

**The Healthcare Experiences of Middle and Older
Age Autistic Women: A Thematic Analysis**

Amy Gillions

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Thesis Declaration Form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

A solid black rectangular box used to redact the signature of the author.

Name: Amy Gillions

Date: 16th June 2023

Overview

Part 1: Literature Review

The first part of this thesis comprises a conceptual introduction of the literature regarding autism and health with a particular focus on gender and ageing. The review highlights the significant health disparities experienced by autistic adults and the lack of research regarding the health of autistic women and older autistic adults in particular. Significant gaps in the literature are identified to justify the focus of the empirical paper.

Part 2: Empirical Paper

This research study qualitatively examines the perspectives of middle and older age autistic women accessing healthcare. The project was completed jointly with another trainee (see Appendix A for a description of each trainee's contributions). Fifteen participants were interviewed, and qualitative data was analysed using thematic analysis. Results suggested that participants experienced a range of negative interactions with healthcare providers, and they reported several barriers to navigating healthcare. Implications for professionals and services are discussed, as well as directions for future research.

Part 3: Critical Appraisal

The final part of the thesis offers an appraisal of the research process. This includes reflections on the design of the project and the experience of consulting autistic people about the study. Some of the difficulties encountered during the project are discussed alongside reflections on the interviewing process. The appraisal concludes with an extended discussion about the study's implications, strengths and limitations.

Impact Statement

There are several ways in which the findings presented in this thesis may be beneficial to the domains of academia, healthcare and policy. Firstly, the conceptual introduction in Part 1 offers a comprehensive overview of the current literature regarding autism, health, gender and ageing and highlights a plethora of directions for future academic research. In addition, the findings from the empirical paper in Part 2 offer insight into the experiences of a significantly under-researched demographic within the autism literature. To the author's current knowledge, this is the first study to qualitatively explore the healthcare experiences of middle and older age autistic women. Therefore, the study provides significant contributions to a nascent area of autism research.

Secondly, findings from this thesis have the potential to shape healthcare delivery for autistic women and inform policy development. This is highly important as the perspectives of autistic people are imperative in informing healthcare practices. There are several implications for clinical practice in both physical and mental health services. Notably, findings suggest the importance of making person-centred adjustments to accommodate the needs of middle and older age autistic women, offering flexibility within the healthcare system and making considerations for sensory sensitivities.

Furthermore, findings could be used to inform policy development by outlining training standards for healthcare professionals to ensure minimum requirements for knowledge about autism. This should include awareness about autism in women and girls, as well as information about autism across the lifespan and in older age. Other areas for potential policy development include health screening for autistic women in middle and older age to ensure appropriate and timely care can be offered.

There is potential for high impact from this thesis through disseminating the findings through academic fields and to healthcare providers. The research team hopes to develop lay summaries of the main findings to share with relevant stakeholders, especially the autistic community. A steering group of autistic people were consulted in the design of this project, and their input will also be highly valuable in designing and creating these documents. Ultimately, it is hoped that findings could meaningfully improve the healthcare experiences of middle and older age autistic women, and by extension the wider autistic population.

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I want to acknowledge my loved ones who have supported me throughout training and propped me up during difficult times. I am indebted to my incredible friends who have shown me unwavering kindness and love which has seen me through. Finally, I want to acknowledge what I have come through personally to reach this point, and I am proud of my resilience and strength.

Part 1: Literature Review

Exploring the Health Status and Healthcare Service Experiences of Autistic Adults Through Gender and Ageing

Abstract

The physical and mental health status of autistic people is a longstanding issue. Compared to the general population, autistic people have an increased prevalence of health conditions, higher service utilisation, greater dissatisfaction with healthcare and greater unmet health needs. In particular, autistic women and older autistic adults are thought to experience exacerbated health disparities. Therefore, this conceptual introduction aims to review the literature regarding autism and health through the lenses of gender and ageing. The review provides a broad and detailed introduction to the topic and is based on a comprehensive literature search. This conceptual introduction includes an exploration of key concepts related to autism, health, gender and ageing and discusses areas of overlap. Gaps in the literature are identified, highlighting the need for more research regarding the health and care experiences of autistic women in middle and later life. Finally, the conceptual introduction concludes with a justification of the empirical paper and research aims.

Overview

The purpose of this thesis is to explore how middle and older aged autistic women experience healthcare services in the United Kingdom (UK). Currently, there is limited research regarding the healthcare needs of middle and older aged autistic people and this gap is widened even further when considering autistic women in this demographic. Most of the autism literature is focused on diagnosis, presentation and service provision for children or young adults and there is far less known about how autistic people experience healthcare services into middle and older adulthood. Potential outcomes of this research include providing recommendations to healthcare providers and professionals so adaptations can be made to better suit the needs of autistic women in middle and older age to perhaps increase the accessibility of healthcare for this population.

In this conceptual introduction, I will review the literature regarding the healthcare needs of autistic women and consider how this demographic engage with services. I will begin by defining autism, outlining the female autism phenotype, and describing differences in presentation and diagnostic rates between men and women. I will then consider the broader literature around autism and health status followed by a discussion about women's health as a distinct area of healthcare compared to men's health. Following this, the physical and mental health status of autistic women will be reviewed in comparison to the broader autistic population and neurotypical people. Healthcare access and experiences amongst autistic people will be discussed, including the lens of gender and the perspectives of service providers and professionals. Finally, I will explore ageing in the autistic population and what is known about the health needs of this group, with a particular focus on women. The review will conclude with an outline of the empirical study including rationale and aims.

Relevant literature was sought in this conceptual introduction through an online search involving a range of databases (e.g. PsychINFO, PubMed) and key journals in the autism field (e.g. Autism, Journal of Autism and Developmental Disorders). Papers were then organised based on their relevance to any topics important to this thesis (e.g. gender or age). Additional literature was identified through online sources such as Google Scholar and by examining reference lists from key papers. Other publications were also reviewed, including policy documents and service-related research.

Overall, this literature review aims to define key concepts underpinning the thesis and to examine the intersections between autism, gender, health, and ageing. Furthermore, this review aims to outline the current body of literature about the healthcare needs of middle and older aged autistic women and what is currently known about how they use and engage with services. Finally, I hope to justify the focus of the empirical paper and its research methodology.

Defining and Understanding Autism

Autism spectrum disorder (hereafter ‘autism’) is a neurodevelopmental condition with two main diagnostic criteria; 1) difficulties in social communication and interaction and 2) restricted and repetitive interests and behaviour (World Health Organisation [WHO], 2019). Autism is a lifelong condition which impacts individuals across the lifespan, though diagnostic criteria require difficulties to be present during the developmental period and most autistic people are diagnosed in early life (WHO, 2019). In the UK, autism is a recognised disability protected under The Equality Act (2010).

The term ‘autistic person’ will be used throughout this review to reflect preferences amongst the autistic community for using identity-first and neurodiversity-

affirming language (Bury et al., 2022). Current estimates indicate that 1% of the population is autistic (Brugha et al., 2016) and the ratio of autistic males to females is approximately 3:1 (Loomes et al., 2017). Generally, females are more likely to be diagnosed later in life than males (Rutherford et al., 2016). Some possible reasons for this include differences in presentation between autistic males and females which will be discussed later in this review.

Alongside diagnostic estimates, it is also important to consider the increasing number of individuals who self-identify as autistic (Lewis, 2017). Many individuals self-identifying as autistic describe several barriers to the assessment process which mean they have not pursued a diagnosis. These reported barriers include having limited finances for private assessments, lack of recognition of autism in adulthood and older age, concerns about stigma, and anticipated lack of benefit from having a diagnosis (Lewis, 2016). For self-identified autistic women in particular, clinician biases towards a male presentation of autism and limited understanding of gender differences is a deterrent from seeking a diagnosis (Lockwood Estrin et al., 2021). Studies show that there is little variability in findings between self-identified autistic adults and those with a formal diagnosis, indicating that this group likely have an accurate understanding of autism and their own autistic traits (Overton et al., 2023)

The autism spectrum refers to the variability in how autistic individuals present and the different ways autism might affect how someone interacts with others and perceives information from the world around them. Autistic people may also have other neurodevelopmental conditions, including intellectual disabilities and attention-deficit hyperactivity disorder (ADHD). It is estimated that as many as 50% of autistic people also have an intellectual disability (Russell et al., 2019) and 50-70% present with co-occurring ADHD (Hours et al., 2022).

Generally, the rate of autism diagnoses is increasing. Changes in the diagnostic criteria in 2013 referring to the 'dyad of impairments' have meant that individuals are more likely to be diagnosed with fewer characteristics (Kulage et al., 2014). Data from a large-scale study in Sweden found that the average amount of autism characteristics in people diagnosed with autism at age 7 or older decreased by 50% from 2004 to 2014 (Arvidsson et al., 2018). This indicates that the diagnostic criteria for autism are becoming broader and more inclusive (O'Nions et al., 2023). In addition, there is increasing public knowledge and awareness about autism amongst the general population (Dillenburger et al., 2015). This is perhaps one of the reasons for the increase in referrals to autism assessment services and diagnostic rates across all age groups in the United Kingdom (Russell et al., 2022).

Autism and Gender

Autism has long been thought of as a condition that disproportionately affects males, and autism has largely been understood, characterised, and researched in male populations. Current diagnostic criteria and assessment practices are largely informed by an evidence base of mostly White and cisgender autistic males (Lai et al., 2022) and this has inevitably impacted diagnostic rates of autism in women. Research shows that females with a similar level of autistic traits to males are less likely to be diagnosed (Dworzynski et al., 2012) and estimates indicate that approximately 39% more girls should be diagnosed with autism (Barnard-Brak et al., 2019). Advances in autism research have led to the recognition of a female autism phenotype, which highlights differences in the way autistic women and girls might present. In addition to variations in autistic presentation, there may be additional characteristics observed in autistic females that are absent from the current diagnostic criteria (Chellew et al., 2022).

One of the significant areas where autistic females are thought to differ from autistic males is regarding social communication and interaction. Research indicates that autistic girls may have less severe or less noticeable difficulties compared to autistic boys. For example, in an educational setting, an autistic girl may be more likely to play alone and therefore missed as having any difficulties in comparison to an autistic boy misunderstanding the social rules of a group game (Dean et al., 2017). Furthermore, autistic females are more likely than autistic males to camouflage or mask their social interaction and communication difficulties (Cook et al., 2021). In the context of autism, camouflaging is defined as the use of compensatory behaviours or cognitive efforts to hide social differences from others and is a known risk factor for mental health problems including depression and anxiety (Hull et al., 2021).

Another key difference between autistic men and women is that autistic females are more likely to present with internalising difficulties, whereas externalised behavioural problems are more commonly seen in autistic males (Hull et al., 2017). Notably, this may be one of the reasons that autism is missed in younger girls as they may be less disruptive in education settings and their internalising difficulties may go unnoticed (Mandy et al., 2012). Restrictive and repetitive interests and behaviours are also thought to manifest differently between autistic males and females. For example, the focused interests of autistic girls are more likely to align with gender norms and stereotypes (e.g. animals or popular music groups) and are therefore less recognisable as possible autistic traits (Sutherland et al., 2017).

Knowledge of the female autism phenotype is especially important when considering how autistic women might present differently in healthcare services to autistic men. For example, autistic women are often misdiagnosed as having internalising mental health disorders such as anxiety or depression whilst their

neurodevelopmental profile is overlooked (Lai & Baron-Cohen, 2015). Furthermore, autistic women are more likely to be diagnosed with personality disorders (Gesi et al., 2021). In addition, autistic females may be more skilled at masking their difficulties to healthcare professionals compared to males.

Generally, autistic people are also more likely to be gender non-conforming than the general population (Janssen et al., 2016). Though these findings are predominantly from populations of younger autistic people, research evidence does suggest there is a higher rate of gender dysphoria amongst neurodiverse populations across the lifespan (Cooper et al., 2023). Therefore, consideration of gender differences is highly important when understanding how autistic individuals may present to healthcare services and how their support needs might differ from neurotypical people.

Physical and Mental Health in the Context of Autism

Autistic people have higher rates of mental illnesses (Lever & Geurts, 2016) and physical health conditions (Croen et al., 2015) compared to the general population. Most notably, autism is associated with epilepsy, sleep disorders and gastrointestinal difficulties (Weir, 2023), and anxiety and depression are amongst the most common psychiatric conditions experienced by autistic people (Croen et al., 2015). Furthermore, as previously mentioned, autistic people are more likely to have other co-occurring neurodevelopmental conditions such as intellectual disability and ADHD (Leitner, 2014).

In addition to the more commonly cited co-occurring physical health conditions outlined above, autistic people are also more likely to have fibromyalgia, fatigue, and joint hypermobility (Csecs et al., 2022). Related to this, autistic people report more pain associated with these conditions and autistic children in particular are twice as likely to experience chronic pain than neurotypical children (Whitney & Shapiro, 2019).

Compared to the general population, autistic people are more likely to die prematurely (Guan & Li, 2017; Hirvikoski et al., 2016) and suicide rates are also four times higher in autistic people compared to non-autistic people (Hirvikoski et al., 2020). Evidently, the complex healthcare needs of the autistic population and concerning suicide and mortality statistics present a significant issue.

There are some hypothesised reasons for the increased prevalence of physical and mental health conditions in the autistic population. One explanation for this might be the difficulties autistic people experience regarding social communication. Interacting with healthcare professionals can be highly stressful in a time-limited appointment and so autistic people may find it difficult to clearly express their concerns (Bauman, 2010). This may mean symptoms are overlooked, not investigated further, or dismissed entirely. Autistic people are also known to have difficulties with interoception, which is defined as the ability to interpret and understand signals from within the body (DuBois et al., 2016). This means they may struggle to report pain or discomfort accurately and may experience these sensations differently to neurotypical people and in a way that is poorly understood by medical professionals.

Furthermore, distressing sensory environments common within medical settings may make it more challenging for autistic people to access diagnostic procedures and attend appointments (Doherty et al., 2022). This can delay investigations and treatment and make it harder for autistic people to access preventative healthcare (Nicolaidis et al., 2013). Therefore, without accommodations and adjustments to support autistic people, engaging with healthcare can be significantly challenging and lead to worsening health.

At a broader level, autistic people are also known to experience high levels of adversity which may impact health outcomes. For example, autistic people

disproportionately experience unemployment, discrimination and abuse which are all associated with poor physical and mental health (Griffiths et al., 2019). Autistic women and girls in particular report elevated rates of childhood sexual abuse and victimisation (Roberts et al., 2015). In the autistic population overall, there seems to be an increased vulnerability to traumatic experiences which confers a greater risk for the development of psychiatric and physical health conditions (Stewart et al., 2022). Finally, there may also be a genetic basis for the increased prevalence of psychiatric or medical conditions among autistic people (Croen et al., 2015).

Within the literature regarding autism and health, it is important to consider the potential impact of undiagnosed autism. Most studies featuring people with a clinical diagnosis may be more likely to find negative outcomes because the subsample of autistic people with a confirmed diagnosis may be more likely to have frequent healthcare contact. Therefore, findings may not accurately represent the wider autistic population, including those who self-identify.

Women's Health

Evidence from the general population highlights that there are specific health conditions and risks associated with being born biologically female, typically related to reproductive health and hormonal differences (Regitz-Zagrosek, 2012). There are also some health conditions which are more common in women generally, including dementia (Beam et al., 2018), mood disorders (Seney & Sibille, 2014) and osteoporosis. (Alswat, 2017). Furthermore, gender is a known social determinant of health outcomes and gender-based inequalities contribute to poorer outcomes for women (Read & Gorman, 2010). Health outcomes are worsened further when considering the intersections between gender, ethnicity and socioeconomic status, with women from

ethnic minorities and low-income backgrounds experiencing the poorest health (Marmot, 2017). These inequalities are further exacerbated when considering outcomes for transgender women in particular (Zeeman et al., 2019).

Women also consistently report having more difficult experiences when accessing healthcare than men. Many women feel misunderstood or disbelieved by healthcare professionals and that their health concerns are not taken seriously (Department of Health & Social Care, 2022). In particular, the management of chronic pain among women is a significant issue, especially when in the context of gender-specific conditions such as endometriosis (Samulowitz et al., 2018).

Disabled women, including autistic women and those with intellectual disabilities, represent another minority group who are further impacted by health inequalities. One study found that disabled women in particular were 7.2 times more likely to have unmet healthcare needs compared to non-disabled men (Sakellariou & Rotarou, 2017). Taken together, these findings across the population demonstrate that health status and experience of healthcare is impacted significantly by gender which has a detrimental impact on health outcomes for women.

Physical and Mental Health in Autistic Females

Current literature suggests that autistic females have higher rates of physical health difficulties compared to both neurotypical females and autistic males (Kassee et al., 2020). In addition, autistic females and non-binary autistic people report experiencing more mental health issues compared to autistic men (Sedgewick et al., 2021). It is therefore important to consider the physical and mental health status of autistic women as a distinct population.

The minority stress model is particularly useful when considering contributory factors to health outcomes in autistic women. This theory suggests that individuals from minority or marginalised groups in society are likely to have worse outcomes due to prejudice and discrimination (Meyer, 2003). Therefore, the marginalised and minority status of autistic women may contribute to their health outcomes due to experiencing greater disadvantage, stigma and discrimination compared to neurotypical women and autistic men (Botha & Frost, 2020).

Mental Health

There is increasing evidence that autistic females generally have poorer mental health in comparison to both neurotypical females and autistic men (Beck et al., 2020). This finding is observed across the lifespan in both autistic children and young adults as well as older populations. One study found that autistic girls and young women aged 16-25 were more likely to have psychiatric diagnoses and be hospitalised for treatment compared to autistic males of the same age (Martini et al., 2022). While this highlights significant gender differences in the prevalence of mental illness amongst autistic people, it is also important to consider the impact of possible misdiagnosis. Notably, autistic women are more likely to report having prior diagnoses of personality and mood disorders compared to men and report having these diagnoses removed following an autism diagnosis (Kentrou et al., 2021). Therefore, whilst autistic females do seem to experience higher rates of mental illness compared to men, it should also be acknowledged that they may also be more likely to be misdiagnosed with psychiatric conditions which overshadow autism (Au-Yeung et al., 2019).

