Autistics, autodidacts and autonomy: exploring how late diagnosed autistic women in the UK and US self-manage their health and wellbeing with dietary and other lifestyle measures

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Signature

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Abstract

Recent literature explores how autistic women have traditionally been underdiagnosed due to male-centric diagnostic criteria and so may experience delayed and reduced access to appropriate health and support services. Considering that autistic individuals have statistically high risks of many physiological and psychological health conditions, and report a lack of availability of support services, it is valuable to recognise efforts made by autistic women in self-managing their own health and wellbeing. Autistic women who have researched and developed their own self-management strategies have greater control over the quality of life that they experience.

Six late-diagnosed women participated in video-interviews with a late-diagnosed autistic health practitioner to share their experiences about how they developed nutrition and lifestyle strategies for self-managing their health and wellbeing; and interviews were analysed with Reflective Thematic Analysis. Participants indicated that being identified as autistic or getting a diagnosis of autism was vital for understanding their health and wellbeing conditions; and that this understanding contributed to prioritising health practices and strategies that positively impacted their life experiences. Four themes were identified (1) understanding needs, (2) individual health practices, (3) individual environments, and (4) creativity and stimming (see glossary p59). It is hoped that this study contributes to knowledge of how autistic women might be better supported in managing their health and wellbeing.

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"Online we came together, and we shared our stories. We devoured what research there was. We experimented on ourselves. We became our own scientists and our own doctors because we had to be." (Brea, 2016)

Introduction

Autistic women, estimated to represent around 1 in 4 of the autistic population, have historically been underdiagnosed due to a male bias in the diagnostic criteria (Bargiela *et al.* 2016). As male autistics are more likely to present with what are often considered problematic behaviours, they have a higher chance of an autism diagnosis in childhood. However, females tend to show a higher vulnerability to internalised problems such as depression and eating disorders (Mandy & Tchanturia, 2015) and so, with less likelihood of a timely diagnosis, may not receive appropriate support for their conditions (Milner *et al.* 2019).

It has been my observation that many autistic women who have not received an autism diagnosis until adulthood have sought relief for multiple co-occurring health and wellbeing challenges in the form of dietary or lifestyle strategies. While autism itself is not curable (and is not wished to be so by many autistic people), successful management of physical and mental health conditions can help alleviate challenges commonly experienced by autistic individuals such as chronic anxiety, sensory sensitivities, sleep disorders, digestive disorders and chronic pain. Such distressing conditions may have existed for an individual a long time before autism is identified or diagnosed, leading to a sense of impairment or disablement. When these challenges are reduced the experience of being autistic may change; with the emphasis being put on the advantages of being autistic, such as attention to detail and pattern-finding, rather than the more disabling aspects.

I have observed first-hand how my own autism-related challenges were lessened with nutrition and lifestyle strategies used both before and after being assessed as meeting the criteria for autism spectrum disorder in 2016. Hendrickx (2015) notes that the hyper-awareness and detail focussed nature of autistic women means that they may turn their health into the focus of an intense interest and become their own project. While this phenomenon has been absent from academic literature it is apparent in the wealth of blogs by autistic women and has been a common theme for female autistic clients in my professional health and nutrition practice. Such women have explored their mental wellbeing, day-to-day functioning and even their cognitive and creative

processes through managing sugar or gluten intake, developing meditation or yoga practices, or learning to treat with herbalism or supplementation.

Milton (Milton, 2014) puts forward that the voices of autistic people regarding their own expertise in knowledge production concerning autism is traditionally the least attended to. Currently there is a lack of literature concerning how autistic women experience their own conditions and a need to generate evidence of the nutrition and lifestyle strategies that autistic women develop to self-manage their health and wellbeing. By exploring themes in these strategies within a perspective aligned with critical theory (thus holding that autistic values and experiences shape reality in the field of autistic health and wellbeing), the current study was designed to contribute to knowledge about the health and wellbeing experiences of autistic women by interviewing late-diagnosed autistic women to explore:

1. What dietary and lifestyle self-managed strategies have been used by late-diagnosed autistic women to improve their health and wellbeing?
2. Which (if any) of these strategies did they feel changed their experience of being autistic?
3. If there are any differences between how autistic women from the UK and autistic women from the US self-manage their health and wellbeing.

Six interviews were conducted, three from the United Kingdom and three from the United States. The participants were identified using the snowball sampling method and all fit the inclusion criteria: (1) participants had gained a formal diagnosis of autism or Asperger's in adulthood or self-identify as autistic; (2) participants had been assigned female gender at birth or self-identified as female; (3) participants had actively sought out and practiced nutrition and/or other lifestyle strategies in order to self-manage their health and wellbeing.

After transcribing the audio-recorded interviews, I analysed the data using Thematic Analysis. Despite years of self-managing their health and wellbeing, many of the participants felt that they were not fully able to address conditions that they had until they had been identified as being autistic or had received a clinical diagnosis of autism. Firstly, because they had not known that symptoms such as fatigue and overload; depression, burnout and sleep problems; and digestive problems and chronic pain might relate to their being autistic. And secondly, some of the strategies that helped alleviate these symptoms were lifestyle measures that came naturally to them as

autistic people but were not societally recognised as necessary. Such strategies included spending time alone and stimming.

The participants used a range of conventional health and wellbeing strategies including the avoidance of 'trigger foods', the inclusion of supplements, and certain movement or exercise strategies. In addition, spending time alone and/or in natural environments; following routines and having creative practices were felt to be equally important. Participants felt that the self-managed nutrition and lifestyle strategies they used enabled them to relieve anxiety, insomnia and chronic pain; and to function better in their day-to-day lives. Although the UK and US participants had different access to health services, there did not appear to be any appreciable difference between the self-managed strategies that they used.

Literature review

This study focuses on how late diagnosed autistic women self-manage their health and wellbeing. Currently there is a paucity of peer reviewed literature directly relating to this and so the review that follows will discuss the reasons for the phenomenon.

