with RCIs

Participant	UCLA Time 1	UCLA Time 2	Change	RCI
11	64	41	-23	-2.871*
33	33	52	19	2.372*
24	54	37	-17	-2.122*
35	55	38	-17	-2.122*
30	62	46	-16	-1.998*
31	68	52	-16	-1.998*
3	71	56	-15	-1.873
40	68	53	-15	-1.873
46	65	51	-14	-1.748
1	75	62	-13	-1.623
49	74	62	-12	-1.498
52	65	53	-12	-1.498
13	71	61	-10	-1.248
41	62	52	-10	-1.248
42	34	44	10	1.248
45	41	51	10	1.248
28	48	39	-9	-1.124
14	37	45	8	0.999
32	60	52	-8	-0.999
51	65	57	-8	-0.999
26	45	38	-7	-0.874
12	74	68	-6	-0.749
16	80	74	-6	-0.749
25	61	55	-6	-0.749
27	59	53	-6	-0.749
36	78	72	-6	-0.749
48	48	42	-6	-0.749
56	64	58	-6	-0.749
58	63	57	-6	-0.749
60	69	75	6	0.749
4	68	63	-5	-0.624
23	69	64	-5	-0.624
43	58	63	5	0.624
10	66	70	4	0.499

20	65	61	-4	-0.499
34	57	53	-4	-0.499
37	69	73	4	0.499
38	76	72	-4	-0.499
47	60	64	4	0.499
59	50	54	4	0.499
5	67	64	-3	-0.375
6	71	74	3	0.375
7	59	62	3	0.375
8	62	59	-3	-0.375
9	77	80	3	0.375
39	76	73	-3	-0.375
50	80	77	-3	-0.375
53	59	62	3	0.375
21	60	62	2	0.250
22	51	53	2	0.250
2	55	54	-1	-0.125
15	63	64	1	0.125
17	63	62	-1	-0.125
19	74	75	1	0.125
29	71	70	-1	-0.125
44	76	77	1	0.125
55	72	71	-1	-0.125
57	76	75	-1	-0.125
18	52	52	0	0.000
54	70	70	0	0.000

Note: asterisks indicate the significant changes.