Suicide rates for autistic people have already been outlined in this review, but the figures suggest even poorer outcomes for women as the rate of suicide attempts and

risk for death by suicide for autistic women without intellectual disability is higher than for autistic males (Kölves et al., 2021). These findings are also applicable to autistic people who are transgender or non-binary in comparison to cisgender autistic populations (Newell et al., 2023). There is limited research available to explain this gender difference, though it is likely to be caused by a complex interaction of individual and environmental factors which disproportionately impact autistic women (Hirvikoski et al., 2020).

In addition to mood disorders, autistic women are also more likely to experience other psychiatric conditions such as eating disorders compared to autistic men (Brede et al., 2020). This is in line with differences observed in the general population, though autistic women are disproportionately represented in eating disorder services and there is significant overlap between female autism traits and eating disorder symptomatology that is often missed by clinicians (Carpita et al., 2022). Eating disorders are thought to be especially prominent in autistic women as a result of sensory sensitivities and rigidity around food, with restriction viewed as a possible attempt to cope with difficulties associated with being autistic and to exercise control (Brede et al., 2020).

Overall, there are significant gender differences in the presentation and experience of mental health difficulties across the autistic population. There are many factors involved that account for these differences which consistently place autistic women at a disadvantage regarding accurate identification of mental health issues, being offered appropriate support and understanding how mental illnesses interact with and relate to neurodiversity (Tint et al., 2021).

Physical Health

A recent scoping review concluded that autistic women have more physical health difficulties, poorer overall physical health and lower quality of life than autistic men (Kassee et al., 2020). More generally, autistic women also have a greater mortality risk than autistic men (Hirvikoski et al., 2016). These findings indicate that it is important to assess the physical health needs of autistic women as a separate clinical issue and presents another significant point of concern.

There is limited evidence about which specific health conditions are more prevalent in autistic women, however, it is consistently reported that epilepsy is more common (Supekar et al., 2017). Further, joint hypermobility is more common in neurodivergent females (Csecs et al., 2022) as well as specific conditions such as Ehlers-Danlos syndrome (Casanova et al., 2018). In addition, autistic women have the added burden of reproductive and endocrine health issues which do not affect cisgender autistic men (Kassee et al., 2020).

When looking outside the autistic population, there are also differences between the physical health of autistic and non-autistic women. In younger autistic girls, research indicates that the onset of menstruation (menarche) is associated with an intensification of autistic characteristics (e.g. heightened sensory issues) leading to increased emotional distress (Steward et al., 2020). Some research indicates that autistic females are also more likely than non-autistic females to experience pre-menstrual symptoms (Hamilton et al., 2011), although the reasons for this are unclear. The limited nature of the literature regarding autism and menstruation is not surprising given the historic research focus on autistic males and the wider societal stigma around menstruation.

When moving towards middle and later life, cessation of menstruation and onset of menopause is another significant milestone for women in terms of their physical health. Encouragingly, there has been an increasing research focus on the experience of the menopause in autistic women in recent years and quantitative findings suggest that autistic women do experience more menopausal difficulties compared to non-autistic women (Groenman et al., 2022). Autistic women who have been through the menopause describe an exacerbation of existing difficulties associated with autism such as sensory sensitivities, as well as a reduced ability to mask these difficulties (Moseley et al., 2020). There are also some common experiences between autistic and non-autistic women's experience of the menopause, with both populations experiencing an association between menopausal difficulties and depression (Groenman et al., 2022). This indicates that known menopausal complaints reported by neurotypical women are also present in autistic women, and perhaps further complicated by being autistic.

Some autistic women report that the menopause caused such an exacerbation of their autism-related difficulties that they felt unable to cope and became increasingly suicidal (Moseley et al., 2020). This highlights the importance of recognising the interplay between physical health and mental health for autistic women and the reciprocal role that they have on one another (Kassee et al., 2020).

Autism and Healthcare Access

Compared to the general population, autistic people are more likely to access healthcare services, including ambulatory care (Hand et al., 2019), emergency departments (Vohra et al., 2016), psychiatric care and general practice (Weiss et al., 2018). Despite having higher service utilisation than the neurotypical population, many autistic people find it challenging to access suitable care for their physical and mental

health needs (Malik-Soni et al., 2022). This is concerning given the increased prevalence of health conditions amongst the autistic population and the anticipated amount of support required. This poses a question of whether autistic individuals are accessing a high amount of healthcare that is reflective of their needs, or whether they are repeatedly accessing ineffective care (Tint et al., 2023). This might mean that autistic people have to navigate the healthcare system multiple times before accessing appropriate support or finding a service with suitable knowledge about autism (Zerbo et al., 2019).

Several barriers explain the disparity in access and reported dissatisfaction with healthcare services amongst autistic people. Earlier in this review, autism-specific difficulties such as issues with interoception, sensory needs and challenges interacting with healthcare professionals were highlighted as possible barriers to healthcare. Another barrier to access is the lack of knowledge about autism among healthcare professionals and service providers, which leads to ineffective care (Walsh et al., 2020). From the perspective of professionals, many report not receiving enough training and lacking self-efficacy in their skills to provide healthcare to autistic people (Corden et al., 2022). On a more systemic level, healthcare systems are often inadequate for autistic people based on the isolation of services and difficulties coordinating care for the multiple co-occurring health conditions autistic people experience (Mason et al., 2019).

Many autistic people also cite sensory sensitivities as another barrier to healthcare. The physical environment of medical settings can cause sensory overload, as well as medical procedures themselves (Dern & Sappok, 2016). Factors such as noise, bright lights, physical touch and the busyness of waiting areas can make healthcare appointments very challenging for autistic people (Mason et al., 2019).

Evidently, access to healthcare services and quality of care provided is an area of great difficulty for autistic people. The organisation of services and reliance on the patient to navigate complex healthcare systems means autistic people may not receive reasonable adjustments to facilitate access (Ghahari et al., 2021). The consequences of this are concerning, and the multiple barriers to healthcare might explain why autistic people across the lifespan have more unmet health needs than their neurotypical counterparts (Nicolaidis et al., 2013).

Healthcare Use in Autistic Women

Given the gender differences between the physical and mental health status of autistic people that have already been described, it is unsurprising that there are also differences in healthcare usage between autistic women and men, as well as non-autistic women. Firstly, there are gender differences in specific service use between autistic men and women. Notably, research has shown that autistic women are more likely to attend emergency departments, see general practice or family doctors and access neurology services compared to autistic men (Tint et al., 2023). The same study found that autistic women were also more likely to be admitted to hospital for any reason compared with autistic men.

When compared to non-autistic women, findings consistently show that autistic women attend fewer gynaecological appointments and are less likely overall to access obstetrics and gynaecology services (Zerbo et al., 2019). Specifically, autistic women are less likely than non-autistic women to attend cervical smears (Nicolaidis et al., 2013), meaning that autistic women access less preventative gynaecological healthcare. This has concerning implications as many autistic women may be missing early detection of serious diseases such as cancer.

There are several possible explanations for the difference in healthcare utilisation observed in autistic women. Sensory issues may have a role in explaining why autistic women attend fewer cervical screening appointments than non-autistic women given that it is an invasive and sometimes uncomfortable procedure. There are also several possible reasons for the difference in service access between autistic men and women. Earlier in this review, the minority stress model was applied to possibly explain the increased prevalence of health conditions in autistic women and there is further utility here. For example, autistic women may be more likely to present to certain services due to multiplicative stressors and risk factors. Late diagnosis of autism is also likely to be relevant as autistic women may not have accessed appropriate services prior to their diagnosis, causing an accumulation of unmet healthcare needs (DaWalt et al., 2021).

Experiences of Services

Whilst there are some established findings regarding the barriers to healthcare for autistic people, there is less research including the voices of autistic people to understand how they experience services (Nicolaidis et al., 2015). Of the studies available, autistic people report feeling ignored and disempowered (Calleja et al., 2022), as though they are falling through the gaps between services (Griffith et al., 2012a) and frustrated by receiving ineffective care that does not accommodate their neurodiverse needs (Camm-Crosbie et al., 2019). Autistic adults report that adjustments in healthcare settings are highly important to them, but rarely available (Brice et al., 2021).

One qualitative study found that autistic adults' experiences of healthcare are impacted by cognitive factors, professionals' knowledge about autism and consistency of care (Mason et al., 2021b). The patient-provider relationship has been highlighted as

important to autistic adults, and satisfaction with care is linked with adjustments at the service level alongside having positive interactions with understanding and knowledgeable professionals (Mazurek et al., 2023). Many autistic people also describe the significant impact of sensory sensitivities affecting all aspects of their healthcare experiences, including the way they communicate with professionals (Williams et al., 2022). Overall, autistic people report more negative experiences of healthcare services compared to non-autistic people (Nicolaidis et al., 2013).

Autistic Women's Experiences

Most of the literature regarding the service experiences of autistic people predictably focuses on the needs of younger adults and males. Despite the disparities in health status and access to services for autistic women, far less research attention has been paid to how they experience and engage with services. The first study about the healthcare experiences of autistic women was published in 2018 and the qualitative findings reported that participants felt misunderstood and their compensatory masking behaviours minimised some of their difficulties to service providers (Tint & Weiss, 2018). Though it could be argued that autistic men may share similar views regarding their experience of services, there is a clear rationale for focusing specifically on the viewpoints of autistic women given the established gender disparities in autism research. Moreover, there are currently no studies which attempt to qualitatively understand any potential differences in perspectives between autistic men and women about their experiences of healthcare.

The perspectives of autistic women accessing eating disorder services have had some research attention. Autistic women have reported that some of their autistic traits were misunderstood as eating disorder symptomatology and felt that therapeutic

interventions such as cognitive behavioural therapy or group treatments were not suitable (Babb et al., 2021). Furthermore, there is some evidence regarding how autistic women experience gendered healthcare services compared to non-autistic women. Focusing on maternity and post-natal healthcare services, autistic women overall reported less satisfaction with the care they received, increased sensory overload during labour and experienced more communication difficulties with professionals during appointments than neurotypical women (Hampton et al., 2022a). Building upon these quantitative findings, qualitative studies have found that autistic women feel that maternity professionals have a limited understanding of autism and therefore helpful accommodations and adjustments are rarely made during pre-natal appointments or during labour (Hampton et al., 2022b).

To summarise, autistic women show different patterns of service access compared to autistic men. In addition, there are further differences in the use of gendered health services between autistic women and neurotypical women. There is minimal research focusing specifically on how autistic women perceive the support provided by healthcare services, though there is some emerging evidence to suggest that they feel misunderstood and that their neurodiversity is inadequately integrated into their healthcare.

Perspectives of Service Providers and Healthcare Professionals

In addition to the voices of autistic people, it is important to include the views of service providers and professionals regarding their knowledge of autism and perspectives on providing healthcare to autistic people. Involving professionals in this discussion is imperative as having a limited understanding of autism can be both a

barrier for autistic people accessing healthcare and a contributory factor for worse health outcomes (Doherty et al., 2022).

General practitioners (GPs) are especially important within the UK healthcare system as they are often the first point of access for support, hold an individual's medical records and coordinate referrals to other services. Concerningly, evidence shows that GPs do not receive adequate training about autism and this may contribute to the observed health inequalities for autistic people (Chown et al., 2023). This finding is generally consistent across a range of studies globally, highlighting that the lack of adequate knowledge about autism within primary care is a significant issue.

A recent systematic review found variability in professionals' understanding of autism and self-efficacy towards providing healthcare to autistic people (Corden et al., 2022). Some research has shown that mental health professionals such as psychologists and psychiatrists demonstrate a better understanding of autism compared to primary care providers (Heidgerken et al., 2005). Despite this, therapists report feeling unconfident about adapting treatment for the autistic population, regardless of years of experience (Cooper et al., 2018).

However, the full breadth of health inequality experienced by autistic people cannot be solely explained by lack of adequate training about autism. This places responsibility on individual healthcare professionals and providers alone, minimising wider systemic and organisational issues in the healthcare system. These system-level factors create further barriers for autistic people to access effective healthcare, in addition to the limited understanding of autism amongst health professionals (Chown et al., 2023).

Understanding Autism in Middle and Later Life

Another specific characteristic that will be explored next in this conceptual introduction is ageing in autism. The research literature on autism is predominantly focused on the experiences of younger autistic people and/or their parents or caregivers. There is far less research on the trajectory of autistic people as they progress into the middle stages of adulthood and older age. In the past decade, of all publications about autism, only 1% have focused on older age research (Mason et al., 2022). This is especially concerning as autism is a lifelong condition and there is an increasing number of autistic people being diagnosed in adulthood (Russell et al., 2022). Furthermore, given that the overall population is ageing and living longer, there will be an increasing number of older autistic people requiring healthcare support (Sonido et al., 2020).

One of the main issues when considering autism and ageing concerns the specific age categories used to constitute middle and later life. In the general population, older adults are typically defined as having a chronological age of 65 years or over (Orimo et al., 2006). Given the premature mortality observed in the autistic population, research about ageing and autism tends to have a looser and more arbitrary definition of older age (Roestorf et al., 2019). This is particularly relevant for autistic people with co-occurring intellectual disability for whom the premature mortality rate is even higher (Krantz et al., 2023).

One study observed the mean age of death in an autistic population to be 54 years (Hirvikoski et al., 2016), suggesting a lower threshold for ageing may need to be considered. However, findings from this study should be interpreted lightly as the reported mean age of death was for those who had died during the study follow-up, only 3% of the sample. The remaining participants were still alive, meaning that this statistic is heavily biased.

In addition to the cohorts of children first diagnosed with autism now entering later stages of life, there are also an increasing number of middle and older aged people getting a diagnosis or self-identifying as being autistic for the first time (King & Bearman, 2009). Seeking a diagnosis during middle or later adulthood can be challenging given that parts of the diagnostic process rely on information about an individual's early developmental history. For many adults, the death of a parent or the absence of reliable family members to provide information can be a barrier to diagnosis (Wise, 2020). In addition, older autistic people may have spent a lifetime compensating or masking their autistic traits which means their presentation might differ from diagnostic standards and increase the likelihood of misdiagnosed psychiatric problems (Roestorf et al., 2019).

Broadly, research attempting to understand the life experiences of autistic middle and older aged adults focuses on employment, living status, relationships, health, and quality of life. Generally, many autistic adults report difficulties with employment and social isolation (Griffith et al., 2012a) and these findings are also seen in older autistic adults (Hickey et al., 2018). A report from the Office for National Statistics ([ONS], 2021) stated that only 21.7% of autistic adults in the UK are in employment, indicating that autistic adults face significant barriers to obtaining work. Though there are known difficulties for autistic people finding employment, research beyond middle-stage adulthood is minimal and there is a paucity of literature about retirement in autistic people (Wise, 2020).

Regarding living status, autistic adults are more likely to live with family or in a residential setting and this is observed more frequently in autistic adults with a co-occurring intellectual disability (Hewitt et al., 2017). Given that autistic adults are more likely to live with their parents than adults with any other disability (ONS, 2021), there

is an increasing awareness of the housing needs of autistic adults whose parents are ageing themselves and requiring their own care and support. Parents of autistic middle-aged adults living at home describe significant worries about what will happen to their child when they pass away and to whom the caring responsibility will go (Griffith et al., 2012b).

Findings suggest that autistic adults generally have a poorer quality of life compared to the neurotypical population (Mukaetova-Ladinska et al., 2012). It can be challenging to separate health status from quality of life, given that having significant unmet healthcare needs will impact quality of life. In addition, there are many more factors affecting quality of life in autistic adults, including availability of social support, engagement within the community and independence (Lawson et al., 2020). Social support is a significant predictor of quality of life in middle and older aged autistic people, even when demographic factors and health-related factors are accounted for (Charlton et al., 2023). These findings are in keeping with the existing literature regarding younger autistic adults, suggesting that there is some similarity between different age groups within the autistic population. However, an important critique to raise here is that quality of life measures are based on what neurotypical people consider to represent quality of life, which may differ from autistic people (Evers et al., 2022).

There is variability in the literature regarding differences in autism-related traits and behaviours amongst younger and older autistic people. Some studies have found a reduction in autism characteristics from childhood to middle adulthood (Lever & Geurts, 2016), whereas others have found no association between age and self-reported autism characteristics (Yarar et al., 2022). Inconsistencies in the current literature may be due

to issues with self-reported versus parent-reported or clinician-reported autistic traits and a lack of longitudinal research.

Autism, Ageing and Health

Evidence does suggest that middle to older age autistic adults have distinct healthcare needs compared to younger autistic people. Notably, older autistic adults are more likely to present with gastrointestinal difficulties (Wise et al., 2017) and show a decreased prevalence for psychiatric diagnoses (Lever & Geurts, 2016) than younger autistic people. The reasons for these differences are unclear and are also impacted by the method of reporting and limited sample sizes.

Older autistic adults will also experience typical age-related health decline observed in the general population, though there are differences related to ageing and health observed in autistic people (Happé & Charlton, 2011). A significant study assessing the health status of Medicare-enrolled autistic adults in the United States found that autistic older adults had significantly higher odds of most physical health conditions compared to an age-matched control group (Hand et al., 2020). Specific conditions associated with ageing (e.g. cardiovascular disease and arthritis) were also more common in autistic older people.

In the general population, ageing is typically associated with cognitive decline and an increased risk for developing dementia, including conditions such as Alzheimer's disease and Parkinson's disease. There is limited research exploring the link between autism and risk for dementia in older age, though there is some indication that older autistic adults are at greater risk for developing dementia compared to neurotypical older people (Hategan et al., 2017). Autistic adults are also more likely to be diagnosed with early-onset dementia compared to the general population (Vivanti et al., 2021).

Furthermore, studies show that higher levels of autistic traits are associated with a faster pace of ageing, as well as poorer self-reported physical health (Mason et al., 2021a). This indicates that autistic older adults seem to have greater health needs compared to older people in the general population, in keeping with findings for younger cohorts of autistic people. In addition to this, autistic people seem to experience greater age-related health decline and show an increased prevalence of health conditions associated with ageing (Torres et al., 2020). However, these studies do not typically adjust for the more challenging life circumstances many autistic people have experienced which may negatively impact health in older age, including discrimination, abuse and unemployment (Griffiths et al., 2019). Increased occurrences of negative experiences across the lifespan may be more common for older autistic people and should therefore be considered as a possible reason for the health outcomes observed in this population.

Despite this, it should be acknowledged that there is significant variability within the autism and ageing literature. Studies have opposing conclusions, namely that autism is either associated with a faster pace of ageing, that autistic people age at a similar pace to neurotypical people, or that autism protects against typical ageing (Tse et al., 2022). There is also an absence of longitudinal studies and limited inclusion of autistic adults aged 50 or over. Therefore, it is important to interpret these findings with caution in the absence of several high-quality longitudinal studies with a large sample of older autistic people.