To inform this review, a literature search of journal articles written between 2014-2019 was carried out during May and June 2019 with AMED, CINAHL Plus, MEDLINE and PsychINFO using the search terms:

- Women
- Autis* OR ASD OR ASC
- Experience

In addition, the snowballing technique was used by searching through references from and citations of these and other journal articles found through autism networks on social media, Researcher App and various other online searches from September 2018 to June 2019.

In this review I begin with discussing traditional medical approaches to autism and recognised comorbid conditions, to explain why the health and wellbeing of the autistic population is a concern. I then outline how accessibility to healthcare services affects the health and wellbeing of autistic people through the perspectives of the Social Disability Theory and Critical Autism Studies. Finally, I focus on studies exploring women's lived experiences of being autistic and consider how and why these women

may find themselves developing their own self-managed strategies to improve their health and wellbeing.

Medical approaches to autism and comorbid conditions

Since the first clinical descriptions of autism by Dr Kanner and Dr Asperger in the 1940s, various theories have attempted to explain the causes, nature and management of autism, whether biological, cognitive or behavioural. In this chapter I will be outlining the medical model of autism, and how it encompasses comorbid, or co-occurring medical conditions.

Defining autism

Currently, a clinical diagnosis of Autism Spectrum Disorder (ASD) is positioned within a triad of impairments: difficulty since childhood with social communication and social interaction combined with restricted and repetitive patterns of behaviours or interests (American Psychiatric Association, 2013). These impairments may present alongside other medical or genetic conditions and be associated with additional neurodevelopmental, mental or behavioural disorders. The causes of autism have long been debated and research in the last twenty years has pointed towards genetic origins; however there is still no clear evidence of biological markers or biologically based models that explain autism itself (Fletcher-Watson & Happe, 2019).

Estimates of the prevalence of autism vary widely. Review figures on The World Health Organisation website suggest that 1 in 160 children has an autism spectrum disorder (WHO, 2016); America's Centers for Disease Control and Prevention estimate that 1 in 59 children has been identified with autism spectrum disorder (Centers for Disease Control and Prevention, 2016), and Northern Ireland's 2019 report states a prevalence rate of 3.3% for school age children (Department of Health, 2019). The UK's National Autistic Society estimates that around 1.1% of the population is likely to be autistic (National Autistic Society, 2019) and that autistic males outnumber autistic females 3:1 (Loomes *et al.* 2017).

Current medical research into autism and comorbidities

Several quantitative studies looking at the prevalence of co-occurring health conditions in the autistic population have found that psychiatric conditions such as anxiety, bipolar, depression, obsessive compulsive disorder, schizophrenia and suicidality; and medical conditions including autoimmunity, diabetes, epilepsy, gastrointestinal disorders and sleep disorders are significantly more common in autistic adults than in

controls, and higher in autistic women than in autistic men (Baldwin & Costley, 2015; Croen *et al.* 2015; Gotham *et al.* 2015; Jones *et al.* 2016; Tint *et al.* 2017; Rydzewska *et al.* 2019; Tye *et al.* 2019).

For bio-medical researchers these correlations raise many questions around potential genetic or environmental links between autism and comorbidities. In the UK, 56% of research grant funding into autism between 2008-2011 was on the brain, biology and cognition; and a further 15% on causes; while in the US 37% was spent on risk factors and 18% on underlying biology (Pellicano *et al.* 2014). 2016 saw 44% of autism research funding (a total of £10.4million) spent on animal research (Warner *et al.* 2016). With much of the autism discussion taken up with causation research the more practical implications for making the lives of autistic people easier have been overshadowed (Ne'eman, 2010).

With such a high rate of co-occurring medical and psychiatric conditions autistic individuals are more likely to require health services than non-autistic individuals. However, healthcare services, such as GP services, clinical referrals for co-occurring health and psychiatric conditions such as those outlined above and, in particular, mental health services, are under-accessed by the autistic population, potentially leading to further or worsened health conditions (Croen *et al.* 2015), an area which I explore below.

The social model of autism and access to healthcare

The social model of disability, as developed by disabled people, reframes perceived medical impairments as disabilities created by barriers which are driven by societal factors (Oliver, 2013). Societal structures such as public understanding, environmental adjustments and technology etc. can all be utilised to reduce the impact of a disability. The provision of flexible work hours, wheelchair access and subtitles are examples of how societal structures can empower disabled individuals. Access to healthcare is also a societal structure and so in this chapter I will outline how Critical Autism Studies, a critical thinking offshoot of the social model of disability; and participatory research methods, which give a voice to autistic people, contribute to the discussion about why much needed health services are not as accessible to autistic individuals as they could be.

Critical Autism Studies and participatory research

Traditionally, autism studies have largely been carried out within a positivist medical model which views autism as a deficit or pathology (Woods *et al.* 2018). Positivist philosophy in disability research generally uses methods such as controlled trials, statistical samples and structured questionnaires to focus on searches for cures, means of reducing impairments, or to assess clinical interventions (Oliver, 1998). When autism is understood as separate from the person, i.e. 'person with autism' rather than 'autistic person', then objective, medicalised motivation may focus on eradicating the condition in order to free the 'normal' person inside. As a result, the autism research hegemony has been dominated by diagnosis, genetics, behavioural modifications, and medical treatments with interventions that focus on children, adults diagnosed with both autism and a co-occurring intellectual disability; and with mice displaying 'autistic behaviours.'