Based on the author's current knowledge, there are no qualitative studies specifically focusing on older autistic people and their health experiences. A study featuring predominantly middle age autistic adults concluded that this group experience significant uncertainty about the future and worries about deteriorating health and

future support needs (Rodgers et al., 2019). This highlights a significant gap in the autism literature, where the perspective of older autistic people is largely absent. There is an emphasis on quantitative research to determine the prevalence of health conditions and whilst this is important, there is a lack of understanding about how the older autistic population perceive healthcare.

Middle and Older Aged Autistic Women

Narrowing the focus further, there are some differences between middle and older aged autistic men and women regarding health status. One study found that autistic women reported significantly higher concerns on a dementia screening tool than autistic men, and this may be evidence for increased vulnerability to cognitive decline in autistic women (Klein et al., 2023). The mean age of the sample in this study was 55, so findings may be less applicable to older autistic adults 65 or over.

Compared to cisgender autistic men, middle-aged autistic women also have the additional burden of navigating the menopause and the impact of hormonal and reproductive changes, such as reduction in oestrogen levels and risk for osteoporosis (Kassee et al., 2020). Some research has also shown differences between the health status of older autistic women compared to neurotypical women of the same age. For example, older autistic women aged 65 and over show a significantly greater risk for epilepsy, Parkinson's disease and gastrointestinal conditions compared to non-autistic women (Hand et al., 2020).

Overall, the scope of the research exploring gender differences between older autistic people is extremely limited. The intersection between ageing and gender is an area within autism literature which has received minimal attention in line with a historic bias towards younger cisgender males. Few studies assessing the health status

of older autistic adults make comparisons by gender, possibly due to low sample size (Stewart et al., 2023). Advocates within the autistic community have highlighted this as a significant issue and have called for more studies on the experiences of older autistic women especially (Michael, 2016). In this way, middle and older age autistic women can be considered part of the lost generation of autistic adults described by Lai and Baron-Cohen (2015). Overall, knowledge about this demographic is poorly established within the autism literature and inadequately captured by current diagnostic criteria. Inevitably, this impacts how middle and older age autistic women are understood and perceived by healthcare professionals.

Empirical Study

The literature discussed in this review highlights significant health disparities experienced by autistic women. In addition, older autistic adults are a significantly under-researched group, though there are some emerging findings regarding the health status of this population. When including gender in the ageing and autism intersection, there is a scarcity of research output. Hence, there is evident justification for the empirical study featured in this thesis which aims to explore the healthcare experiences of middle and older age autistic women. The known gender differences amongst autistic adults regarding health status and service utilisation indicate that it is important to consider the perspectives of autistic women separately. Crucially, older autistic women have noted the lack of research including their views and experiences and have suggested that this should be a priority for autism researchers (Michael, 2015).

Broadly, the aims of the empirical paper are as follows:

1. To understand the experiences of middle and older age autistic women seeking support and accessing services for their health.

2. To explore barriers and facilitators reported by middle and older age autistic women when it comes to finding and accessing healthcare services.

A qualitative approach was chosen to amplify the voices of autistic women to better understand their perspectives and expand what is currently known about barriers to healthcare for autistic people. This approach has further justification based on calls for qualitative research regarding the lived experience of autistic adults beyond early adulthood (DePape & Lindsay, 2016; Hwang et al., 2017). The aims have been kept purposefully broad given the lack of previous literature available, further supporting the use of an inductive qualitative approach.

Summary and Conclusion

In summary, this conceptual introduction has provided an overview of the current literature to understand the relationships between gender, health and ageing in relation to autism. In comparison to the general population, autistic people show higher rates of physical health conditions and mental illness across the lifespan as well as significant barriers to healthcare and greater unmet needs. There are heightened concerns when considering autistic women, who generally have greater health needs compared to both autistic men and non-autistic women, indicating that the healthcare needs and experiences of autistic women are significant issues warranting research attention. Finally, including age as another factor highlights the limited knowledge about the middle and older aged female autistic population. Therefore, the empirical study aims to better understand the perspectives of this group of autistic women to address the prominent gaps in the literature. To the author's knowledge, this is the first study specifically exploring autistic women's perspectives about healthcare generally, as well as being the first study to focus on those in middle and older age.

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Part 2: Empirical Paper

The Healthcare Experiences of Middle and Older Age Autistic Women: A Thematic Analysis

Abstract

Aims: Autistic women show a higher prevalence of physical and mental health conditions compared to both autistic men and non-autistic women. They present with greater mortality and suicide risk and have a high proportion of unmet healthcare needs. Despite this, little is known about how autistic women experience healthcare services in middle and later life. The aim of this study was to qualitatively explore the perspectives of middle and older aged autistic women on their healthcare experiences.

Method: Fifteen middle to older age autistic women participated in semi-structured interviews about their experiences of accessing healthcare services. Interviews were analysed using thematic analysis alongside some quantitative measures of autism traits, health status and health literacy to characterise the sample.

Results: Five main themes were generated using thematic analysis: 1) Stigma and stereotypes in professionals' understanding of autism, 2) Intersectionality, 3) Accumulation of negative healthcare experiences, 4) Efforts required to navigate healthcare systems and 5) Future: age-related concerns and hopes for change.

Conclusions: Multiple barriers to accessing healthcare were reported by the autistic women in this study and participants felt stigmatised by repeated negative interactions with healthcare providers. Age and gender were important in how participants felt they were perceived in healthcare settings related to autism stereotypes. Implications for services and directions for future research are discussed.

Introduction

Autism spectrum disorder (hereafter 'autism') is a neurodevelopmental condition diagnosed on the basis of repetitive and restricted behaviours and difficulties with social interaction and communication (World Health Organisation, 2019). Approximately 1% of the population is autistic (Brugha et al., 2016) and the ratio for male to female diagnosis is estimated to be 3:1 (Loomes et al., 2017). Throughout this paper, identity-first and neurodiversity-affirming language will be used based on preferences expressed by some of the autistic community (Bottema-Beutel et al., 2021).

Though most autistic people are diagnosed in childhood, autism is a lifelong condition and the cohorts of children first diagnosed with autism in the 1940s are now in older age. Over the last decade, the number of autism diagnoses has increased significantly, particularly among female adults (Russell et al., 2022). Estimates indicate that in the United Kingdom (UK) there are currently 240,000 autistic adults aged 50 or over (Stewart et al., 2021).

Autism and Health

Consideration of the middle and older-aged autistic population is highly important given the implications for health and social care provision. Compared to the general population, diagnosed autistic people have a higher prevalence of physical and mental health conditions across the lifespan (Croen et al., 2015; Lever & Geurts, 2016). Autism is also associated with other neurodevelopmental conditions such as attention-deficit hyperactivity disorder (50-70% comorbidity rate; Hours et al., 2022) and some reports suggest that as many as 50% of autistic people also have an intellectual disability (Russell et al., 2019). Gastrointestinal issues, sleep difficulties, epilepsy, depression and anxiety are among the most common co-occurring conditions

experienced by autistic people (Fortuna et al., 2016). In addition to the specific conditions more prevalent in the autistic population, autistic people also have a lower overall life expectancy (DaWalt et al., 2019) and a higher risk of death by suicide (Hirvikoski et al., 2020) compared to neurotypical adults.

Despite the complexity of their health needs, autistic people have significant difficulties accessing healthcare (Weir et al., 2022), resulting in health inequalities. This contributes to the high level of unmet healthcare needs in the autistic population, for both physical and mental health conditions (Platos & Pisula, 2019). Autistic people also report lower satisfaction with healthcare (Gerber et al., 2017) and higher utilisation of services compared to non-autistic people (Zerbo et al., 2019). Research suggests that there are several barriers which make accessing healthcare a challenge for autistic people at the individual, service provider, and systemic level (Walsh et al., 2020). These barriers include insufficient knowledge about autism amongst healthcare professionals, the isolation of healthcare services, sensory sensitivities, and communication difficulties.

Autism, Health and Ageing

In line with other autism research, the focus of many healthcare studies is primarily on younger autistic children or those in early adulthood and there is a paucity of research considering the health status of autistic adults in middle age or older adulthood (Mason et al., 2022). Of the available literature, findings show that autistic older adults are at a greater risk for most physical health conditions compared to the general older adult population (Hand et al., 2020; Torres et al., 2020). Furthermore, high levels of autism-related traits are associated with a faster pace of ageing and worse self-reported physical health (Mason et al., 2021a). The limited amount of research on

autism in later life means that findings are mixed, with studies reporting contradictory findings about the impact of autism on ageing (Tse et al., 2022). Sample sizes are often low, and there are few longitudinal studies involving autistic people aged 50 or over. Whilst there are some studies regarding the health status of middle and older aged autistic people, little is known about how they experience services (Nicolaidis et al., 2015).

Health Status of Autistic Women

Health inequalities experienced by autistic people appear to be widened further when considering the intersection between gender and neurodiversity. Autistic women show a higher prevalence of certain health conditions compared to autistic men and poorer health outcomes overall compared to non-autistic women (Kassee et al., 2020). Mortality risk for autistic women is also greater than for autistic men (Hirvikoski et al., 2016) and autistic women without intellectual disabilities are the group most at risk for death by suicide (Kölves et al., 2021). Women's health issues including menarche and menopause seem to have a greater impact on autistic women (Groenman et al., 2022), suggesting that this population have distinct healthcare needs when compared to both the autistic and non-autistic population. The marginalised and minority status of autistic women is thought to contribute to the health disparities they experience, highlighting how prejudice about this demographic, as well as stigma and discrimination, can lead to poorer health outcomes (Botha & Frost, 2020).

There is also a dearth of research regarding the health status and healthcare experiences of autistic women, which is unsurprising given the historic male bias in the autism field (Lai et al., 2022). Of the available literature, evidence suggests that middle-aged autistic women may be at greater risk for age-related conditions such as dementia

(Klein et al., 2023). There is also a greater prevalence of mental health conditions among autistic women compared to autistic men (Beck et al., 2020). Autistic women are more likely to be misdiagnosed with mental health conditions without recognition from professionals that undiagnosed autism may be contributing to their poor mental health (Kentrou et al., 2021). Additionally, late diagnosis of autism is more common in women than men and may contribute to poorer health outcomes due to the unsuitability of services and treatment (DaWalt et al., 2021).

There are some studies focusing on the healthcare experiences of autistic women, mostly limited to gendered healthcare services such as maternity care (Hampton et al., 2022) or eating disorder services where autistic women are over-represented (Babb et al., 2021). These studies found that autistic women feel that their needs are not met by services, based on professionals' minimal understanding of autism in women and the lack of suitable adjustments to accommodate their neurodiversity. Generally, autistic women also report feeling disregarded by services and that masking may contribute to this (Tint & Weiss, 2018).

However, to the author's current knowledge, there are no studies which focus specifically on the perspectives of middle and older age autistic women regarding their healthcare experiences. This significant gap in the literature warrants research attention to better understand gender and age-based health inequalities experienced by autistic women. In addition, middle and older age women may be more likely to access health care due to typical age-related health decline, so it is important to better understand their experiences. Furthermore, autistic women have called for more research related to health and ageing as a priority (Michael, 2015) and there is an absence of qualitative research regarding the lived experiences of autistic people in middle and older adulthood (Hwang et al., 2017).

Present Study

The aim of this study was to qualitatively explore the healthcare experiences of autistic women in middle and older age. Given the lack of previous research related to this topic, the aim was kept purposefully broad and exploratory. A qualitative approach was chosen to investigate the following research questions to generate an in-depth understanding of autistic women's experiences:

- How do middle and older age autistic women perceive support from healthcare services?
- What are the barriers and facilitators reported by middle and older age autistic women when it comes to finding and accessing healthcare services?

Method

Research Design

This study was part of a wider project about autism, health and ageing and was completed jointly with another trainee (see Appendix A for a summary of each trainee's contributions). As part of this project, an online survey featuring a series of questionnaires was developed to quantitatively explore the health needs of older autistic adults. Data from this survey will be analysed and reported separately to this thesis. At the end of the survey, participants had the option to leave contact information to express interest in participating in this qualitative study. The online survey also facilitated the collection of demographic information about participants. To incentivise potential participants, those who completed the survey and provided contact information were entered into a prize draw to win one of five £20 vouchers. The information sheet and consent form for the survey are presented in Appendix B.

A panel of four autistic adults aged 50+ including three females and one male were involved in the development of all study materials, including the online survey and interview schedule, as well as providing feedback on practical aspects of completing the survey (e.g. timings, readability). The panel were formed as part of an autism and ageing research steering group facilitated by the National Autistic Society (NAS).

Participants

Eligibility for participation was based on the following inclusion criteria:

- Being female (assigned female sex at birth or currently identifying as a female)
- Aged 50+
- Having a diagnosis of autism or self-identifying as autistic
- Able to hold a conversation in English (this was established through communicating with participants to arrange the interview)
- UK resident

The only exclusion criterion was having multiple and profound intellectual disabilities that may prevent participation in an interview and capacity to consent. Information about autism diagnosis was based on self-report only, and participants who self-identified as autistic but had not been formally diagnosed were also included. Whilst it is recognised that this may create issues with credibility and validity, there are many justifications for this.

Notably, many older autistic people may choose not to pursue a diagnosis or have difficulty obtaining historic medical records if they were diagnosed in childhood. A recent paper examining the underdiagnosis of autism in the UK highlighted that fewer than one in 10 autistic adults over 50 were diagnosed based on primary care records as of 2018 (O’Nions et al., 2023). Therefore, limiting the sample to only diagnosed people

could mean the sample is unrepresentative. The panel of autistic people involved in the design of the study also felt it was important that self-identified autistic people were eligible to participate.

Recruitment and Selection

The study was advertised through a range of online sources including social media (e.g. Twitter and Facebook) and established autism research recruitment networks (e.g. Autistica and the NAS). Posters were created to advertise both the online survey and this qualitative study separately. This was to enable people to contact us directly about participating in the interview-based study without completing the survey should they wish. Despite offering this option, all participants in this study were recruited from the online survey.

The online survey was active for six months between June 2022 and December 2022. Responses to the survey were monitored weekly and individuals who left their contact information (email or telephone number) were contacted to discuss the qualitative study. At this stage, older participants (65+) were purposively sampled as this age group has been significantly underrepresented in previous studies. Once all potential participants from this group had been contacted, we then contacted participants below this age group. If participants did not initially respond, they were contacted again a week later. Other minority demographic characteristics including ethnicity and sexuality were also purposively sampled to make attempts at increasing the generalisability of the sample.

We aimed to recruit 15 participants based on pragmatic considerations such as time constraints and possible difficulties reaching this demographic given the known issues with underdiagnosis of autism in women. Based on previous qualitative research

about older autistic people which included a similar number of participants (see Hickey et al., 2018), it was felt that 15 participants would be sufficient to enable a broad and in-depth exploration of the research questions. Ideas from information power were also used to make informed considerations about sample size (Malterud et al., 2016).

Demographic Information

There were 15 participants in total and all were cisgender women. Participant demographic information is presented in Table 1.1. The age of participants ranged from 51 to 73 years (mean = 59.6). Twelve participants reported having a diagnosis of autism and three self-identified as being autistic. Participants were all diagnosed or started to self-identify as autistic in adulthood, mostly between the ages of 51-60 (n=7) or 41-50 (n=6) and a minority between the ages 61-70 (n=2). One participant self-identified as having a mild intellectual disability and one participant reported having a diagnosed mild intellectual disability. The other 13 participants reported having no intellectual disabilities.

Materials

Quantitative Measures

A range of quantitative measures were featured in the survey to characterise the sample based on autistic traits, health literacy and health status (see Table 1.2). Demographic information was also collected as part of the online survey and these questions were co-produced with the steering group of autistic adults. All measures used in the survey are provided in Appendix C.

Table 1.1*Participant Demographic Information*

Participant Number	Age	Autism Diagnosis	Intellectual Disability Diagnosis	Ethnicity	Sexuality	Marital Status	Living Status	Education	Employment Status	Care Received
1	73	Professional	Self-identified, mild	White British	Heterosexual	Widowed	Alone	Did not complete formal education	Retired	1-19 hours a week, informal
2	62	Professional	No	White British	Heterosexual	Single	Alone	Up to undergraduate level	Unemployed	1-19 hours a week, formal
3	52	Professional	No	White British	Heterosexual	Married	With spouse	Up to undergraduate level	Employed (full-time)	None
4	65	Professional	Diagnosed, mild	White British	Heterosexual	Single	Alone	Up to undergraduate level	Retired	1-19 hours a week, formal and informal
5	69	Professional	No	White British	Heterosexual	Married	With spouse	Up to postgraduate level	Retired	None
6	57	Professional	No	White British	Heterosexual	Co-habiting	With partner	Up to undergraduate level	Retired	None
7	66	Self-Identified	No	White British	Heterosexual	Married	With spouse	School to age 18	Retired	None
8	68	Self-Identified	No	White British	Heterosexual	Married	With spouse	School to age 16	Employed (part-time)	None
9	53	Professional	No	White British	Prefer not to say	Married	With spouse	Up to postgraduate level	Employed (part-time)	1-19 hours a week, informal
10	58	Professional	No	White British	Heterosexual	Married	With spouse	Up to postgraduate level	Employed (part-time)	None
11	52	Professional	No	Mixed or Multiple: White and Asian	Asexual	Married	With spouse	Did not complete formal education	Unemployed	None
12	58	Professional	No	White British	Heterosexual	Married	With spouse	Up to postgraduate level	Self-employed	None
13	51	Professional	No	White British	Heterosexual	Single	Alone	Up to undergraduate level	Employed (full-time)	None
14	55	Self-Identified	No	White British	Heterosexual	Co-habiting	Alone	Up to postgraduate level	Employed (full-time)	None
15	56	Professional	No	White European	Prefer not to say	Married	With spouse	Up to postgraduate level	Volunteer	1-19 hours a week, informal

Table 1.2*Participant Characteristics: Autism Traits, Health Literacy and Health Status*

Participant Number	AQ-10 Score	HLS-EU-Q16 Score	SCQ Score	SCQ Reported Conditions
1	10	14	3	Gastrointestinal condition, back pain
2	10	2	3	Depression
3	10	14	1	Depression
4	10	6	6	Depression, lung disease
5	10	16	8	Lung disease, high blood pressure, liver disease, back pain, arthritis
6	5	16	5	Hypermobility Ehlers-Danlos Syndrome, Mast Cell Activation Syndrome, osteoporosis, heart condition
7	9	8	9	Depression, back pain, thyroid condition, Irritable Bowel Syndrome, arthritis
8	7	14	4	Osteoporosis, back pain, gastrointestinal condition
9	9	13	4	Anxiety, depression, back pain, thyroid condition
10	8	9	7	Anxiety, depression, thyroid condition, anaemia, cancer
11	4	8	14	ADHD, depression, liver disease, arthritis chronic pain, Ehlers-Danlos Syndrome, genetic condition
12	7	4	6	ADHD, gastrointestinal condition, thyroid condition, high blood pressure, liver disease
13	8	14	4	Depression, chronic fatigue, back pain
14	8	8	8	Depression, anxiety, Irritable Bowel Syndrome, chronic fatigue, arthritis and other muscular-skeletal conditions
15	8	9	7	Hypermobility Ehlers-Danlos Syndrome, chronic fatigue, low blood pressure, back pain, cancer

Note: A score of 6 on the AQ-10 is considered indicative of autism. Health literacy (HLS) is categorised by the following scores: inadequate (0–8), problematic (9–12), and sufficient (13–16). The maximum SCQ score for conditions listed on the questionnaire is 36. Higher scores would indicate a higher number of health conditions, amount of treatment received and impact of health on daily activity.

10-item Autism Spectrum-Quotient (AQ-10). The AQ-10 is recommended by the National Institute for Health and Care Excellence (NICE) as a valid measure of autistic traits (Allison et al., 2012). It is widely used within research and clinical settings as an autism screening tool that can be completed quickly with high sensitivity (Taylor et al., 2020). The steering group of autistic adults also felt the conciseness of the questionnaire meant it was easy to complete, meaning that people would be more likely to complete the survey. Though it was not a requirement for participation, thirteen participants scored above the threshold on the AQ-10 and two participants scored below.

Health Literacy Survey (HLS-EU-Q16). The HLS-EU-Q16 measures perceived ability to find, understand, appraise, and apply health information to tasks related to personal healthcare, disease prevention, and health promotion (Sorensen et al., 2013). The construct validity of this 16-item measure has been established across several different countries (Bas-Sarmiento et al., 2020). It was also felt that the HLS-EU-Q16 has good face validity for the purposes of this research. Participants' scores were mostly categorised as either sufficient (n=7) or inadequate (n=6), and a minority scored in the problematic category (n=2), suggesting diverse health literacy in the sample. The average HLS-EU-Q16 score was 10.3 placing the sample overall in the problematic range.

Self-Administered Comorbidity Questionnaire (SCQ). The SCQ is a self-report measure of common mental and physical health conditions (Sangha et al., 2003) and it was chosen to characterise the current health status of participants. Whilst it has not been validated with an autistic population, it has been found to have good reliability and validity with older adults.

Qualitative Measures – Interview Schedule

A semi-structured interview was developed by the research team in collaboration with the steering group of older autistic people (see Appendix D). The creation of the schedule began with broad questions about current health status and experiences of healthcare. This included questions about barriers and facilitators to healthcare alongside opportunities to talk about gender, ageing and neurodiversity. Adaptations were made based on feedback from the panel of autistic individuals, such as including specific prompts, providing definitions, and simplifying language. The

schedule was used flexibly during interviews, allowing the interviewer to intuitively follow the conversation whilst having a basic framework to guide the discussion.

Procedure

Individuals who expressed an interest in participating were sent an information sheet and consent form (see Appendix E). Once completed, a date and time for the interview was arranged and all participants were sent the interview questions beforehand. Interviews took place remotely either on the telephone or online via Zoom and reasonable adjustments were offered. All interviews were recorded on an encrypted voice recording device and audio files were stored securely on the university's Data Safe Haven. The first author transcribed all 15 audio files verbatim, removing any identifying information. Anonymised survey data was then linked with a transcript through the allocation of a participant number. Participants each received a £15 voucher for taking part.

Data Analysis

Quantitative questionnaires were scored and interpreted according to their respective publications and author instructions. Thematic analysis (TA) was chosen to analyse the qualitative interviews based on its flexibility and applicability to accounts of individual experiences. For this study, flexibility in the analytic approach was important given the breadth of the topic and lack of previous research.

Instructions for TA outlined in Braun and Clarke's (2006) seminal paper were followed alongside updated guidelines and protocols from reflexive TA (Braun & Clarke, 2019). Before embarking on the analysis, a bracketing interview was completed with another member of the research team to position the author's identity and pre-existing

assumptions about the topic. A position statement was written based on this interview (see Appendix F). This is an important aspect of reflexive TA, accounting for the subjectivity within the research process and exploring how researchers engage with data and the analytic process (Braun & Clarke, 2019).

The first stage of TA involves familiarisation with the data (Braun & Clarke, 2006) which was achieved by transcribing the interviews and reading the transcripts several times. Following this, the interview transcripts were coded using N-Vivo. Rather than using a pre-existing coding framework, an inductive data-driven approach was followed to capture meaning as communicated by participants using an experiential orientation (Braun & Clarke, 2013). Hence the analysis was conducted using a 'bottom-up' approach and without attempts to align the data with existing theories. Codes were produced at both the latent and semantic level and an example of a coded transcript is provided in Appendix G. Themes were generated by actively searching for patterns in the data to create clusters of similar codes. These clusters were used to create a set of initial themes, which were developed further using a thematic map. Final themes were named and refined through discussion with the research team.

Two of the coded transcripts were shown to another member of the research team. The purpose of this was to discuss coding ideas and explore assumptions made about the data. This process was more about enhancing the richness of the coding rather than checking for consistency, as advocated for by Braun and Clarke (2021). For the same reasons, coding concepts and theme names were also discussed with research supervisors.

Ethics

The study received ethical approval from the University College London (UCL) Research Ethics Committee (see Appendix H).

Results

Using TA to analyse qualitative data from the interviews generated five main themes related to participants' healthcare experiences. These overarching themes and any associated subthemes are outlined in Table 2.

Table 2

Themes and Subthemes Inductively Generated Using Thematic Analysis

Overarching Theme	Subthemes
1. Stigma and stereotypes in professionals' understanding of autism	1.1. Gender differences 1.2. Misdiagnosing mental health difficulties 1.3. Feeling misunderstood and mistreated
2. Intersectionality	
3. Accumulation of negative healthcare experiences	3.1. Avoiding accessing support 3.2. Feeling like a burden 3.3. Emotional distress
4. Efforts required to navigate healthcare systems	4.1. Masking 4.2. Practical and cognitive aspects 4.3. Coping with sensory overload
5. Future: age-related concerns and hopes for change	

Theme 1: Stigma and stereotypes in professionals' understanding of autism

Participants reported that their healthcare experiences were significantly impacted by professionals' understanding of autism. Specifically, participants found it challenging to interact with professionals who held stereotypes about how autistic people 'should' present. Overall, having repeated encounters with healthcare

professionals who held stereotypical views about autism made participants feel stigmatised.

The amount of stigma that I've experienced when I do disclose [...] so if I say I'm autistic or they see that in the file, what they do with that information depends so much on their level of knowledge. And generally I would say, level of knowledge amongst health professionals about being autistic and what that means is extremely poor and usually results in them being absolutely patronising and treating you like you're some sort of idiot. (P15)

This created a sense of uncertainty amongst participants about whether they should disclose their diagnosis. Importantly, participants felt that experiences of ineffective healthcare were directly related to professionals' lack of understanding about autism. Furthermore, participants raised concerns about having to educate professionals about autism to receive better support or treatment. One participant recounted this happening with her therapist:

My most recent counselling support person recognised she didn't know anything about autism [...] she was prepared to go away and read and learn but I felt like I was a bit of a guinea pig and actually, I'm there for support, but I felt like I was having to support somebody to support me. (P9)

1.1. Gender differences

Participants specifically commented on the lack of understanding amongst healthcare professionals about how autism can present in women based on stereotypes informed by autistic males. The following quote highlights several misunderstandings about autism, gender and age experienced by one participant, which has become a barrier to disclosing her diagnosis in the future:

They seem to have an idea about what autism is and isn't [...] so you're talking to people who've got no understanding and still think maybe that women can't be autistic. And especially with ageing as well, it gets worse. A lot of people seem to think it's something that only affects children, so it's actually at a point where I've decided not to even bother saying anything about it anymore. (P11)

Participants also described experiences where their diagnosis was questioned by healthcare professionals because of their gender and how they presented in appointments. Commonly, this was impacted by the fact that participants were interacting with healthcare professionals in ways that are incongruent to stereotypically male autistic behaviour: *They were saying, oh, she can't be autistic 'cause she can do this and she can do that, because they had a really narrow-minded view of what autism was like. (P8); One healthcare professional said to me, you can't have autism, I said why not? He said, 'cause if you had autism, you wouldn't be able to talk about your feelings (P11).*

Participants were left feeling discouraged and unsure whether it was worth informing services that they are autistic. The way they were positioned depended on the professional they were interacting with; some took on an educator role where they needed to inform professionals about autism in women. Others seemed to have their neurodiversity dismissed due to their gender and were positioned as naïve or misinformed.

1.2. Misdiagnosing mental health difficulties

Perceived professional stereotypes about autism seemed especially related to participants' experiences of mental health care. These experiences were strongly linked with being a woman, with many participants feeling that gendered stereotypes influenced how they were perceived by professionals in relation to their mental health

and subsequently affected the treatment they were offered. Participants described how professionals had routinely misdiagnosed possible autistic behaviours as mental illnesses, leaving them feeling frustrated in middle and later life due to their neurodiversity being overlooked for so long:

[...] instead of being blinkered saying it's depression, and instead [someone] thought, why does she keep coming back for the same thing? Telling us that she's suicidal, she doesn't want to live. She's having these panic attacks. You know, you look on these sites and you think all the symptoms I've had for years and years have all been signs of autism. Why has nobody thought that it might not be depression?

(P7)

You go to the GP, they put it down to anxiety or depression, I've had a history of things being attributed to that, and I'm not saying that those things don't exist in and of themselves, but they were manifestations of undiagnosed autism. (P6)

For many of the participants, longstanding issues related to misdiagnosed mental illness were associated with having a late diagnosis or identification with autism. Their autistic behaviour was often minimised and mislabelled as a mood or personality disorder and participants felt misunderstood by healthcare professionals who were unable to identify or suggest they might be autistic: *I've had an awful lot of counselling-type therapy over the last 25 years, not one of them picked up that I was autistic* (P14).

Based on misdiagnosis, participants described having treatments for mental health difficulties which were ineffective, notably due to lack of adaptations for their neurodiverse needs: *There's nothing really that's particularly tailored for autistic people and I haven't found CBT delivered in the standard manner very helpful* (P10). Lack of adaptations meant that participants felt that something was inherently wrong with

them and their autistic styles of thinking, rather than understanding that the treatment they were offered may not have been a good fit:

Where you're being supported for anxiety and depression, you are led to believe that your way of thinking is wrong and your way of thinking needs to change and there's something very wrong about you. And actually, that's just not true. I just need to be supported differently. (P9)

Participants also reflected on the consequences of being misdiagnosed with mental illnesses whilst remaining unaware about being autistic for most of their adult lives. There was a sense of frustration and sadness associated with having to repeatedly access different types of support to try and find something that helps. This was linked with participants' sense of identity and insight about their difficulties, with many participants internalising problems finding support within themselves rather than the system. This quote illustrates the exasperation experienced by participants around attempts to find adequate mental health treatment:

*From my 20s on I've tried f***ing everything under the sun, any kind of random weird little therapy you've ever heard of, I've probably tried it [...] you then end up in your 50s and think, so this is never going to go away then? This struggle, this never fitting in and not being able to figure out why. (P15)*

1.3. Feeling misunderstood and mistreated

One of the consequences of interacting with healthcare professionals who have limited knowledge about autism was that participants felt misunderstood, and therefore mistreated as a result. Misunderstandings were described on two levels, firstly participants described feeling like their specific health needs were misunderstood but also that their overall identity as an autistic woman in the context of healthcare was

misunderstood. The following participant describes anticipating misunderstandings with healthcare professionals (e.g. doctors) and how she perceives them as a “confrontation”, presumably based on prior experiences:

As an autistic person, I don't want to have to do this because I know it will be a confrontation. I know it will because you, the doctor, doesn't understand my perspective at all. And so you, the doctor, are going to dismiss me. (P14)

The concept of mistreatment from professionals and the experience of stigmatisation was captured in several ways. Participants felt that being autistic, and specifically an autistic woman, made it more likely professionals would not believe them, minimise their concerns and treat them poorly. Confusion and misunderstandings during communications with professionals were also common, leading to a sense that participants’ views and ways of expressing themselves were not acceptable to service providers:

I'm not listened to, I'm not understood. When I'm trying to explain things, they don't give me the chance to explain. They dismiss what I'm saying, they're more interested in reading what's on the computer, what somebody else has written. And then they try to tell you what you're saying isn't true. (P11)

Theme 2: Intersectionality

Overlapping aspects of one’s identity were found to contribute to how participants experienced healthcare. For the participants in this study, experiences were shaped by the interactions between their gender, neurodiversity, and age. Their accounts suggest that this affected how healthcare professionals perceived and interacted with them during medical appointments. Participants often felt overlooked, judged or dismissed due to their status as middle or older-aged autistic women.

I'm also hypervigilant because I've been judged as a parent, I've been judged as a woman, as a middle-aged woman, as an autistic woman, I'm hypervigilant, probably oversensitive, so I'm looking all the time for ways to make sure I'm not being misjudged. (P13)

I just felt like I was being dismissed and as a woman, really, I felt that I was being ignored. And then when I mentioned about being autistic, I was dismissed for that as well, so I just thought, what's the point? (P14)

Another area of intersection discussed by some participants was their role as a woman within their family and how this related to their health needs and experiences of accessing support. For some, this was associated with caring for their parents and having responsibility for the health of their parents in addition to their own:

The age 50 group, you've got your parents as well. They're always saying like you've got elderly parents to care for so that's another additional sort of pressure that I think, your own health is like right down the bottom of the list. (P3)

For others, their healthcare experiences were impacted by being a mother and the intersection of parenting. The experience of being an autistic mother to autistic children seemed especially important, with some participants expressing concerns that their own difficulties with healthcare were mirrored when trying to find support for their children. One participant reflected on how her late diagnosis of autism specifically affected this: *As an autistic woman, I'm trying to get help for my autistic children. I didn't know I was autistic, so I found that really difficult, and my daughters have never really had the right sort of help (P3)*. Layers of neurodiversity within the family structure and the range of healthcare services encountered across different life stages seemed to interact with participants' own experiences of accessing healthcare: *There's some of the same difficulties and challenges that I experience when accessing it myself, but they're magnified*

when accessing it for my children. They're both autistic also, and so it's like an amplified effect (P9).

It seemed integral for participants that their intersecting identity was considered to fully understand their healthcare experiences. One aspect alone (e.g. age) was inadequate to explain their experiences and how they feel they are perceived by professionals. Instead, multiple parts of their identity contributed to their perspectives and shaped interactions with services.

Theme 3: Accumulation of negative healthcare experiences

Repeatedly accessing ineffective healthcare across the lifespan created an accumulation of negative healthcare experiences over time. Many participants described having complex healthcare needs and needing to attend many appointments across a variety of services. For most participants, each interaction with a service provider or individual healthcare professional presented challenges which have accumulated and created negative anticipation about accessing healthcare. The following extract illustrates the consequences of this for one participant, who describes the process of having repeated difficult experiences and feeling abandoned as a result:

So you might get through one appointment and what happens if that's a bad appointment? Then you've got to go for another one, and then another one. You know you can't do it 'cause it's so bad for you with the anxiety and stuff [...] I think it just makes you feel like you've got to suffer on your own. (P2)

The accumulation of so many difficult encounters with services meant that positive healthcare experiences were associated with emotions such as surprise or confusion. Negative healthcare experiences were the norm for most participants and interactions with healthcare professionals that were perceived positively were rarely

reported. Participants' perceptions of healthcare seemed to be on the foundation of many negative experiences throughout adulthood, leaving them unsure how to respond when things go well: *When I do come across someone that does have that element of empathy or humanity, it's jarring because it's unusual* (P12).

3.1. Avoiding accessing support

One of the main outcomes of having several negative experiences was that participants actively avoided accessing support or felt so disillusioned with healthcare services that they did not want to bother seeking help anymore. Many participants described finding their own healthcare advice for minor concerns through the internet or other sources as an easier alternative. The overall sense was that participants felt let down and therefore questioned whether potential benefits from accessing healthcare were worth putting themselves through difficult encounters: *If you have enough things go wrong, enough let-downs, enough bad experiences, you just think it's really not worth it for like a small niggle* (P3).

In addition, many participants discussed having to repeatedly attend appointments for the same health issues. The lack of appropriate healthcare meant that participants felt hopeless, and as though their only option was to take responsibility for their healthcare by trying to find solutions themselves. This fostered resentment, bitterness and frustration amongst participants who expressed sentiments of feeling fed up with the healthcare system:

Often I'll go back for the same thing over and over again because I'm not getting any help. And then, in the end, I just think what's the point? I know they can't help me so I just deal with it. (P7)

3.2. Feeling like a burden

Another outcome of having an accumulation of negative healthcare experiences meant that participants perceived themselves as a burden to service providers when accessing support. This is illustrated in the following quotes: *There are times when I think to myself, I can't bother them again. I'm going to be perceived as a pain (P12); I sometimes feel that I can be perceived as fussy and difficult and causing the problem [...] I do often feel frustrated and misunderstood and a bit of a nuisance (P9)*. Participants implied that they were problematic users of the system who were burdening service providers by trying to access healthcare. For many, this manifested during encounters with professionals they see regularly: *The pharmacy seem to know my name as soon as I walk in, I don't feel like it's friendly, I just think they feel 'oh no, it's her again' (P2)*. Others felt that the complexity of their health needs meant that they were burdening the system due to the amount of regular care required.