Taking a philosophical stance more in line with Critical Theory which sees disabled people's problems explicitly as the product of an unequal society (Oliver, 1998), Critical Autism Studies (CAS) challenges these predominant constructions of autism and uses inclusive methodological approaches which take autistic narratives and cultural expressions into account (O'Dell *et al.* 2016; Woods *et al.* 2018). CAS, which is underrepresented in the literature, argues that epistemological integrity is lost without autistic authorship (Woods *et al.* 2018). CAS is primarily concerned with the wider knowledge production of autism, autistic people and autistic culture through the concept of epistemic communities who have a valid claim to develop and evaluate knowledge through collective experiences (O'Dell *et al.* 2016). However, this theoretical perspective and related methodologies has relevance to the study of the health and wellbeing of the autistic population. Participatory research, which seeks input from autistic people, rather than just from clinicians, parents and carers, empowers autistic communities to make differences in policy and social change.

Participatory research sets to undermine the traditional power balance between research and participants by incorporating the views and values of autistic people at each stage of the research design process to widen inclusivity of the research environment, methodology and dissemination routes (Fletcher-Watson *et al.* 2018). In order to do this, communication modes, language preferences and the need for individualised accommodations should be recognised and respected (Nicolaidis *et al.* 2019). Participatory methods have been increasing in autism research over the past

few years and have contributed to much of the knowledge around healthcare access as discussed below.

Barriers to healthcare access for autistic people

Adults who receive support feel that they are able to function better in life, experience less depression and isolation, and enjoy improved confidence and greater independence (Camm-Crosbie *et al.* 2018). This gives weight to the primary goal behind the social model of disability that takes the focus away from the perceived impairment and looks instead to how societal structures can take responsibility for making adjustments (Woods, 2017). These adjustments are commonly understood as removing attitudinal, environmental, organisational and/or communication barriers (Inclusion Scotland, 2017), all of which may be encountered in accessing healthcare support systems. Research within the social model of disability has shown some correlation between autism acceptance and reduced rates of depression and suggests that external acceptance may come hand in hand with increased support (Cage *et al*. 2018).

Recent research in the social sciences has given insight into the mechanisms of how and why autistic individuals experience access problems with health services. Communication challenges and sensory sensitivities triggered by making appointments, waiting rooms and the appointment itself can lead to individuals being unable to access appropriate further diagnoses, support, medication or referrals (Lum *et al.* 2014; Bargiela *et al.* 2016; Camm-Crosbie *et al.* 2018; Tint *et al.* 2018; Crane *et al.* 2019; Tye *et al.* 2019). Autistic individuals overall report higher unmet healthcare needs related to physical and mental health together with lower patient-provider satisfaction (Nicolaidis *et al.* 2013). A recent report by the Autistic Mutual Aid Society Edinburgh found that 42% of participants felt they had problems dismissed by practitioners and that 30% had problems with inaccessible services (Hallett & Crompton, 2018). In particular, autistic adults perceived to be 'high-functioning' were assumed to be already coping and so were less likely to be offered support, even for those experiencing suicidality (Camm-Crosbie *et al.* 2018). This may not be surprising given that GPs are not given standard autism training and lack confidence in advising and referring autistic patients (Unigwe *et al.* 2017; Morris *et al.* 2019).

Despite a clear need to focus on improvements in healthcare and on the wider determinants of health for this population very little research has been done on how to improve healthcare access and delivery for autistic patients. (Rydzewska *et al.* 2019).

A recent review on the interplay between autism and comorbid medical conditions recommends that screening for co-occurring medical problems should be offered at point of diagnosis in order to monitor and maintain general health and wellbeing, and to improve quality of life (Tye *et al.* 2019). However, a diagnosis of autism may actually rule out certain mental health services, as depression and anxiety in autistic individuals are perceived by many health professionals as being a part of autism, and therefore not treatable conditions (Leedham *et al.* 2019). Considering that mental health is of significant concern for autistic girls and women (Baldwin & Costley, 2015; Tint *et al.* 2017) and that there are limited specialist mental health services for autistic individuals (Maddox & Guas, 2019), this is clearly an area that requires better understanding.

Coping Mechanisms and Self-Management

While autism researchers are currently studying and publishing on many aspects of autism, including the mechanisms leading to particular health experiences of autistic individuals, there is very little literature developed and evaluated by autistic communities on how autistic individuals self-manage their own health and wellbeing, particularly given the barriers to accessible and targeted healthcare.

Considering the limited support available, many autistic adults find their own coping mechanisms to deal with stress, sensory sensitivities and other types of self-regulation such as physical activities, physical pressure applied to the body and spending time alone (Kim, 2019). A prior diagnosis of autism can be particularly helpful here as individuals feel validated in developing these coping mechanisms and so allowing themselves to be kinder to themselves, manage social situations differently and let go of associated guilt (Leedham, et al., 2019). However, autistic girls and women frequently slip through the net as far as autism diagnoses are concerned and so I outline some of the reasons for this below.

The female phenotype, camouflaging and the lived experiences of late-diagnosed autistic women

Until recently adult autistic women have been notably absent from studies. A recent review on wellness efforts for autistic women by Tint *et al.* (2018) notes that despite reported lower use of preventative health services, higher unmet care needs and lower satisfaction with healthcare experiences, there is a dearth of research on autistic women's physical health outside of literature focussed on menstrual and reproductive experiences. Meanwhile, mental health tends to be looked at only with reference to diagnosis rather than how to promote lifetime psychological wellness for this

population. In this chapter I outline some of the reasons for the historical lack of studies concentrating on the health and wellbeing of autistic women and then look at the recent growing interest in their lived experiences.

Diagnostic criteria

Mandy and Tchanturia (2015), after identifying undiagnosed autistic women currently treated for eating disorders, suggest that autism is inadequately assessed in women and that action should be taken to redress this. Autism has long been considered a predominantly male phenomenon due to the common perception that autistic people lack in social reciprocity and social communication, generally considered to be female attributes. This stereotype has been enforced by studies such as Baron-Cohen's Extreme Male Brain Theory (Baron-Cohen *et al.* 2015) which pits the scores of an Empathy Quotient questionnaire and a Systemising Quotient questionnaire to demonstrate that autism represents an extreme male pattern. As such, autistic women have historically been under diagnosed and research to date has largely been based in a male-centric conceptualisation of autism (Tint *et al.* 2018).