There was a knock-on impact to self-esteem for some participants, who felt that their perception of repeatedly burdening healthcare services and individual professionals reduced their confidence and sense that they were worthy of accessing support:

I'm a bit of a people pleaser, I don't want to cause a fuss. And in the back of your head, you're always thinking there's people worse off than you [...] so there's a lot of that to do with still valuing yourself and looking after yourself. And I suppose you just feel very much like you should take responsibility for yourself. It just seems easier to do that. (P3)

3.3. Emotional distress

Across the interviews, there was a noticeable pattern related to the significant emotional distress resulting from healthcare interactions. Feeling continually let down by services had a significant emotional impact on participants. Firstly, there was a group of participants who felt overwhelmed and anxious prior to engaging with services in anticipation of difficulties: *It's just hell. I feel anxious and stressed before I go. It always turns into a bad experience so I'm in a heightened state of alert* (P11). Other participants described significant distress during or after healthcare encounters, perhaps because of what happened during the interaction and the overwhelming emotions that follow: *I can feel like waves fear coming up through the body, it's like pulsing. You know, that's why I can't think straight when I'm talking to the GP.* (P7)

Every contact I have these days when I contact the GP, it's full of emotion. I come away from that phone call and I just am emotionally wiped out and it's so visceral. I can't say traumatic, but that's too strong. What's another word for if it's nearly traumatic? I struggle to find the words [...] just emotionally distraught (P12).

Other participants also reflected on whether they could describe their experiences as harmful or traumatic. Some felt doubtful because healthcare professionals had not been overtly harmful, but that their experiences were traumatic in the context of the repeated number of negative healthcare encounters across their lives.

Theme 4: Efforts required to navigate healthcare systems

One of the main barriers to healthcare reported by participants was the sheer effort required to effectively navigate the system: *You know it's like a maze trying to get your way through* (P12). This theme encapsulates the cognitive, emotional, and physical efforts to access healthcare, interact with professionals and receive treatment for

physical or mental health conditions. Participants felt that an enormous amount of effort was required of them, above and beyond what neurotypical people may experience.

Several participants equated their interactions with the healthcare systems to a “fight” or “battle” when describing the challenge of finding the correct support: *I have it in my mind that no matter what I go to the GP for, I'm going to have to fight to be heard.* (P14). For many participants, the persistence and perseverance required to navigate healthcare systems left them feeling uncared for, resulting in very low expectations about the support they would be offered.

Navigating healthcare has been a lifelong journey for many participants, involving the management of multiple chronic health conditions. Within this experience, late diagnosis of autism and spending most of their lives not knowing they were autistic made navigation even more of a challenge. The effect this had on participants was substantial, with many attributing the exhaustion from navigating healthcare systems to their autistic burnout, as exemplified in the following extract: *The diagnostic quest that's been ongoing since my 40s to try and get answers to these things has probably contributed to my burnout because it's been so fundamentally exhausting.* (P6)

4.1. Masking

One of the common features involved in navigation of the healthcare system was masking. Participants described efforts to conceal their autism-related difficulties, specifically related to social communication and interactions with healthcare professionals. Generally, participants wanted to present as compliant to avoid being perceived as a burden: *I don't want to be a problem, I don't want you to know if I'm worried. I try really hard to cover that all up and I don't want to be a nuisance* (P9).

Importantly, masking seemed to be both a barrier and facilitator to healthcare. For some, masking enabled them to cope in appointments and therefore get the support they need, whereas for others masking concealed the extent of their difficulties and meant they were offered inadequate or unsuitable care. The following quote highlights the ambiguity experienced by one participant regarding whether she found masking to be helpful:

I think it's 50/50 actually because it [masking] helps me in the sense that I can put across what I need, I can stand up for myself and say what it is that I need or how I feel and things like that. But then again, I do think people assume that I am more capable. (P14)

In both instances, masking acted as a layer of protection for participants to reduce the likelihood of stigma from healthcare professionals by concealing their neurodiversity. Some participants also expressed concern at the lack of awareness about masking amongst healthcare professionals as a feature of autism in women, which relates back to Theme 1:

It would be nice for healthcare professionals to be aware of quite how much autistic women can mask and how capable we are of coming across as neurotypical if we've got the energy and the resilience to be able to do that at that time. (P13)

4.2. Practical and cognitive aspects

Another component of the effort required to navigate healthcare described by participants was related to the practicalities of getting themselves to appointments and engaging with professionals once they are there. In particular, participants cited cognitive difficulties related to ageing, being autistic or both, as significant barriers to healthcare.

The organisation of oneself to attend an appointment, utilise cognitive skills such as memory, and communicate effectively with professionals required significant effort from participants. The following quotes demonstrate some of these difficulties as experienced by two participants: *I'd say the main problem has been my severe disorientation and my disorganisation about knowing where and when I'm supposed to be somewhere (P1); It's just taking in all the information with the appointment, 'cause of my poor short-term memory and obviously you're nervous anyway when you're at an appointment, so you're not able to concentrate as much (P8).*

Many participants described having to schedule their days in order to manage these practical barriers and be able to attend healthcare appointments. Planning around appointments gave participants a sense of control and preparedness, as well as time to decompress afterwards: *If I know I'm gonna have to do it, I have to plan it into my day to prepare to do it, to deal with it and then to recover from it (P13).* Participants described a relationship between the practical difficulties of getting to appointments (e.g. parking, travel, timings) and the cognitive aspects (e.g. planning, memory), with each stressor having a negative impact on their ability to engage with the appointment effectively or function well afterwards: *There's the physical difficulty of going to appointments because it might only be like a 20-minute or 10-minute appointment, but that is my whole day's activity gone 'cause I've got no energy left for anything else (P4).*

4.3. Coping with sensory overload

Finally, coping with sensory sensitivities and managing sensory overload was another effortful aspect of navigating healthcare described by the women in this study. Tolerating distressing sensory environments and aspects of medical procedures had a significant impact on participants, contributing to their avoidance of healthcare and

difficulties engaging in appointments. The following extracts highlight the challenging sensory components of hospital-based healthcare: *The fact that they chatted all night and made a racket really kept me awake and made me feel so upset I even thought of discharging myself* (P5); *The environment is horrible. Waiting in these rooms with a loud noisy TV on, it's hot and I feel uncomfortable. You're left in environments where you feel unsafe, it's crowded, there's no attempt to make any reasonable adjustments* (P11).

This subtheme was especially pertinent from a women's health perspective. There was a noticeable link between participants' difficulties attending screening appointments such as cervical smears and mammograms and their description of related sensory sensitivities, especially pain and touch: *I'm afraid I never went for smears, it just felt too much. I simply couldn't cope with it so I just made an excuse* (P10). Participants demonstrated an awareness of the consequence of missing these screening appointments but felt that avoiding significant sensory distress outweighed the potential benefits to health.

I'm hypersensitive to pain, so I feel everything with every sense. Mammograms I found especially painful. I've only had one, I didn't go to my last one. And I'm worried about my health and I know I'm at the age where these things need to be explored. (P9)

One participant described her overwhelming sensory distress during an invasive medical procedure which she eventually refused: *I can't bear them touching me, I just jump and cry and push them away. I had to actually shove them away and I don't really want to do that* (P1). Overall, participants felt that managing their sensory needs was extremely effortful and exacerbated existing difficulties navigating healthcare.

Theme 5: Future: age-related concerns and hopes for change

Alongside reflecting on their historic experiences, participants also looked ahead towards their future and anticipated healthcare needs. This was strongly related to ageing where participants felt worried about how a system that currently does not meet their needs could provide adequate care for them in later stages of life.

My needs of the health service are already huge and it worries me with the state of the NHS how that is going to be moving forward as I get older. I worry about the impacts of age on my already existing conditions and my autistic sensitivities. (P6)

Based on previous negative experiences related to seeking support for minor health needs, participants expressed concerns about the potential onset of more significant health conditions: *If I had a really major issue, would I be listened to? (P12)* and fears about hospitalisation:

If I had to be on a ward for a week, I would really really struggle, and that is when the mask would come off, that's when they would see me unravelling and I would worry very much about how I would be treated, how I would be perceived and whether my needs would be met. (P9)

Reflecting on the future left many participants feeling extremely let down by the healthcare system and scared about what might happen to them. Older participants in particular reflected on whether they would need to move into residential care homes in the future and the likelihood they would not be suitable for them: *If an autistic person were put in a care home, I think they would have particular needs and I hope I don't have to go near one (P5).*

Amongst many accounts of negative healthcare experiences, participants also described some examples of good practice. This offered them some hope for the future and participants showed an empowered stance in advocating for the healthcare that

they deserve by making clear suggestions for ways forward. Particularly, the Covid-19 pandemic and the introduction of telemedicine seemed to offer participants hope that flexible healthcare was feasible, fostering more choice for appointments and acceptability of different ways of interacting with healthcare professionals: *To have the option of an online appointment is a good thing for me, and so there was some improvements. There's a bit more flexibility (P7).*

Participants' hopes for change were positioned around an individualised approach to healthcare for autistic people: *Healthcare professionals need to treat us and talk to us as individuals. There might be some common themes but we're all very different (P9).* On the background of upskilling professionals' knowledge about autism generally, participants highlighted the importance of healthcare professionals asking individuals about their specific needs related to autism, avoiding making assumptions and offering appropriate adjustments using person-centred care:

I'd like healthcare professionals to know that everybody who's autistic is different. And to just say, how does it affect you? And know that it might affect you in positive ways as well as negative ways. Or ask, what's the best way for us to communicate? It would be useful just for people to say, what does being autistic mean for you?
(P13)

Participants offered countless suggestions for changes that they would like to see, many of which were reported several times. Areas of particular importance included: facilitating communication preferences, providing clear written information prior to and after appointments, asking about sensory needs, making health screening appointments more autism-friendly, providing mandatory autism training to professionals, and proactively asking individuals if they require adjustments.

Maybe have quieter rooms that you can sit in, something for distraction and somewhere to have a hot drink. But just to keep you informed like, 'you're gonna have another 10 minutes to wait, is that OK?'. And maybe just being able to give you a simple information sheet about what the appointment might involve or what might happen next [...] just make it easier for us to go to appointments, make it calmer. (P2)

Discussion

This study sought to explore the perspectives of middle and older age autistic women regarding their experiences of accessing healthcare. The broad aims of the study were to understand how this population perceive support from services and to explore reported barriers and facilitators to healthcare. A qualitative approach was chosen to facilitate an in-depth and nuanced exploration of this topic. Findings from this study contribute significantly to gaps in the autism literature regarding gender, ageing and health.

Summary of Findings

The findings from this study have garnered several insights into the healthcare experiences of middle and older aged autistic women. Repeated negative interactions at both the system and professional level accumulated across the lifespan and resulted in low expectations and dissatisfaction with healthcare services. Reported barriers to accessing and engaging with effective healthcare included professionals' limited understanding of autism in women, stigma, misdiagnosis and feeling misunderstood. Accessing healthcare required immense effort from participants to navigate the system and receive support. The practical and cognitive components of attending appointments,

as well as sensory sensitivities, created further barriers. Distress associated with sensory overload, particularly when undergoing procedures, was related to avoidance or refusal of healthcare in many cases. Masking seemed to both facilitate and hinder engagement with healthcare, with some participants describing how masking helped them get through appointments and others suggesting that masking eclipsed their actual needs.

The impact of these barriers was substantial, creating a sense of being a burden and leading to participants avoiding accessing healthcare altogether in some cases. For others, this fostered a sense of disillusionment and a reluctance to seek support for minor health concerns. Suggested facilitators to healthcare were described, but these were in the context of hopes for change in the future rather than something that was regularly being offered. Some examples of good practice were described, typically related to having an increased choice of appointment type resulting from Covid-19. Alongside hopes for change, participants also expressed concerns about the future of their healthcare needs and how services would adapt and accommodate them as they aged further.

Intersectionality and having the specific identity of an autistic woman in middle or later life underpinned the way participants understood their interactions with healthcare. Participants perceived several healthcare disadvantages related to their age, gender and neurodiversity and their overall intersecting identity was related to descriptions of stigma and stereotyping. In addition, many participants were responsible for the healthcare of other members of their family which influenced their own perceptions of healthcare and interactions with professionals. For example, autistic mothers of autistic children seemed to have mirrored healthcare experiences and encountered difficulties with accessing support for their children as well as themselves.

Professionals' Knowledge About Autism, Gender and Mental Health

Findings from this study are in keeping with existing research about autistic adults' experiences of healthcare (Calleja et al., 2022; Mason et al., 2021b; Mazurek et al., 2023). This suggests that previous findings about barriers to healthcare for autistic adults are also relevant for middle and older age autistic women. Importantly, these findings contribute a new and unique perspective to extend the current base of research. Knowledge about autism among healthcare professionals has been raised by autistic people as a significant barrier to accessing healthcare (Walsh et al., 2020) and is also acknowledged by professionals themselves (Corden et al., 2022). These results highlight additional concerns from autistic women about professionals' lack of knowledge specifically related to the female autism phenotype.

Experiences reported by the women featured in this study are unsurprising given the lack of formal training about autism received by healthcare professionals (Unigwe et al., 2017). Whilst new legislation in the UK requires that health and social care professionals receive training about autism (Gallaher et al., 2023), it is unclear to what extent such programmes include information about autism in women and girls. Our findings suggest that reduced awareness about how autism can present differently in women compared to men can impact how seriously autistic women feel their diagnosis is viewed by professionals (Tint & Weiss, 2018). Many participants felt that the accuracy of their autism diagnosis was questioned by professionals, that their health concerns were dismissed as a result, and their neurodiversity was not accommodated as part of their care.

Another qualitative study featuring autistic adults aged 18 to 35 also found that participants felt that their diagnosis was dismissed in healthcare settings due to stereotypical views about autism (Mazurek et al., 2023). This suggests that perceiving

healthcare professionals as having a limited understanding of autism is a common experience among autistic adults. The present study additionally highlights specific concerns regarding how professionals understand autism in middle and older age women, and how this may relate to their negative experiences of healthcare.

Related to this, one of the subthemes generated in this study suggests a perceived relationship between healthcare providers' lack of understanding about autism in women and the misdiagnosis of mental health difficulties. In the absence of an autism diagnosis or awareness that they might be autistic, many women and girls receive a diagnosis of an internalising mood or personality disorder to describe their difficulties (Lai et al., 2022). Across the lifespan, possible autism-related behaviours in women are often misattributed to mental health difficulties instead of recognising that undiagnosed neurodiversity may offer an explanation, with associated experiences also contributing to poorer mental health (Beck et al., 2020). Many participants in this study described a journey across adulthood of understanding and recognising their own mental health needs whilst not knowing they were autistic and receiving a lack of appropriate mental health support from services and individual professionals.

Previous research has shown that autistic women are more likely to have certain diagnoses such as personality disorders removed following an autism diagnosis (Kentrou et al., 2021). This experience was qualitatively described by some participants in this study, with others explaining how their mood disorders such as anxiety and depression were actually related to undiagnosed autism in early adulthood. Furthermore, many participants felt that the support they were offered from mental health services was inadequate and was not tailored to accommodate neurodiversity. This finding is supported by a study which explored how autistic women perceive

therapy for eating disorders which also highlighted dissatisfaction with the lack of adaptations (Babb et al., 2021).

A significant contribution from the current study is understanding how autistic women navigate these experiences in middle and later life. Other studies focusing on the experiences of autistic women typically focus on people in their thirties or younger (Babb et al., 2021; Tint & Weiss, 2018). Crucially, this study included the perspective of autistic women and their journey with mental health and misdiagnosis from childhood to middle or older adulthood. One participant referred to this experience as a “diagnostic quest” which highlights the ongoing difficulties autistic women experience in middle and older age to understand their mental health needs, have these understood by healthcare professionals and find suitable support.

Negative Healthcare Experiences

One of the main themes generated from this study was related to dissatisfaction with healthcare services and low expectations of care and support due to an accumulation of negative experiences across the lifespan. This finding is in keeping with the general autistic adult population who show greater dissatisfaction with healthcare than neurotypical adults (Gerber et al., 2017). Participants reported an array of negative experiences with service providers and individual healthcare professionals, which is another established finding among autistic adults (Mason et al., 2019). In the current study, an important finding related to ageing was that these negative experiences accumulated over time and left participants feeling resigned in their decision to avoid seeking support for their health. Whilst previous research explored the views of autistic adults (Mason et al., 2021b), the current study offers a lifespan perspective regarding the impact of repeated negative healthcare experiences for autistic women in middle

and later life. For example, participants described repeated negative experiences as having a significant impact on their emotions and how this then makes them want to withdraw from healthcare as a result.

The intense emotional distress experienced in relation to negative healthcare interactions seems to be a novel finding within the field. There are some findings about the experience of anxiety related to healthcare appointments reported by autistic adults (Mazurek et al., 2023), but findings from this study suggest that middle and older autistic women experience a heightened emotional reaction before, during and after engaging with healthcare. Due to the dearth of other research and the qualitative nature of this study, it is challenging to draw wide conclusions about this, and more research is needed to explore this further. This finding also highlights the importance of establishing the autistic voice in healthcare research to better understand lived experiences (Sonido et al., 2020). Ultimately, this appears to be a significant finding which is likely to have transferability to the broader autistic population.

Barriers to Healthcare

Findings from this study concerning participants' reported barriers to healthcare are also observed in existing research. Difficulties with cognitive processes related to attending appointments and sensory sensitivities are established barriers to healthcare for autistic adults (Calleja et al., 2022; Walsh et al., 2020) and this study suggests that they are also relevant for middle and older age autistic women. Bright, loud and busy environments common in healthcare settings created sensory overload for many participants in this study. Overall, this suggests that sensory difficulties related to healthcare are experienced by autistic people across the lifespan and presents a clear rationale for the need to make adaptations in appointments.

This study offers further insights into barriers to healthcare through the lens of gender. Notably, participants described sensory difficulties with gender-specific medical procedures such as cervical smears and mammograms. Sensory sensitivities were a barrier for participants attending preventative health screening, with some women in the study never having attended these appointments. Given that autistic women are less likely to attend these appointments compared to non-autistic women (Nicolaidis et al., 2013), it is imperative the sensory experiences of autistic women within healthcare are considered. More research is also warranted to inform potential adjustments to these procedures and make them more accessible for autistic women.

One study about the service experiences of autistic women reported masking as a barrier to engagement (Tint & Weiss, 2018) whereas results from other studies about autistic adults' experiences of healthcare do not mention masking (Brice et al., 2021; Mason et al., 2021b; Mazurek et al., 2023). This may suggest that masking in healthcare settings is particularly relevant for autistic women, though evidently more research is needed. In the current study, participants reflected on a lifetime of masking and assessed both the costs and benefits of masking during interactions with health professionals. Given that little is known about older autistic people's experiences of masking (Sonido et al., 2020), the current study offers some early insights into how autistic women of this demographic describe masking in the context of healthcare.