Women have a stronger likelihood of displaying camouflaging or masking behaviours which results in them being even less likely to be identified as autistic (Bargiela *et al.* 2016). 'Camouflaging' describes the behaviours that hide aspects of the individual in order to more easily fit into neurotypical society and avoid bullying (Cage & Troxell-Whitman, 2019). Whether camouflaging is a conscious or an unconscious behavioural decision it is associated with higher risk of exhaustion, anxiety, depression and eating disorders; and being targeted with manipulation and abuse (Bargiela *et al.* 2016; Cage & Troxell-Whitman, 2019). Additionally, life changes such as puberty, pregnancy and the menopause are documented as being particularly difficult times for autistic women (and more so than for non-autistic women) as hormonal changes appear to cause increased difficulties in anxiety, sensory sensitivities, sleep and digestion (Hamilton *et al.* 2011; Steward *et al.* 2018; Milner *et al.* 2019;).

Bargiela *et al.* (2016) suggest that some of the challenges of being an autistic female reflect cultural expectations for women, and that these expectations may be instrumental in autistic women showing a tendency to internalise their difficulties. It has been hypothesised that this tendency to internalise rather than express difficulties outwardly may present a risk factor both in securing a diagnosis and in gaining access to support (Baldwin & Costley, 2015; Bargiela *et al.* 2016). This phenomenon may be compounded by many autistic women's feelings of ambivalence about their own

gender, lack of quality social relationships and feelings of persecution due to being 'different' (Kanfiszer *et al.* 2017) This has implications for the level of targeted and specific health and wellbeing support offered to autistic women (Cage & Troxell-Whitman, 2019) and presents a need for deeper understanding of potential sex and gender impact across the area of wellness efforts for autistic adults (Tint *et al.* 2018).

Analytic frameworks employed in studies into the health and wellbeing of autistic women

The existing field of studies looking at the health and wellbeing of autistic women has predominantly looked at identifying clinical needs and exploring healthcare experiences through quantitative methodology. However, there has been a recent increase in qualitative literature exploring the lived experiences of autistic women; in particular, showing the impact of autism and autism diagnoses on the health and wellbeing of individuals. The methodologies employed have offered different insights into these explorations and so I will outline the key studies in this field with reference to how the various analytic frameworks enabled the authors to identify themes and disseminate knowledge about autistic women's experiences.

The female autism phenotype (Framework Analysis)

Bargiela et al (Bargiela *et al.* 2016), in their investigation into the female autism phenotype, used Framework Analysis, a flexible approach popular in health and policy driven research to generate theories and promote the development of new measures. The data from in-depth interviews with fourteen women diagnosed with autism in late adolescence or adulthood was intended to address the nature of the female autism phenotype, explore how this phenotype might influence autistic female's experiences due to missed diagnoses, and see how late diagnosed women adapt to challenges as a result. Four main themes were identified: (1) you're not autistic, (2) pretending to be normal, (3) passive to assertive, and (4) forging an identity as a young woman with ASD. Each of these themes were implicated in reduced wellbeing through misdiagnoses and misunderstanding; camouflaging, abuse and lost identity. The authors concluded that training is required for teachers and clinicians to more easily identify these women in order to mitigate such risks and promote wellbeing.

In contrast, autistic women who are empowered to see themselves as agents of change and develop their own coping strategies as a result of gaining a diagnosis, appear to have a higher outcome of wellbeing, as shown in the following studies.

Exploring the female experience of autism (Thematic Analysis)

Two coping strategies, outlined by the eighteen female autistic participants and four mothers of autistic girls as interviewed by Milner et al. (Milner *et al.* 2019) include spending time alone and keeping to a routine in order to avoid becoming overwhelmed. The authors employed Thematic Analysis as developed by Braun and Clark and outlined in their seminal paper, Using Thematic Analysis in Psychology (Braun & Clarke, 2006). TA offers a robust, systematic framework for coding qualitative data which can then be used to identify patterns across the dataset. Employing TA enabled the authors to explore the female experience of autism, by creating themes and subthemes, and data to support the following themes: (1) fitting in with the norm, (2) potential obstacles for autistic women and girls, (3) negative aspects of autism, (4) the perspective of others and (5) positive aspects of autism.

Successful autistic women (Narrative Analysis)

Webster and Garvis (2017) interviewed ten autistic women, who considered themselves successful, and conducted a Narrative Analysis to review the data for meaningful and relevant themes that figured importantly and repeatedly. The authors describe the creation of the main themes through explaining the socio-political, physical and structural aspects, reconstructing the events of the participants and capturing transitions in how stories were told and retold. All the women saw themselves as agents of change; many spoke of influential people who enabled them to believe in themselves; all felt that their diagnosis had helped them to construct a new identity for themselves and, in turn, they all began to see that they could become role models for other autistic women. While not a key theme, the authors noted that each of the ten participants spoke of their diagnoses as pivotal points which sparked them to seek out new information, giving them a greater sense of their own selves.

Experiences of women receiving a late diagnosis (Interpretive Phenomenological Analysis)

Similarly, while many of the eleven women diagnosed with autism after the age of forty and interviewed by Leedham et al. (2019) described ongoing anxiety and depression, some had been able to make adaptations in their lives, based on new understandings since diagnosis, and so experienced far less stress. They were able to let go of blame, meet their own needs and develop identities as women who did not need to conform to be acceptable.

This study employed Interpretive Phenomenological Analysis (IPA) which enables focus on subjective accounts of how individuals makes sense of, respond to and interpret their lived experiences; and gives some consideration to how historical, societal and cultural contexts shape these experiences. IPA is favoured by researchers working within the field of psychology rather than those within a socio-cultural context and may only be used to answer research questions about experiences, understandings and perceptions (Braun & Clarke, 2013). The key themes generated for this study were (1) a hidden condition, (2) the process of acceptance, (3) the impact of others post-diagnosis and (4) a new identity on the autism spectrum. These themes show a marked resemblance to those identified in the previously outlined study by Webster and Garvis.