Facilitators to Healthcare

Participants offered their perspectives on what facilitates their engagement with healthcare services and what factors contribute to effective support. For many, positive healthcare experiences were infrequent and were surprising when they did occur due to their background of accumulated negative interactions. Similar to findings from other

studies, participants had clear suggestions about facilitators to healthcare but rarely experienced them in practice (Mazurek et al., 2023). There was a clear distinction between the desired expectations for healthcare and reality.

The suggestions made by participants in this study are echoed in other research regarding barriers and facilitators to healthcare for autistic adults (Adams & Young, 2021; Mason et al., 2019; Nicolaidis et al., 2015). This indicates that many factors which facilitate healthcare are relevant across the autistic population and are currently lacking in services. Ultimately, broad facilitators to healthcare included flexibility, patient choice, openness and individualised care. These important considerations are relevant across the autistic population but may be especially important for autistic adults in middle and older age who may be more likely to use healthcare services (Mukaetova-Ladinska et al., 2012). In addition, a significant proportion of the research regarding facilitators to healthcare for autistic people is based on predominantly male samples, so the voice of autistic women in this study is crucial.

Intersectionality and Multiple Minority Status

One of the possible theoretical explanations for the present findings is that middle and older age autistic women represent a population with multiple minority status. The minority stress model (Meyer, 2003) suggests that individuals from minority groups (e.g. LGBTQ+ folk, ethnic minorities or disabled people) experience greater stress resulting from discrimination, oppression and societal prejudice. Consequently, these individuals are more likely to experience mental and physical health difficulties due to repeated experiences of minority stress. Whilst women are not a statistical minority, women are considered to have marginalised status due to issues with power, the widespread derogation of women and the normalisation of misogynist narratives in

society. Botha and Frost (2020) suggest that this model can be applied to the autistic population to help explain health disparities and the high prevalence of unmet health needs.

Autistic women in particular represent a group with multiple minority status due to their gender and neurodiversity. In the current study, the lens of ageing is also relevant as another minority characteristic due to age-related discrimination (Allen, 2016). Participants themselves highlighted the importance of talking about their experiences from the position of intersectionality, and how the convergence of the different aspects of their identity influenced their perceptions of healthcare and how they were perceived by professionals. Therefore, the individual and collective impact of possible sexism, ageism and ableism experienced by middle and older age autistic women is likely to influence healthcare experiences. For autistic women from ethnic minorities, race is likely to be another relevant factor.

Limitations

Though this study presents many strengths in its contribution to a nascent area of research, there are several limitations that should be discussed. Firstly, demographic characteristics of the women featured in this study limit generalisability of findings. Whilst generalisability is an issue that applies to qualitative research generally, there are some concerns specific to the sample featured in this study. Notably, all participants but one were White, which significantly reduces the representativeness of the findings. Race and ethnicity are known to influence health status and experience of healthcare services, with individuals from ethnic minority backgrounds experiencing the greatest health inequalities (Marmot, 2017). Therefore, most of the findings from this study have

been generated from the perspective of White individuals whose ethnicity is likely to have conferred privilege and advantage in their experience of healthcare.

Secondly, due to recruitment methods, participants in this study represent autistic women in middle and older age with access to technology and who are technology-literate, which biases the sample. Though online recruitment facilitated significant interest in this study and connection with potential participants, the demographic of middle and older age autistic women without internet access may have been missed. Whilst internet usage in older adults is increasing significantly (Zhang et al., 2021) and there is some evidence autistic people prefer computer-mediated communications (Westerberg et al., 2021), it is unclear how older autistic adults use the internet. Therefore, offline recruitment methods may also be useful in targeting the demographic featured in this study.

Another limitation is the reduced inclusion of individuals with autism and intellectual disability. This is a significant issue with the majority of autism research (Russell et al., 2019), and is especially important in the context of healthcare given that individuals with co-occurring autism and intellectual disability experience greater inequalities and premature mortality (Krantz et al., 2023). Though two participants reported having a mild intellectual disability, this study did not include the perspectives of autistic women with moderate forms of intellectual disability. The vast majority of participants were also educated to degree level. This indicates that findings are biased toward an intellectually able and affluent demographic which is likely to impact healthcare experiences.

Finally, this study relied on self-reported autism diagnosis and no formal medical reports were required to confirm this. Similarly, it could be argued that including self-identified autistic people is another limitation. Whilst it is acknowledged that this

presents some challenges to the validity of the study, there are several barriers for autistic adults seeking an autism diagnosis (Lewis, 2017). In addition, many autism researchers and individuals in the autistic community highlight the importance of being receptive to those who self-identify (Overton et al., 2023). Furthermore, our goal as a research team was to reduce barriers to participation in a vastly under-researched population.

Implications for Healthcare Providers and Professionals

The results of this study present several implications for healthcare providers and professionals. Whilst it is important not to overgeneralise or overstate findings from a small qualitative study such as this, given the extensive health inequalities experienced by middle and older age autistic women, these findings hold value. Furthermore, Braun and Clarke (2021) advocate for the consideration of how transferable qualitative findings are as an alternative to generalisability. Therefore, the main strength of this study is the transferability of useful and relevant findings informed by lived experiences of autistic women.

The findings from this study are highly relevant to current legislation and the development of health services in the UK. For example, the National Autism Strategy (HM Government, 2021) has highlighted healthcare access for autistic people as an area of priority and the perspectives of autistic people themselves are imperative in informing recommendations. It is worth noting that implications from this study are likely to benefit the general autistic population regardless of gender or age, but there are some specific recommendations salient to middle and older age autistic women.

Professional and Patient Level

At the individual professional level, a clear implication from this study is the need for high-quality training about autism including specific content about gender and ageing. Involving autistic people in the development and facilitation of training should also be a priority, as evidenced in The Health and Care Act (2022) and the recent introduction of ‘The Oliver McGowan Mandatory Training on Learning Disability and Autism’ in the UK. These efforts have only come into place within the last year, so it will be important to monitor outcomes from this training and assess feedback from healthcare professionals.

For patients themselves, findings from this study suggest implications for ways of supporting autistic women in middle and older age to attend healthcare appointments. Reasonable adjustments that are individualised and person-centred should be readily offered, and the onus should not always be on the patient to make these requests (Brice et al., 2021). The goal of these adjustments should be to reduce cognitive load and emotional distress for autistic women when engaging with healthcare. Some examples include choice of appointment type, offering extended appointments and accepting different communication methods.

Service Provider Level

There are further implications at a broader service provider level. Whilst educating individual health professionals is important, it is also imperative that this is accompanied by systemic efforts to improve healthcare access and experiences for autistic women. Firstly, consideration of sensory sensitivities for gendered healthcare screening should be prioritised to make it easier for autistic women to attend such appointments. This should be considered in conjunction with broader service-wide

adjustments to cater for sensory needs across the autistic population, such as offering people a separate place to wait for appointments (Strömberg et al., 2022).

Secondly, for adult women with multiple chronic physical health conditions and ongoing mental health difficulties, services could consider screening for autism as part of routine healthcare (Kassee et al., 2020). This would likely contribute to earlier diagnosis of autism in women and enable their neurodiversity to be incorporated into their physical and mental health treatment plans. A good example of this in current healthcare practice has been demonstrated by a female eating disorder inpatient ward in London where all patients complete an autism screening measure upon admission (Tchanturia et al., 2020).

Nonetheless, it is important that these implications and recommendations are contextualised based on the state of the current National Health Service (NHS) in the UK. Lack of funding, staff burnout and stretched resources mean that many implications from this study would be challenging to implement. Many NHS professionals will already be aware of issues affecting healthcare for autistic people (Warfield et al., 2015), suggesting the need for higher-level policy and legislation changes to enable professionals and services to meet better meet the needs of autistic people.

Directions for Future Research

Given the distinct lack of other research about the healthcare experiences of middle and older age autistic women, there are various directions for future research. Firstly, studies should seek to include the views of women from ethnic minority backgrounds to better understand their experiences, which are likely to differ on the grounds of race. Furthermore, little is known about the healthcare experiences of middle and older age autistic women with co-occurring intellectual disabilities or the

views of carers (Mason et al., 2022), which highlights another area for potential research.

More broadly, there is limited research about specific gendered healthcare experiences in autistic women. Advocates in the autistic community have indicated the importance of research regarding menopause, hormone-replacement therapy and experience of appointments such as mammograms (Michael, 2015). While this study was purposefully broad and encompassed general experiences of physical and mental healthcare, further research is needed to create an in-depth understanding of how middle and older age autistic women experience specific types of healthcare and whether this differs from neurotypical women.

Findings from this study also demonstrate the importance of further research about health and social care provision for autistic women in older age with physical health decline. For example, research should consider how older autistic women perceive healthcare in residential settings (Rodgers et al., 2019). This would be an important direction for future research about autism and ageing generally regardless of gender to ensure that care homes are better suited to the needs of older autistic people.

Finally, more research is needed from the perspective of service providers and professionals. Specific studies focusing on healthcare professionals' understanding of autism in women are required to identify gaps in knowledge and assess provider confidence in supporting autistic women. The extensive issues with mental health misdiagnosis and ineffective treatment identified in this study indicate the need for research exploring how mental health professionals distinguish between mental health disorders and autism in women. This is especially important in the context of ageing and late autism diagnosis.

Conclusion

Findings from this study provide an in-depth account of the healthcare experiences of autistic women in middle and older age accessing support for their physical and mental health across a range of services. As the first study to explore the perspectives of this population, the qualitative results provide an initial contribution to the significant gaps in the literature. Further research is required to address the significant unmet healthcare needs and healthcare dissatisfaction amongst autistic women as a priority. Access to effective healthcare and feeling heard and validated by healthcare professionals is of paramount importance for this disadvantaged population, and efforts should be made to improve healthcare experiences and reduce health inequalities for autistic women across the lifespan.

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Part 3: Critical Appraisal

Appraisal Overview

The purpose of this appraisal is to provide a critical commentary on the journey to producing the empirical paper presented in this thesis. Firstly, the process of designing the project and reflections on the experience of involving a panel of autistic advisors will be discussed. Personal reflections about the interview stage of the project will be considered, including the use of bracketing interviews and position statements as part of the thematic analysis. Experiences of interviewing and using the interview schedule are also mentioned. Difficulties encountered during the research will also be explored, including how some of these were overcome. The appraisal will conclude by expanding on the strengths and limitations of the project, implications, and directions for future research.

Project Design

This research was designed as part of a wider longitudinal project about autism and ageing. I was initially drawn to the project based on significant pre-training experience working with autistic individuals and aspirations to have a career as a Clinical Psychologist working with autistic children and their families. I was particularly interested in the opportunity to contribute to a significantly under-researched area by focusing on older autistic adults. The following section will discuss the origins of the project, challenges with recruitment and subsequent changes to the research topic.

Project Origins and Recruitment Difficulties

One of the challenges encountered in the study design and recruitment was involving autistic people with intellectual disabilities and their carers. The original focus of the empirical paper presented in this thesis was intended to be about the healthcare

experiences of older autistic adults with intellectual disabilities and those who care for or support them in accessing healthcare. Given the established selection bias against autistic people with intellectual disabilities within autism research (Russell et al., 2019), the research team felt it was important that we make efforts to recruit from this population.

The study was designed with autistic people with intellectual disabilities in mind, and recruitment was carefully thought about to target this population. I managed to arrange support with advertising the study from national charities such as Mencap, as well as local groups working with adults who had intellectual disabilities. Specific intellectual disability services were contacted using social media and the study was widely advertised online. In order to recruit carers, local and national charities which offer support to carers were also contacted. Most of the services I contacted were highly responsive and they circulated posters advertising the study through social media or mailing lists.

Despite these significant efforts, there was a limited expression of interest from autistic people with intellectual disabilities or carers. There are several possible reasons for this, including issues with the accessibility of our study and online advertisement methods. For example, suggested strategies for recruiting people with intellectual disabilities in research include meeting potential participants on a one-to-one basis to explain the study in detail (Cleaver et al., 2010). This was not feasible in this study, and therefore using online recruitment methods only may not have been fully inclusive.

Whilst study materials were reviewed by autistic people, perhaps we could have also piloted them with a group of autistic adults with co-occurring intellectual disabilities. Though many efforts were made to simplify language and consider readability for people with intellectual disabilities, gaining the perspective and

experience of this population may have been advantageous for recruitment.

Furthermore, carers are likely to be overwhelmed with significant workloads and may find it challenging to get time off to participate in research (Green, 2007). Therefore, the various demands and pressures on carers might mean it is challenging for them to prioritise research participation.

Revision of Thesis Topic

Consequently, the lack of interest from potential participants and the time constraints of the thesis meant that I needed to revise my original topic. My decision to focus only on autistic women came from my stance as a feminist and my awareness of issues within women's health generally. I decided to broaden the age group featured in the study to include middle age (50+) to capture a wide range of perspectives. Despite the topic change, I still hoped to recruit autistic women with mild intellectual disabilities where possible.

Involving Autistic Adults

In recent years, the autistic community have raised several concerns about their lack of involvement with research projects. Autistic people are seldom included in making decisions about what research gets conducted, the design of projects or deciding how findings are disseminated. Many autistic people feel disconnected from projects developed by non-autistic researchers and feel that research is done about them rather than with them (Chown et al., 2017). The research team for this project felt that it was imperative to consult older autistic adults across the design and implementation of our study. Establishing networks with communities of autistic people can be challenging for researchers (Pickard et al., 2022). For this study, I was able to seek consultation from a

pre-established group of autistic advisors through the National Autistic Society for which I am very grateful.

I found the process of consultation insightful and rewarding at all stages of the project and the opportunity to build ideas with a panel of autistic people served as a significant strength to this study. The discussions I had with autistic people helped me to notice my own biases and assumptions I had made about the project. Overall, I felt that the consultation process was mutually beneficial by enhancing the quality of our project whilst hopefully being an empowering experience for the autistic people who were involved (Keating, 2021).

Nonetheless, some challenges came with involving a broad range of autistic individuals. There were some disagreements amongst the panel during the design process, and some of the feedback was contradictory which made it hard to make a final decision. Furthermore, most of the panel were educated, White and cisgender which is likely to have influenced their feedback. Going forwards, I would be mindful of including the perspectives of autistic people from marginalised and minority groups and finding ways to include their perspectives within research.

Providing feedback to the steering group was important to show how we had incorporated their views into the project and to demonstrate that we had listened to everyone's feedback. For instances where we had to make a methodological decision based on contradictory feedback, we provided clear reasons and acknowledged that some members of the steering panel may disagree. Overall, this experience has shaped my views on conducting research going forwards and reminded me how important it is to meaningfully involve experts by experience.

The Interviewing Process

The following section will discuss personal reflections on using reflexive practices during the interviews and data analysis. Including reflexivity as part of the research methodology challenged my longstanding assumptions about thematic analysis (TA). I noticed that I had some erroneous assumptions which were based on misconstrued ideas about TA from the oversimplification of Braun and Clarke's (2006) seminal paper. Furthermore, I had other incorrect assumptions about the importance of quantifying data extracts within TA and considering inter-rater reliability in coding. Reading updated publications from Braun and Clarke (2013, 2021) was imperative in informing my stance as a researcher and facilitating my reflexivity.

Notably, I completed a bracketing interview and drafted a position statement prior to conducting the interviews. This process helped me consider my subjective engagement in the analytic process by highlighting my pre-existing assumptions and biases to ground my identity as a researcher (Braun & Clarke, 2019). Consequently, during the interviews, I felt more mindful of my position and bracketing this beforehand helped me to consider how I might be perceived by participants. I appreciated how the intentional reflexivity encouraged me to adopt a more active role in the data analysis and thoughtfully consider my approach to data analysis.

Using the Interview Schedule

I found that the semi-structured interview schedule facilitated my reflexivity as it allowed me to ask follow-up questions based on individual participants' experiences and I did not feel constrained. Other times, the interview schedule seemed to hinder the flow of a natural conversation as some participants wanted to answer every question (participants were sent the schedule beforehand). Some participants also focused

repeatedly on specific experiences and seemed to find it challenging to speak about general experiences of healthcare. I wondered if my frustrations about this were based on how I would answer the questions myself, perhaps influenced by my education and the fact I am not autistic.

Participants themselves offered feedback on the interview schedule which I found extremely helpful. It felt like the schedule was evolving with the research, with some participants making comments about the phrasing of certain questions and offering suggestions about topics to include. This process felt collaborative and helped me to think even further about the bracketing interview I had completed beforehand. I was interested in what participants seemed to be drawn to when answering questions, and noticing when this differed to areas I felt were more important as the researcher. This enabled me to be more curious during interviews and recognise when I was perhaps following my own agenda rather than allowing participants to decide what was important for them to speak about.

Researching Autism as a Neurotypical Researcher

One of the main areas I was particularly mindful of during the research process was my status as a neurotypical researcher. One participant asked me directly if I was autistic and if not, why I had an interest in autism research. She mentioned that it would be important for me to reflect on how my analysis of the qualitative data would be impacted by the fact I am neurotypical. This participant was pleased to hear that autistic people had been consulted in the design of the project and creation of study materials but felt that it was important for me to consider the potential biases I have as someone who is allistic (non-autistic).

I was also mindful of my potential to enact ableist ideas in the way I carried out interviews and during the write-up of the project. Ableism is a significant issue within autism research, particularly when autistic people are not involved (Botha & Cage, 2022). I was also aware of ongoing controversies within the autism field based on reactions from the autistic community about specific publications they disagree with. This enhanced my sense of responsibility towards the autistic community whilst conducting this research, but also created some worry about making sure this study was acceptable to autistic people. Alongside involving autistic older adults in the project design, I also consulted guidelines about conducting autism research (Gowen et al., 2019). This enhanced my thoughtfulness about the project overall and enabled me to be more transparent with participants during interviews.

Difficulties Encountered During the Research

Diversity in Recruitment

In the early stages of the project, I was extremely passionate about ensuring that we recruited a diverse range of participants. Going into this research, I was aware of significant disparities experienced by racial and ethnic minorities in autism diagnosis (Mandell et al., 2009). Furthermore, there are significant issues with lack of reporting about ethnicity and limited inclusion of participants from minority racial groups in autism research (Steinbrenner et al., 2022). Therefore, efforts were made to purposefully recruit ethnic minority groups. For example, local autism networks in diverse London boroughs were contacted to advertise the study. Online social media groups, such as '@BlackAutistics' on Twitter, were also contacted to request that they post our advertisements. Furthermore, we hoped to recruit participants from other minority groups to increase the representativeness of our findings. Encouragingly, there

were several respondents to the online survey from the LGBTQ+ community, though not all expressed an interest in participating in the interviews for this qualitative study.