While medical understandings of the links between autism and psychological and physiological conditions are useful, it is important to recognise both how societal attitudes and structures can either hinder or support life quality for autistic people. Qualitative explorations of autistic women's experiences in the literature demonstrate how a diagnosis and societal supports can enable autistic women to more easily recognise and meet their own needs. The current study aims to contribute to that conversation.

Theoretical Framework

Navigating a world not designed for autistic needs

This study explores the experiences of late-diagnosed autistic women who self-manage their health and wellbeing, from a social constructivist perspective which argues that people will have different experiences and perceptions of reality and that the ways we commonly understand the world are historically and culturally specific (Burr, 2015; Patton, 2015). Constructivist philosophy holds that two people may live in the same empirical world and experience it differently, but that each person's way of making sense is equally valid (Patton, 2015). Research within such a perspective relies on qualitative methodology; of collecting and analysing data in the form of words in order to explain or predict (Braun & Clarke, 2013).

Healthcare decisions are generally made on behalf of autistic people by non-autistic people, but it seems likely that non-autistic people would not always easily or accurately predict the needs of autistic people given that their lived experiences will be very different. Milton (Milton, 2012) puts forward that disabled people are the experts of

their own requirements and that within social theory a key difficulty of autism is navigating a world not designed for the autistic individual's needs. If autistic people are to be less disabled by the world it is imperative that decision makers appreciate that autistic people's experiences and perceptions are historically and culturally specific; autistic voices are necessary to inform knowledge about suitable healthcare and support. Qualitative methodology was, therefore, a clear choice for this study.

Reviewing potential analytical frameworks

Reflexive Thematic Analysis, as developed by Braun and Clarke (Braun & Clarke, 2006) was used to analyse the data. Interpretative Phenomenological Analysis, Narrative Analysis and Thematic have all been used in similar studies interpreting data from qualitative interviews with autistic women about their experiences and views. The reasons for using Narrative Analysis are outlined below.

Interpretive Phenomenological Analysis

IPA, as a methodological approach gives a voice to individual participants by providing an interpretative account of their experiences in their unique context. Non-verbal interactions, emotions and personal thoughts of the participant and researcher are recorded in detail and considered reflexively. McCleod (2019) observes that Milton's double empathy problem (Milton, 2012), which acknowledges that while autistic people may find it difficult to 'read' non-autistic people, non-autistic people may find it equally difficult to 'read' autistic people, can be an issue in terms of subjectivity and reflexivity in IPA. However, as an autistic researcher I would have the advantage of finding autistic people easier to read than a non-autistic researcher might. While I felt that IPA could have been an interesting and useful methodology for this study, I felt that the analysis of non-verbal interactions could unintentionally detract from the overall communication by participants, making this methodology less useful for this study.

Narrative Analysis

Narrative Analysis (NA) similarly offers insights into lived experience but, unlike IPA is directed on the socio-cultural constitution of the experience (Braun & Clarke, 2013). Kanfiszer *et al.* (2017) employed NA specifically to challenge existing constructs and allow autistic participants voices and experiences to inform understandings of autism in relation to gender and social relationships. Their analysis was designed to focus on how the participants storied their lives and how they understood and conceptualised specific aspects of their lived experiences.

The current study is not intended to capture stories so much as the interplay between self-managed health and wellbeing strategies and the experience of being autistic and so narrative analysis is not a suitable analytic method in this case.

Thematic Analysis

Thematic Analysis is a method of analysing various types of data, and can be used to answer most types of research questions. Themes may be identified with a 'bottom-up' data driven approach or developed to explore theoretical ideas, in a 'top-down' approach. Braun and Clarke's reflexive version of Thematic Analysis offers a robust and systematic framework for developing codes and identifying themes from these codes in relation to the research question (Braun & Clarke, 2014).

Flexibility in terms of theoretical frameworks is a feature of Thematic Analysis, which suits the social constructivist perspective employed by this study. It is also an accessible analytical method for researchers such as myself with less research experience.

Methods

Participants were recruited by snowballing and six semi-structured interviews were conducted via videoconferencing, three participants from the US and three from the UK. After transcribing the audio-recordings Thematic Analysis was employed to generate themes from the data.

Participant sampling, criteria and recruitment

Two initial participants (one from the UK and one from the US) were invited to be interviewed from my own autistic-centred networks and were both asked to provide contact details of another who fit the inclusion criteria:

(1) Having either a formal diagnosis of autism or Asperger's in adulthood, or to self-identify as autistic
(2) Assigned female gender at birth or self-identifying as female
(3) Having actively sought out and practiced nutrition and/or other lifestyle strategies in order to self-manage their health and wellbeing.

Each subsequent participant was asked to provide contact details of another fitting the criteria until six interviews had been carried out. Two additional individuals,

recommended by previous participants, stated their enthusiasm in participating in interviews but did not reply to emailed requests for a confirmation of an interview time.

Ethical issues

Information sheets and consent forms were emailed in advance with consent forms signed and returned before interviews were scheduled. Participants were assured that participation was voluntary and that they would be given the opportunity to ask questions before giving informed consent. Informed consent was transparent and clearly defined in terms of responsibility and accountability. All data collection was treated sensitively, with full confidentiality and anonymity maintained.

Without knowing the full context of a conversation, a delay in verbal response can be caused from autistic interviewees needing to consciously translate what's been heard before being able to formulate a reply, often causing anxiety (Beardon, 2017), and so interview guides were provided which outlined the structure of the interview and the questions to be asked. This allowed participants to more easily access memories and 'script' their answers to some degree.

These procedures are in line with the AASPIRE (Academic Autism Spectrum Partnership in Research and Education) practice-based guidelines for the inclusion of autistic adults in research (Nicolaidis *et al.* 2019) which state that attempts should be made to avoid coercion and exploitation while maximising autonomy and inclusion; and that the consent process should made as accessible as possible with an interview guide provided in advance of the interviews.

An ethical checklist and an application form for ethical review of research involving human participants were completed in advance of recruitment. As this study was considered to pose minimal risk to participants and myself this study was given ethical approval by my supervisor Stuart McClean. The information sheet, consent form and interview guide are provided in the appendices.

Interview procedure

Consent forms were returned from all participants in advance of Skype interviews and I verbally checked with each participant that they had fully understood what they were consenting to. All, except for one interview, lasted under one hour, were audio recorded and later transcribed verbatim by me. Nobody withdrew or appeared

distressed. All participants stated that they had enjoyed the interview and were keen to hear about the findings on completion (appendix G).

Data analysis

Reflexive Thematic Analysis guidelines were applied to identify themes in the data from both a data driven "bottom-up" and a reflexive, researcher standpoint "top-down" approach. Reflexive Thematic Analysis, developed by Braun and Clarke, provides a robust and systematic framework for coding qualitative data and identifying patterns across the dataset in relation to the research question (Braun & Clarke, 2014). Following initial coding and analysis by myself, a selection of transcripts was also analysed by Stuart McClean to reflect on coherence, consistency and clarity of themes.

To identify themes within the study data I followed Braun and Clarke's (Braun & Clarke, 2006) six-step process.

Phase one – becoming familiarised with the data

I transcribed the interviews verbatim myself, checked them against the recordings, and read them, both individually and as an entire data set, several times to search for meanings and patterns. Transcribing the interviews enabled me to gain a more thorough understanding of the data, particularly through noting pauses in conversation, vocal tone and the structure through which the participants told stories in order to make a point that was important to them.

Phase two – generating initial codes

Generating the initial codes meant analysing the data numerous times. Firstly, I re-read each transcript to identify codes of interest and made handwritten notes of these codes. Secondly, I went through these codes to simplify and clarify any that were overly detailed. Thirdly, I checked that the codes were thorough, inclusive of the dataset and comprehensive. Finally, I dismissed many which, although interesting, were not relevant to the current study's aims of exploring how autistic women manage their own health and wellbeing, such as *support from others* and *validation from others.*

Commonly marked deductive codes, those I expected to see, *included managing my diet, meditation/breathing* and *supplements.* Inductive codes, those that I was not expecting *included spending time alone, creativity* and *accepting/understanding my autism.*

With a simplified and clear list of twenty initial and relevant codes (appendix B) I marked the data by hand in coloured pens with notes on the right-hand sides of the transcripts. I then collated the data by hand.

Phase three – searching for themes

In order to identify significant, broader levels of meaning I sorted the codes that I had into candidate themes or central organising concepts (Braun & Clarke, 2013). Some codes such as *creativity* became the basis of potential themes, such as *creative practices* and others, such as *sensory sensitivities* became supportive of potential themes such as *beneficial environments, routine and spending time alone.* A few codes did not fit comfortably within a theme at all and were collated into a miscellaneous category. At this point I had identified several candidate themes and subthemes and worked them into a visual map of candidate themes, as shown in appendix C.

Phase four – reviewing themes

Reviewing the candidate themes was necessary to ensure that they were able to effectively answer the research question. Firstly, I reviewed my candidate themes against the coded and collated data to check that all the relevant material would be covered. Secondly, I reworked the candidate themes into four non-hierarchical themes, each distinct and coherent, with one theme containing three subthemes that captured specific aspects of that theme's concept. Finally, I checked these revised themes against the coded data to be sure that each theme could effectively demonstrate the breadth and diversity of the data (Braun & Clarke, 2013)

Phase five – defining and naming themes

Writing the first draft of the Findings chapter enabled me to define and explain my themes further. As a result, the theme names were shortened for more clarity.

Phase six – producing the report

I removed repetitions and hesitations from the data extracts, represented missing data with ellipses, used square brackets to identify pertinent words missing from the original data; added punctuation to ensure readability, removed details that could identify a participant and took care within each theme to give approximately equal weighting of extracts from each transcribed interview. As the participant sample was small and some of the participants are well known in the blogging community the anonymous

data extracts were included without referencing pseudonyms or codes, to ensure that participants would be more difficult to identify.

Findings

This study sought to explore how late diagnosed autistic women in the UK and US self-manage their health and wellbeing through dietary and other lifestyle measures. Six autistic women whose ages spanned four decades were interviewed, three from the US and three from the UK. All participants had been identified as, or had a clinical diagnosis of autism or ASD in adulthood.

Analysis of the data demonstrated how getting a diagnosis of or identifying themselves as autistic was pivotal in how the participants researched and developed strategies to effectively support their health and wellbeing. From the data, I identified four main themes, (1) understanding needs, (2) individual health practices, (3) individual environments, and (4) creativity and stimming.

Theme 1: understanding needs

> *[It's] only since getting my diagnosis that I actually started treating myself well.*

This theme explores how a diagnosis or identification of autism enabled the participants to more effectively tailor how they supported their own health and wellbeing. Three subthemes focus on the importance of appreciating specific challenges common to autistic individuals in terms of (1) fatigue and overload, (2) mental health: anxiety, burnout and sleep problems and (3) physical health: digestive problems and chronic pain.

All participants noted that until they had been identified or diagnosed as autistic, they had found it difficult to manage their health and wellbeing effectively due to not fully understanding or appreciating their particular needs. This difficulty was largely down to two main causes, (1) masking or camouflaging and (2) disassociation or alexithymia.