Unfortunately, there were extremely few responses from autistic women from ethnic minority backgrounds. More generally, responses to the survey overall were from a significant White majority regardless of gender. There are several possible reasons for the difficulties we encountered recruiting individuals from ethnic minorities. Firstly, distrust of researchers and institutions amongst racial minority groups may be a deterrent to participation (Shaia et al., 2020). Structural racism within the autism field may also reduce the sense that ethnic minority groups are welcome in research (Jones et al., 2020). Additionally, women from ethnic minorities face significant barriers to obtaining an autism diagnosis and neurodiversity in this demographic is poorly understood within society. Black women and girls in particular are significantly absent from the autism literature and experience systemic inequalities in accessing autism services and diagnosis which may hinder inclusion in research (Diemer et al., 2022).

If time constraints and resources were less of an issue, recruitment of autistic women from ethnic minority groups may have been increased by using additional recruitment strategies. For example, building trusting and respectful relationships with researchers has been highlighted as a facilitator to research participation amongst minority groups (Steinbrenner et al., 2022). For this project, I could have met face-to-face with local autism groups to build rapport and trusting relationships in the community. This may have increased the likelihood of participation by showing a genuine interest in learning more about the experiences of specific racial groups and making meaningful efforts to include them. It would also be important that efforts to include minority groups in autism research are not tokenistic or generalising. For example, potential differences within and between different ethnic minority groups

should be acknowledged to avoid categorising ethnic minorities together.

Interference from Bots and Scammers

Another major difficulty encountered during the research process was interference with participant recruitment. My university email address was targeted by bots and scammers pretending to meet participation criteria and requesting to take part in the interviews. As a research team, we hypothesised that the reason for this was the advertised financial incentive on the study posters which stated that participants would receive a £15 voucher for completing an interview. My suspicions about possible bot infiltration were raised because of a series of emails where the email addresses were all very similar and the wording of each email was almost identical. Furthermore, the emails came through at a similar time and in large batches. On one occasion, I received over 60 emails in one day. The survey was also targeted with fake responses from bots, likely because there was a voucher prize draw for taking part if individuals left their contact information.

This experience was upsetting and frustrating for me as I felt that the project was being sabotaged. Sorting through the fake emails and survey responses was taking up a significant amount of time and I was concerned I might be mistaking genuine participants for scammers or bots. I was concerned about how I would continue to adequately identify the bots to avoid compromising the integrity of the project. Though I was aware online participant recruitment can present issues with credibility (Griffin et al., 2022), I did not anticipate difficulties to this scale. Proactively, myself and the trainee who I conducted this project with sought advice from the university, and we added an IP address tracker to the survey which helped us identify potential bot responses. For example, it was obvious that scammers were using Virtual Private Networks (VPNs) as

the IP addresses of imposter participants were typically international, despite recording on the survey that they were a resident of the United Kingdom.

Eventually, my confidence in identifying genuine potential participants increased and I noticed commonalities in bot responses which made them easier to recognise. Since the recruitment phase of this study concluded, other research teams have described similar issues and presented guidance on how to reduce potential bot infiltration and recognise false responses (see Lawrence et al., 2023). The threat of imposter participants is becoming increasingly recognised as a potential threat to data integrity in qualitative research (Ridge et al., 2023) and has recently been acknowledged within the autism field specifically (Pellicano et al., 2023). Despite this being a challenging setback during the project, I learned how to cope with significant hurdles during the research process and persist with recruitment. I am more mindful of the potential risks and benefits of online participant recruitment methods, but also clear on my ability to identify bots or scammers and advise others in the future.

Extended Discussion of Study Limitations and Strengths

The main strengths, contributions and limitations of this study are discussed in the empirical paper. Here, I want to expand on one of the limitations related to not verifying the autism diagnosis of participants and including women who self-identify as autistic. Many studies within the autism field use standardised assessment tools to confirm autism diagnoses, such as the Autism Diagnostic Observation Schedule (ADOS or ADOS-2; Lord et al., 2012). Other studies state that they require verification of diagnostic reports from participants' medical records. In the current study, we made the choice not to do this because we felt it would create barriers to participation for older

participants especially. We also intentionally wanted to include autistic people who self-identify to broaden the inclusivity of our research.

One of the main reasons that this is a limitation is because it may compromise the veracity of the research. The absence of confirmatory procedures is often criticised in the autism literature and reliance on self-report only is discouraged. However, this warrants further discussion relevant to this study. Notably, standardised diagnostic tools do not adequately identify autism in females (Tillmann et al., 2018). In this study, the short version of the Autism Quotient (AQ-10; Allison et al., 2012) was used as a measure of autistic traits which may offer some confirmation about participants' autism diagnosis or identification with being autistic. Though, we used this measure liberally and requiring a score reaching the cut-off indicative of autism was not required for participation. This decision was based on possible issues with the AQ-10 in accurately identifying autism in females (Murray et al., 2019). Overall, there are several issues with the inclusion of females in autism research. Confirmatory diagnostic procedures have been highlighted as a barrier to inclusion for autistic women (D'Mello et al., 2022) and this is likely exacerbated when considering those in middle and older age. Therefore, whilst this limitation is acknowledged, it should be reviewed in the context of wider issues within the autism field related to gender.

Next, I want to briefly expand upon one of the main strengths of the study. The findings contribute significantly to an under-researched demographic within the autism population and offer clear suggestions for changes to improve healthcare for middle and older age autistic women. Importantly, these strengths are underpinned by suggestions from the autistic community (Michael, 2016) and other autism researchers (Sonido et al., 2020) about the importance of this topic. Though one of the criticisms of qualitative research is that it lacks generalisability, the strength of this study is providing an in-

depth exploration of a highly important topic (Van Schalkwyk & Dewinter, 2020). Braun and Clarke (2021) also advocate instead for the transferability of qualitative research, highlighting the strength of this study regarding the usefulness and relevance of the results. Findings offer a rich perspective on how middle and older age autistic women experience healthcare and the study gives voice to a demographic seldom included in autism research.

Implications and Directions for Future Research

Several implications for service providers and professionals as well as suggestions for future research were discussed in the empirical paper. In this section, I want to expand on issues related to training for healthcare professionals and the need for more research about professionals' views of autistic women in middle and older age. Research about this topic is needed to understand the level of current knowledge amongst a range of healthcare professions to better inform training programmes. This is likely to be especially important for mental health professionals who may be more likely to interact with autistic women or undiagnosed autistic women, based on the high prevalence of mental health conditions and service utilisation amongst this demographic.

The NAS already offers a training entitled 'Women and Girls' which is promising, though it is unclear how healthcare professionals engage with this resource. Currently, there are conflicting findings about what healthcare professionals know about autism in women. Some studies report no significant differences in professionals' level of knowledge about how autism can present in men and women, whereas others actually report higher levels of awareness about autism in females compared to males (Corden et

al., 2022). This demonstrates the need for further research to create some consensus about professionals' level of knowledge.

The importance of service provider training was also discussed in the conceptual introduction featured in this thesis. It was acknowledged that training of healthcare professionals alone would be inadequate to create the system-level changes required to appropriately accommodate the needs of middle and older age autistic women and improve their healthcare experiences. Broader systemic issues such as funding, staff levels, limited resources, service entry criteria and waiting times mean it can be highly challenging for healthcare professionals to implement knowledge from training in their practice. Therefore, implications from this study should be taken in the context of the healthcare system they are related to. Evidently, healthcare services and staff need adequate support to implement long-term and meaningful change for autistic women.

Summary

The purpose of this appraisal was to offer reflections on specific aspects of the research process and expand some of the ideas raised in the discussion of the empirical paper. Overall, despite some challenges, engaging in a reflexive qualitative study and involving autistic older adults in the design was highly rewarding for me. Finally, it was also important for me to use this appraisal as an opportunity to contextualise some of the limitations and implications of the study within the wider autism research field and the healthcare system.

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Appendices

Appendix A

Outline of Trainee Contributions

This study was part of a joint research project with another trainee, HM. The focus of the joint project was to understand the views of older autistic people on their healthcare needs, facilitators and barriers to support, and how to overcome these barriers.

Joint Contributions

Both HM and the current author, AG, contributed to the conceptualisation and design of the research study alongside supervisors. Each trainee contributed to:

- Writing the ethics application
- Producing study materials including information sheets, consent forms and the interview schedule with input from autistic adults
- Creating the online survey and selecting questionnaires to include

Individual Contributions

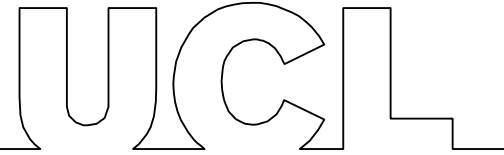
AG and HM both produced separate research proposals. For Part 1, AG undertook a literature review and produced the conceptual introduction independently. For Part 2, HM focused on a different research question and participant demographic. Whilst the current study by AG focuses on middle and older age autistic women (50+), the paper produced by HM explores the healthcare experiences of older autistic adults only (65+) and from all genders.

AG and HM interviewed participants separately and transcribed their own interviews. Data analysis was completed independently, though both trainees met to discuss coding and explore assumptions about their data. AG also amended the interview schedule independently using feedback from autistic women to include further questions about gendered healthcare experiences.

Appendix B

Survey Information Sheet and Consent Form

RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY



Autism and Ageing Research Project – Survey Information Sheet for Participants

UCL Research Ethics Committee Approval ID Number: 22117/001

Study Title: Understanding the Healthcare Needs of Autistic Adults aged 50 or over (Survey Study)

Department: UCL Division of Psychology and Language Sciences

Research Team and Contact Details: Amy Gillions and Hassan Mansour (Trainee Clinical Psychologists), amy.gillions.20@ucl.ac.uk and hassan.mansour.17@ucl.ac.uk

Research Supervisors: Dr Joshua Stott (j.stott@ucl.ac.uk) and Dr Liz O’Nions

UCL Ethics Committee Contact Details: ethics@ucl.ac.uk

UCL Data Protection Officer: Alexandra Potts

You are being invited to take part in a research project. Before you decide whether to take part, please read through this information sheet to find out what taking part will involve. If you have any questions, please contact the research team using the information above.

Project overview

In the United Kingdom, very little is known about the healthcare needs of autistic adults aged 50 or over and their experiences of getting help with physical and mental health problems from the NHS or other services. The aim of this study is to find out more about the healthcare needs of autistic people aged 50 or over. The research aims to explore things that help or hinder people in accessing healthcare. We hope that our findings will show how services can better meet the needs of autistic people aged 50 or over.

Who can be involved in the project?

We are inviting autistic adults aged 50 or over to take part. We welcome autistic people who have a formal diagnosis and those who think they are autistic (self-identify). We also want to include people who have learning disabilities and autism. You can take part by yourself or with help from someone else.

What does participating involve?

You will be asked to complete a survey. You can complete the survey anonymously. If you are interested in completing follow-up research, there will also be a section where you can provide your contact details. During the survey you will be given the option to provide information around your gender, ethnicity, age, and sexuality. This is to help us understand more about the people taking part in this study. It will also help us see if these characteristics affect a person's experience of accessing healthcare support. You will also be asked to complete some questionnaires which will help us develop a better understanding of your current healthcare needs. We also want to know more about what helps people access support and what barriers they might experience. If you find it difficult to access the online survey, please get in touch with a member of the research team so that we can assist you.

What will happen if I choose to take part?

If you decide to take part, you will first complete a consent form on the next page. You do not have to answer all questions and you can exit the survey at any time. At the end of the survey, you will be asked whether you would like to provide contact information so the research team can invite you to another part of the research. This will be an interview about your healthcare experiences. If you provide your contact details, we will add you to the list of people we might contact about doing an interview. There will be a separate information sheet and consent form for this part of the study. If you do not wish to take part in an interview, you do not need to give us your contact details. You can also choose to withdraw your results after completing the survey for up to 1-month. However, this will only be possible for those who also provided their contact details during the survey.

Are there any possible risks to taking part?

We do not expect there to be any risks to participating in our research. We have consulted autistic people to review our survey to make sure it is user-friendly. If you experience any distress at any point, please contact the research team (amy.gillions.20@ucl.ac.uk, or hassan.mansour.17@ucl.ac.uk).

Are there any possible benefits to taking part?

Whilst there are no immediate benefits to taking part in the project, we hope that our findings will help us to better understand the healthcare needs of autistic adults aged 50 or over and their experiences of using healthcare services. Also, everyone who completes the survey and provides their contact details will be entered into a prize draw to get one of five £20 vouchers.

How will survey information be stored?

Responses to the survey will initially be stored securely on the Qualtrics software servers. We will then move the data to a secure UCL data storage system. All data will be kept confidential. If you choose to take part anonymously, your data will not be linked to you personally.

What will happen to the results of the survey?

All data collected in the survey will be anonymised, analysed and written up for the

purposes of two doctorate research projects completed by Amy and Hassan (research team). Following this, we also hope to publish the results in a research journal. We aim to finish the project by September 2023.

Summary

This survey aims to better understand the healthcare needs and experiences accessing healthcare services for autistic adults aged 50 or over. We also want to interview some of the people who complete the survey. If you have any questions that are not addressed in this information sheet, please contact the research team before completing the consent form.

Privacy notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice. The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices. The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data. Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. 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 in the first instance at data-protection@ucl.ac.uk.

Autism and Ageing Research Project – Survey Consent Form for Participants

Title of Study: Understanding the views of autistic people aged 50 or over on their healthcare needs

Department: UCL Division of Psychology and Language Sciences

Contact Details of Researcher(s): amy.gillions.20@ucl.ac.uk and hassan.mansour.17@ucl.ac.uk

Contact Details of Principal Researcher: j.stott@ucl.ac.uk

UCL Ethical Approval ID Number: 22117/001

Please complete this form after you have read the Information Sheet on the previous page. If you have any questions then please contact the research team.

Before agreeing to completing the survey, please read all the following statements and tick each one you agree with:

	Tick Box
I confirm that I have read and understood the information sheet.	
I consent to participate in this study voluntarily and understand that I can stop completing the survey at any time.	
I understand that I can complete the survey anonymously which means that the information I provide will not be identifiable as relating to me. If I complete the survey anonymously, I will not be entered in the prize draw.	
I understand that if I choose to provide my contact details at the end of the survey (optional), my data will not be anonymous but will remain confidential.	
If I choose to provide my contact details, I confirm that the research team can contact me about completing an interview for the purposes of this research project.	
I understand that all survey information will be stored securely and will only be accessible to the research team.	
I understand that I can choose to withdraw my responses for up to 1-month after completing the survey. However, this will not be possible if I complete it anonymously.	
I am aware of the contact details of the research team if I have any concerns about the study.	
I confirm that I am aged 50 or above and I can confirm that I have been diagnosed autistic or I self-identify as autistic.	

Appendix C

Survey Questionnaires

Autism Quotient Short Version (AQ-10):

<i>Please tick one option per question only</i>	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
I often notice small sounds when others do not				
I usually concentrate more on the whole picture, rather than the small details				
I find it easy to do more than one thing at once				
If there is an interruption, I can switch back to what I was doing very quickly				
I find it easy to 'read between the lines' when someone is talking to me				
I know how to tell if someone listening to me is getting bored				
When I'm reading a story, I find it difficult to work out the characters' intentions				
I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc.)				
I find it easy to work out what someone is thinking or feeling just by looking at their face				
I find it difficult to work out people's intentions				

Health Literacy Survey Shortened European Version (HLS-EU-Q16):

<i>Please tick one option per question only</i>	Very Easy	Easy	Difficult	Very Difficult	Don't know
1. How easy or difficult is it for you to find information on treatments of illnesses that concern you?					
2. How easy or difficult is it for you to find out where to get professional help when you are ill (e.g. doctor, pharmacist or psychologist)?					
3. How easy or difficult is it for you to understand what your doctor says to you?					
4. How easy or difficult is it for you to understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?					
5. How easy or difficult is it for you to judge when you need to a second opinion from another doctor?					
6. How easy or difficult is it for you to use the information the doctor gives you to make decisions about your illness?					
7. How easy or difficult is it for you to follow instructions from your doctor or pharmacist?					
8. How easy or difficult is it for you to find information on how to manage mental health problems such as stress and depression?					
9. How easy or difficult is it for you to understand warnings about behaviour (e.g. smoking, low physical activity and drinking too much)?					
10. How easy or difficult is it for you to understand why you need health screenings (such as breast exam, blood sugar- or blood pressure test)?					
11. How easy or difficult is it for you to judge if the information on health risks in the media is reliable (e.g. from TV or internet)?					
12. How easy or difficult is it for you to decide how you can protect yourself from illness based on information in media (e.g. newspapers, leaflets and internet)?					
13. How easy or difficult is it for you to find out about activities that are good for your mental well-being (e.g. meditation, exercise and walking)?					
14. How easy or difficult is it for you to understand advice on health from your family members or friends?					
15. How easy or difficult is it for you to understand information in the media on how to get healthier (e.g. from the internet, daily or weekly magazines)?					
16. How easy or difficult is it for you to judge which everyday behaviour is related to your health (e.g. eating habits, exercise habits and drinking habits)?					

Self-Administered Comorbidity Questionnaire (SCQ):

The following is a list of common problems. Please indicate if you currently have the problem in the first column. If you do not have the problem, skip to next problem. If you do have the problem, please indicate in the second column if you receive medications or some other type of treatment for the problem. In the third column, indicate if the problem limits any of your activities. Finally, indicate all medical conditions that are not listed under “other medical problems” at the end of the page.