> *I was unable to recognise my own patterns. I was unable to make allowances for myself and I was unable to build any kind of wellbeing and healthiness for myself without that knowledge.*

Without the knowledge that they were autistic, participants unconsciously masked by trying to keep up with non-autistic peers under conditions that they found difficult. This

was often because they were not aware or did not wholly appreciate that they had different needs to others.

> *I would get angry sometimes about the environment "why is everyone being so loud, why are the lights so bright... they should know, this is horrible." [Now it's] like "oh, no one else can hear that!"*

This unconscious masking was felt to cause exhaustion and burnout.

> *[I kept] pushing myself to keep up and then collapsing or having health repercussions.*

Masking could be implicated in both mental and physical health. One participant talked about a particularly difficult period in her life when nobody around her realised that anything was wrong.

> *I think the not outwardly showing the neurotypical, correct emotion or flagging things up with the right sense of panic and seriousness probably led to setbacks.*

Secondly, disassociation or alexithymia meant that they didn't always recognise their health and wellbeing challenges or were unable to describe these challenges to caregivers or practitioners, resulting in lack of support from others or self-understanding to develop appropriate self-care practices. One participant explained how her disassociation resulted from overwhelm and that it took self-managed strategies she had discovered around the time of her diagnosis to work through this

> *I was just constantly disassociated... I don't think it's just a mental health thing, I think it's a neurological thing as well. It was my brain being like "everything's too much, let's check out!"*

One participant noted that a long bout of chronic pain was probably down to stress, but that she hadn't realised she was stressed until later. Another felt that while she'd had many problems in her life, she assumed everyone else was having the same problems and so maybe her own weren't that bad. Others discussed how not having the vocabulary for their challenges meant that they often didn't realise that they had these challenges at all.

> *I don't think I knew how to take care of myself, I mean I really didn't. I had no idea that sensory overload was part of my experience.*

A diagnosis or identification of autism was a pivotal moment in empowering the participants to more effectively manage their health and wellbeing. Once participants were able to understand and appreciate certain challenges of being autistic and network with other autistic people (mostly online) about these challenges then they were able to develop health and wellbeing practices that took their individual needs into context. Through getting to know other autistic women through social media and blogging, many were signposted to common health concerns and the resources to better understand them. Health and wellbeing issues became easier to understand and tackle with the understanding that more tailored approaches to self-managed strategies could be more effective.

> *[Now] I'm much better informed as to what all the things might be that are going on with my mind and body. If I'm not feeling great, I can put two and two together really quickly. And that's super helpful.*

Equally, getting to know other autistic women online through social media and blogs, could be empowering in terms of thinking about autism positively. This provided encouragement for finding more holistic ways to treat and understand, rather than just managing individual symptoms. Participants referred to ceasing the habit of blaming-and-shaming themselves for perceived shortcomings and learning instead to treat their minds and bodies with respect and kindness.

> *I realised that our brains are so powerful, and we need a lot of resources and we need to be very wise about how we operate our bodies.*

For some participants, understanding that they were autistic made them aware that they had a previously unacknowledged disability. Rather than seeing this disability as a fault within themselves it meant that they had some validation for why the social environment might be more difficult to thrive in than for individuals who are not autistic.

> *I do definitely identify as disabled because people who aren't autistic don't have to allocate their resources [like this] for the day. And I very much do... it means a lot of extra management.*

Subtheme 1.1: fatigue and overload

> *Fatigue is so huge. Sensory overload... I will lose executive functioning like I basically can't do anything for the rest of the day.*

Fatigue and overload were common to all the participants, and even more so before they were identified or diagnosed and not necessarily aware of their individual needs.

I was constantly exhausted. I was constantly overexerting myself.

Triggers such as lighting or sounds provoking sensory sensitivities, lack of routine or changes to routine; socialising and other stressful situations were mentioned as contributing to breakdowns, meltdowns, shutdowns, blackouts, becoming mute or inarticulate, lacking physical coordination, losing executive function; and/or as feeling hungover the following day.

If I don't really look after myself... it will have repercussions, probably fairly quickly... and then the next day I will be exhausted or having a meltdown or unable to concentrate.

A greater understanding of triggers leading to fatigue and overload that autistic individuals are particularly susceptible to empowered each of the participants to avoid or mitigate the results of exposure to them. Tools such as sunglasses and noise reducing headphones were used to help limit some sensory exposure and later themes explore how participants alleviated long-term exposure to triggers.

Subtheme 1.2: mental health: anxiety, burnout and sleep problems

I think most of my issues have really been rooted in anxiety

All the participants had found that mental health challenges were something that they had had or were currently managing with self-help measures. Anxiety was a particular concern and so managing or mitigating anxiety was felt to be key to wellbeing. Anxiety was also felt to be implicated in health issues such as chronic pain and digestive issues.

Understanding how anxiety affected their life was instrumental in enabling participants to develop self-help strategies that improved other areas of their health and wellbeing.

The more I can manage calm, balance my nervous system... the better my health will be.

In addition, some of the participants described in different ways how autism meant they had a narrow band to work within in terms of what their nervous system could handle. Their wellbeing might be fine if they respected their own boundaries but once they had

to cross those boundaries or 'use too many spoons' then fatigue and overload, anxiety and burnout would be almost inevitable.

> *I feel like [we] have a little narrow balance beam. As long as we can be on the beam, we can be OK... but it's really easy to step off that beam.*

Some of the participants mentioned having felt depressed or having been diagnosed with depression but they were more likely to refer to burnout, a period of extreme fatigue, lack of focus, low mood and executive dysfunction following periods of life stress. Burnouts could last for months and were debilitating; the resulting exhaustion was felt to make self-help strategies difficult to research, implement and enjoy.