PROBLEM	Do you have the problem?		Do you receive treatment for it?		Does it limit your activities?	
	No (0)	Yes → (1)	No (0)	Yes → (1)	No (0)	Yes → (1)
Heart disease	N	Y	N	Y	N	Y
High blood pressure	N	Y	N	Y	N	Y
Lung disease	N	Y	N	Y	N	Y
Diabetes	N	Y	N	Y	N	Y
Ulcer or stomach disease	N	Y	N	Y	N	Y
Kidney disease	N	Y	N	Y	N	Y
Liver disease	N	Y	N	Y	N	Y
Anaemia or other blood disease	N	Y	N	Y	N	Y
Cancer	N	Y	N	Y	N	Y
Depression	N	Y	N	Y	N	Y
Osteoarthritis degenerative arthritis	N	Y	N	Y	N	Y
Back pain	N	Y	N	Y	N	Y
Rheumatoid arthritis	N	Y	N	Y	N	Y
Other medical problems (please list):						
	N	Y	N	Y	N	Y
	N	Y	N	Y	N	Y
	N	Y	N	Y	N	Y

Demographic Questions:

1. What is your age? (Please note we are only looking to recruit autistic adults aged 50 years or over)

Open response option

2. How would you describe your gender?

Male / Female / Non-binary / Prefer not to say / Other (please specify)

3. Does your gender identity match your sex registered at birth?

Yes / No / Prefer not to say

4. How would you describe your sexual orientation?

Heterosexual / Homosexual (Gay/Lesbian) / Bisexual / Asexual / Prefer not to say / Other (please specify)

5. How would you describe your ethnicity?

White: English, Welsh, Scottish, Northern Irish or British

White: Irish

White: Gypsy or Irish Traveller

Any other White background

Mixed or Multiple ethnic groups: White and Black Caribbean

Mixed or Multiple ethnic groups: White and African Caribbean

Mixed or Multiple ethnic groups: White and Asian

Any other Mixed or Multiple ethnic background

Asian or Asian British: Indian

Asian or Asian British: Pakistani

Asian or Asian British: Bangladeshi

Asian or Asian British: Chinese

Any other Asian background

Black, African, Caribbean or Black British: African

Black, African, Caribbean or Black British: Caribbean

Any other Black, African, Caribbean or Black British background

Arab

Prefer not to say

Other (please specify):

6. What is your marital status?

Single / Married / Widowed/Widower / Civil Partnership / Other (please specify)

7. Do you have a diagnosis of autism?

Yes, I have a formal diagnosis from a healthcare professional / No, but I self-identify as autistic / No, I do not have a diagnosis and do not self-identify as being autistic

8. What age were you diagnosed with autism/started to self-identify as autistic?

0-10 / 11-15 / 16-20 / 21-30 / 31-40 / 41-50 / 51-60 / 61-70 / 71-80 / 81+

9: Do you have a learning disability?

By learning disability, we mean having a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. We don't mean learning difficulties like dyslexia, dyspraxia, dyscalculia, or ADHD.

No / Yes, I have a formal diagnosis from a healthcare professional / Yes, I self-identify as having an intellectual disability

9a, if yes to Q9: How would you describe your learning disability?

Mild / Moderate / Severe / Multiple and Profound

10: Do you have a formal carer?

Yes / No

10a, if yes to Q10: How many hours a week do you receive care from this person?

1-19 hours a week / 20 - 40 hours a week / 50+ hours a week

11. Do you receive any informal support from a family member or friend in regards to your healthcare?

Yes / No

11a, if yes to Q11: How many hours a week does this person offer you support?

1-19 hours a week / 20 - 40 hours a week / 50+ hours a week

12. What is your highest level of education?

School up to age 16 / School up to age 18 / Undergraduate degree / Postgraduate degree / Doctoral degree / Did not complete formal education

13. Who do you live with?

Alone / With spouse or partner / With relatives / With friends / In residential accommodation / Other (please specify)

14. What is your employment status?

Employed (part-time) / Employed (full-time) / Self-employed / Unemployed / Retired / Volunteer

Appendix D

Semi-Structured Interview Schedule

Healthcare needs:

- What are your current healthcare needs?
 - Do you have a diagnosis for any physical or mental health difficulties?
 - Have you received a diagnosis for a condition which you felt was inaccurate?
 - Do you have any current concerns about your healthcare needs?
- If you have started the menopause, has this affected your healthcare needs?
- What have been your healthcare needs been in the past?

Access to services:

- How often do you access healthcare services, if at all? (this can include GPs, pharmacies, dentists, chiropodists, community or hospital services, outpatient, nursing, opticians, mental health services, occupational therapy etc.)
- What helps when trying to access, or engage with healthcare services?
- How easy is it to access support for any diagnoses you have?
- What is it like contacting your GP?
- Have you been to hospital in the last few years?
 - If yes, what was this experience like?
 - Have you heard of the autism hospital passport? If so, would you consider using it or have you ever used it?
- Does anyone support you to attend healthcare appointments?

Experience of services:

- What is your experience of services that offer healthcare support to you?
 - How do you feel you are treated?
 - Do you feel like they listen or understand?
 - Do you feel respected?

Ageing:

- How have your healthcare needs changed, particularly as you have gotten older?
- How do you think your experience of services or accessing services compares now to how it was when you were younger?

Gender:

- What is your experience of appointments specifically related to women's health (e.g. cervical smear, mammogram)?
- Is there anything you want to say about your experiences as an autistic woman accessing healthcare services?

Facilitators, and barriers to healthcare services:

- Have you experienced any difficulties when trying to access or engage with services? (this can include GPs, pharmacies, dentists, chiropodists, community or hospital services, outpatient, nursing, opticians, mental health services, occupational therapy etc.)

- What are the barriers which prevent you from accessing healthcare services?
- Has anything helped you overcome these barriers in the past?
- How do other aspects of your identity/life influence your healthcare needs and access to services? (e.g. ethnicity, religion, gender, sexuality, socioeconomic status, spirituality, appearance, or your wider social network including family, friends, and support groups)
- Have services tried to adapt to meet your needs?
- What helps facilitate access to healthcare services, particularly in middle/older age?
- What impact has the pandemic had on your experiences with healthcare services?

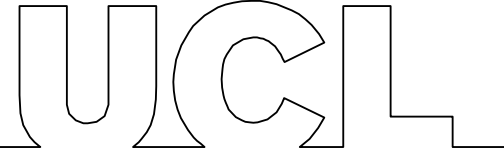
Summing up:

- Do you feel that being autistic affects your healthcare needs? If so, how?
- Do you feel like being autistic affects your experiences of healthcare services? If so, how?
- Is there anything else we should be asking autistic women?
- How could healthcare services be improved for middle-aged/older autistic people?

Appendix E

Interview Information Sheet and Consent Form

RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY



Autism and Ageing Research Project – Interview Information Sheet for Participants

UCL Research Ethics Committee Approval ID Number: 22117/001

Study Title: Understanding the Healthcare Needs of Autistic Adults aged 50 or over (Interview Study)

Department: UCL Division of Psychology and Language Sciences

Research Team and Contact Details: Amy Gillions and Hassan Mansour (Trainee Clinical Psychologists), amy.gillions.20@ucl.ac.uk and hassan.mansour.17@ucl.ac.uk

Research Supervisors: Dr Joshua Stott and Dr Liz O’Nions

UCL Data Protection Officer: Alexandra Potts

You are being invited to take part in a research project. Before you decide whether to take part, please read through this information sheet to find out what taking part will involve. If you have any questions, please contact the research team using the information above.

Project overview

In the United Kingdom, very little is known about the healthcare needs of autistic adults aged 50 or over and their experiences getting help with physical and mental health problems from the NHS or other services.

The aim of this study is to find out more about the healthcare needs of autistic people aged 50 or over. The research aims to explore things that help or hinder people in accessing healthcare. We hope that our findings will show how services can better meet the needs of autistic people aged 50 or over.

Who can be involved in the project?

We are inviting autistic adults aged 50 or over and their carers to take part. We welcome autistic people who have a formal diagnosis and those who think they are autistic (self-identify). We also want to recruit people with a learning disability and autism. You can take part by yourself or with some help from a friend, partner, supporter, or carer.

What will happen if I choose to participate and what does taking part involve?

If you choose to take part in the Interview Study, Amy or Hassan will contact you to arrange a convenient time to talk to you. If you have a preference for a male or female interviewer, please let us know. We will ask you a few questions and listen to your experiences of using the NHS and any other healthcare services.

We will talk to you over a video call platform like Zoom/Microsoft Teams or on the telephone for between an hour and 90 minutes, or less if you would prefer. You can pause the session at any time if you need a break or split it over a couple of days. If you would like a supporter to be with you during the call, that is fine with us.

We will be asking you about your experiences of accessing healthcare support and the impact of ageing onto this. Our conversation will be recorded using a secure voice recorder which we can then listen to and write down exactly what you tell us. All interview texts and recordings will be kept confidential and will only be accessible to the research team or in some instances to a private transcription company called Scrintal. This is compliant with the latest data and privacy rules. We will transcribe recordings within 3-months of the interview and will delete the audio recordings within 1-week after they have been transcribed. When we write up our results, we will leave out any details that could identify you.

If you would rather talk about some of your experiences but not others, that is fine – it is completely up to you what you tell us. If you would like to stop the interview at any time, or if you change your mind about taking part, just let us know. You also have up to 1-month after you have completed the interview to withdraw your responses from the study.

Are there any possible risks to taking part?

You may find that talking about your healthcare experiences makes you feel emotional. Should you experience any distress at any point, we will pause the interview and check if you would like to continue or offer you a break. We have consulted autistic people who have helped us design our questions to ensure they are appropriate.

Are there any possible benefits to taking part?

As a thank you for your time we will provide you with a £15 voucher. Whilst there are no immediate benefits to taking part in the project, we hope that our findings will help us to better understand the healthcare needs of autistic adults aged 50 or over and their experiences of using healthcare services. We can also offer signposting and suggestions for additional support during the interview.

How will interview recordings be stored?

Interview recordings will be transferred from the voice recording device to a secure computer drive to be stored. The recordings will only be used by the research team. Once the recordings have been transcribed, they will be erased.

What will happen to the findings?

The data collected will be written up for the purposes of two doctorate research projects completed by Amy and Hassan (research team). Following this, we also hope to publish the results in a research journal. We aim to finish the project by September 2023.

Summary

This project aims to better understand the healthcare needs and experiences accessing healthcare services for autistic adults aged 50 or over. We want to interview autistic adults aged 50 or over to collect in-depth information about their health.

It is entirely up to you whether you decide to take part. You can keep this information sheet to refer back to and you will also be asked to complete a consent form. You can withdraw from the project at any time.

If you have any questions that are not addressed in this information sheet, please contact the research team before completing the consent form. Our contact details are at the top of this page.

Privacy notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice. The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices. The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data. Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. 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 in the first instance at data-protection@ucl.ac.uk.

Autism and Ageing Research Project – Interview Consent Form for Participants

Title of Study: Understanding the views of autistic people aged 50 or over on their healthcare needs

Department: UCL Division of Psychology and Language Sciences

Contact Details of Researcher(s): amy.gillions.20@ucl.ac.uk and hassan.mansour.17@ucl.ac.uk

Contact Details of Principal Researcher: j.stott@ucl.ac.uk

UCL Ethical Approval ID Number: 22117/001

Please complete this form after you have read the Information Sheet or listened to an explanation about the research. If you have any questions, then please ask the researcher before you decide whether to join in. Before agreeing to be interviewed about your experiences, please read the following statements and tick which boxes you agree with:

	Tick Box
I confirm that I have read and understood the information sheet.	
I consent to participate in this study voluntarily and understand that I can terminate the interview and at any time without giving a reason.	
I understand that I can choose to withdraw my responses for up to 1-month after taking part in the interview.	
I understand that my personal information will be used for the purposes explained to me and will be stored securely following data protection laws.	
I understand that the interview will be recorded and transcribed by the research team or a private transcription company.	
I understand that the interview recording and transcript will be stored securely and confidentially. The recording will be deleted within 1 week after it has been transcribed.	
I understand the potential benefits and risks of participating and the support that will be available to me should I become distressed during the course of the interview.	
I understand that the information I provide during the interview may be combined with that of other participants and published as a report. No details that could identify me will be included in the report.	
I would like to receive a summary of the published report when it is available.	
I confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
I confirm that I am aged 50 or above and I can confirm that I have been diagnosed autistic or identify as autistic.	
I am aware of the contact details of the research team if I have any concerns about the study.	

Name of Participant: _____

Date: _____

Appendix F

Position Statement from Bracketing Interview

A bracketing interview was completed by the two researchers Hassan Mansour and Amy Gillions on 12.08.2022 prior to interviewing participants. The following position statement was written after the interview. Questions were taken from Braun & Clarke (2021).

The position statement was updated on 5.10.2022 by Amy Gillions following an amendment to the thesis topic.

1. How are your positionings and/or life experiences related to your topic?

The main life experiences I have that relate to this topic are through work. Since the age of 16 I have worked in various settings (schools, residential, NHS) with autistic people. I feel strongly positioned and connected to the topic through the lens of autism, but less positioned in relation to ageing. My only life experiences related to interactions with older adults are familial. I also have less interest in my career in working with older adults, and so feel more positioned towards the autism angle of the topic. Furthermore, I am a cisgender woman and identify as a feminist. Gender-related issues are highly important to me. In addition, I bring my own experiences of navigating healthcare as a woman with chronic health conditions.

2. What assumptions do you hold about your topics?

My main assumption about this topic is that people I interview will only be having negative experiences and I would be surprised to hear about good experiences of healthcare. I have some assumptions about gender, for example that women may have more difficulties being listened to than men. I also have assumptions that individuals from more marginalised groups will have more difficult experiences in the healthcare system. Generally, I have an assumption that ageing will have impacted participants negatively in regard to their healthcare needs.

3. How might participants perceive you?

Visibly, I think participants will perceive me as young based on my appearance. I'm aware my accent and conversational skills will mean I am likely perceived as someone well-educated and well-spoken. My Whiteness may also influence how I am perceived. I wonder how participants will perceive me in relation to being a researcher rather than a therapist/clinical psychologist. Importantly, I wonder if participants will want to know if I am autistic or not and whether it matters that I am not. I think because of my gender and age I will perhaps come across as being 'soft' and more of a therapist than researcher. Finally, I wonder if participants will perceive me as having lots of power and influence being associated with UCL as an institution.

4. Where and how do you occupy positions of privilege and marginality in relation to your topic and your participants?

I mostly occupy positions of privilege in relation to the topic. Firstly, I am young and able-bodied which means I do not experience ageism. I am White, cisgender and heterosexual which are all characteristics that make accessing healthcare easier. I am neurotypical and am not marginalised by a society that can be difficult for neurodivergent people to navigate. I do not have experiences of caring, which can be seen as a position of privilege. Perhaps I occupy a marginalised group in terms of being a woman. I feel that women have more difficult healthcare experiences in relation to specific healthcare needs such as menstruation and pregnancy. Overall, I am mindful of the overwhelming privilege I occupy in relation to this topic. I do experience some chronic health conditions which may come under the realm of marginality.

5. Are you an inside researcher or outsider? How might this shape your research and your relationship with your participants? What advantages and risks can you imagine to being an outsider?

Areas to consider: access and recruitment, developing trust and rapport, devising and asking questions, what we latch on to as important in participant's accounts, what we might miss, participants withhold information and representing participants' accounts

I identify as an outsider researcher. Including autistic older adults in the design of all study materials has been helpful to minimise the impact of being an outsider. I wonder if being younger when interviewing an older person might create challenges with rapport and if this will be exacerbated by doing interviews online. I wonder if being neurotypical means that I latch onto different areas of importance to participants during interviews. Though I am an outsider, I wonder if my clinical skills might mean I am able to build rapport and trust despite not being an insider researcher. Finally, being an outsider may convey some advantages in that people will not assume I can understand or relate to their experiences and therefore 'fill in the blanks' or expand on their answers. I am mindful of accurately representing participants' accounts when writing and presenting the thesis findings. I wonder if an autistic person might arrive at different conclusions to me.

Appendix G

Coded Transcript Example

Although coding was completed using N-Vivo, for ease of reading this extract and codes have been copied into a table.

Transcript	Codes
<p>Participant</p> <p>Yes, so my needs for healthcare have snowballed as I said since my sort of 40s, early 40s, onwards with perimenopause and to now and I have great concerns about how all of my health conditions are going to kind of meet the usual challenges of ageing, which obviously has already started because I've got some osteoarthritis amongst everything else that. And it worries me. And my needs of the health service are already huge and it worries me with the state of the NHS how that is going to be moving forward as I get older. Yeah, I worry about the impacts of age on my already existing conditions and my, since my burnout, my autistic sensitivities for sensory stuff are so much greater and it worries me how that's going to work out for me as I get older.</p> <p>Researcher</p> <p>Absolutely yeah. And does anyone support you to attend healthcare appointments or has anyone in the past?</p> <p>Participant</p> <p>Yeah, my partner comes as much as he can, and I think when I was, prior to my burnout and knowing I was autistic, I think I largely went into things on my own because I thought I had to. I didn't think I needed the help so much and I couldn't really understand why I got so overwhelmed by appointments, but. And this is the thing about getting such a late diagnosis, I can now see that if I had known and if I'd felt more able to ask for support to have someone with me and I've got friends who would come with me and now I can clearly ask them and say or you know, would you mind accompanying me? I think I put myself under undue pressure, if I'd have had the knowledge that I was autistic and I needed that support, it might have made it a lot easier, for the multi, multiple appointments I've had over the years, and it's certainly. Like when we, I had an appointment up at [HOSPITAL] a few months ago, and my partner came with me, and it just gave me so much reassurance.</p>	<p>Ageing</p> <p>Concerns about NHS</p> <p>Sensory needs</p> <p>Worries about the future</p> <p>Autistic burnout</p> <p>Emotional distress</p> <p>Late diagnosis/impact of late diagnosis</p> <p>Support from others</p>

Appendix H

Confirmation of Ethical Approval

**UCL RESEARCH ETHICS
COMMITTEE OFFICE FOR
THE VICE PROVOST
RESEARCH**



4th April 2022

Dr Joshua Stott
Research Department of Clinical, Educational and Health Psychology UCL

Cc: Amy Gillions and Hassan Mansour, UCL Research Department of Clinical, Educational and Health Psychology

Dear Dr Stott

Notification of Ethics Approval with Provisos

Project ID/Title: 22117/001: Understanding the views of autistic people aged 50 or over on their healthcare needs

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **1st November 2023**.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' <https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval>

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an

independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol.

The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Office of the Vice Provost Research, 2 Taviton Street University College London

Tel: +44 (0)20 7679 8717

Email: ethics@ucl.ac.uk <http://ethics.grad.ucl.ac.uk/>

Final Report

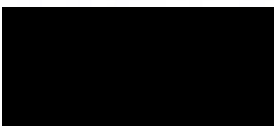
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research;
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



Professor Lynn Ang
Joint Chair, UCL Research Ethics