> *I've had big patches of extremely low energy... lethargic, not engaged, miserable. I don't believe its depression in the classical sense, it's sort of an autistic symptom.*

All the participants talked about sleep difficulties and the effects of limited sleep. One participant talked about how all her self-care strategies were vital in helping her to sleep, and that if she couldn't sleep, she felt in permanent survival mode, trying to manage sensory issues, meltdowns, rage, depression and feeling out of control. Another noted that in times of stress when she needed to process a lot of information, she might need eleven or twelve hours of sleep in one go. Participants were, on the whole, resigned about sleep difficulties, something that they would always have to manage due to other stresses in their lives.

> *Insomnia is such a huge problem, just like a huge issue for us... we're having it because we are overstimulated and there's too much activity so the brain can't turn off*

While none of the participants talked specifically about sleep management strategies there was a general consensus that when a combination of self-care strategies was put in place to alleviate anxiety, sleep challenges were minimised; and equally, when sleep quality and quantity was good, less anxiety was experienced.

Subtheme 1.3 physical health: digestive problems and chronic pain

> *My big health things are pretty much all connected. They're all in the Venn diagram of autism!*

All the participants talked about physical health challenges such as digestive disorders, pain, hypermobility, migraines and autoimmunity.

Most of the participants mentioned having had experienced serious digestive challenges such as irritable bowel syndrome, coeliac disease and small intestine bacterial overgrowth and, due to not having been given appropriate support from their doctors, had needed to put the research in themselves from books, the internet and from self-experimentation to identify foods that they were sensitive to. In turn, they linked digestive issues with other challenges such as anxiety, migraines and eating disorders.

> *I was doubled over with pain... now, with my lens of autism I see that it was very closely related to anxiety.*

Chronic pain was also a feature of daily life for many of the participants due to challenges such as temporomandibular joint pain (TMJ), Ehlers-Danlos syndrome (hypermobility type) (EDS) and chronic muscle pain. Often these conditions had not been recognised until an identification or diagnosis of autism was in place but networking with other autistic people had given the terminology and understanding to interpret long-term symptoms.

Theme 2: individual health practices

> *It should be [doctors'] first clue when we show up with a binder! I'm "what about this study? And there's this, and this!"*

This theme refers to how the participants researched, adapted and developed health-supportive strategies for specific needs, that they implemented for themselves. All the participants had researched diet, supplementation, exercise and movement practices. While some had shown a strong interest in health practices throughout their lifetime this commitment had often increased since diagnosis or identification.

Rather than relying on prescribed recommendations or generic advice from professional sources they generally preferred to learn about these practices for themselves so that they had a full and detailed understanding of a health system before putting strategies into practice. In this way they were also able to work around their own needs and preferences.

> *You can take ownership of it [listening to other's experiences of using strategies] that way. Often, it's difficult to do that when somebody comes in and says, "you should do this; you should do that." It can feel quite "oh no, that won't suit me at all" and so you miss out on the good bits.*

The process of learning about health practices tended to be immersive, gleaning a wealth of information from varied books, medical journals, websites and podcasts, and the need to understand every part of a health system or philosophy. All the participants described their learning processes, demonstrating a strong interest in self-education and 'thinking outside the box.'

> *I dive in and sort of absorb all the details there are to know about a subject... there's this sort of sea of details and out of the details, things start to come up and then they start to connect. You start to see the lines between the connections and then, all of a sudden, it builds up.*

Many described this learning as an enjoyable and intense process, learning as much as they could on and around a subject and then making connections for themselves.

> *I really love going down rabbit holes you know? My head is in books and articles, I'm listening to podcasts... Whatever material I can get my hands on... just connecting all the dots.*

While most had specifically developed structured dietary practices (most commonly avoiding a combination of processed foods, dairy, caffeine, gluten, and/or sugar) to address health challenges such as digestive issues and/or chronic pain, they had also noticed wellbeing improvements in terms of sleep, energy, focus and co-ordination; and reductions in sensory challenges, anxiety and agitation. One participant explained how trial and error had taught her that eating her favourite food, pizza, would increase her chances of a meltdown, either that day or the next, and would leave her feeling low and unwell for days afterwards. As a result, whether or not she ate the pizza became an informed choice.

While executive dysfunction, sensory issues or fatigue made food preparation difficult for some, all the participants tried to base their meals around unprocessed foods such as fresh meat or fish and vegetables; with some also growing their own vegetables, fermenting foodstuffs and making bone broth. These practices were based on the research participants had undertaken but had also involved self-experimentation to measure the effects on their own health and wellbeing levels.

> *Trying to eat right for me is basically not refined foods, eating real food. Vegetables, fruits, I've started adding fermented foods when I read about the gut biome and how much that has to do with our transmitters. For me this really helps.*

Three of the participants had taken or were taking courses in herbs or supplementation and were confident in self-prescribing, but targeted herbs and supplements were also used by some of the others, particularly for mental health and hormone support. Four of the participants also mentioned taking magnesium sulphate baths as a supportive strategy.

> *I have got a toolkit, specific herbs that are to do with regulating my nervous system. And I've specific ones to do with if I have a meltdown... I've got things lined up that I can use, that I've worked out and tested.*

Commonly cited regular movement practices such as martial arts, yoga, walking and strength training were generally utilised to lessen anxiety, improve co-ordination, proprioception and mobility; reduce chronic pain, improve sleep and stave off burnout.

> *As I've been getting stronger, I find that I'm more confident. In moving into spaces like going into a store I just feel myself in my body more. I'm more comfortable in my body.*

Participants noted that part of the draw of such movement practices meant that they could be carried out alone, without the additional strain of socialising. However, those that attended classes were keen to point out that this was only possible when instructors created a supportive and calm environment, allowing them to go at their own pace and tailor movements that might otherwise cause pain or discomfort.

> *That built trust in me, so I felt I can go, and I can push myself because I know he won't push me further than I'm comfortable.*

Theme 3: individual environments

> *How my autism affects me is dependent on my environment*

While the interviews were structured to explore how more traditional self-managed strategies such as diet and exercise were used, all the participants described how finding or creating beneficial environments, routines and time alone was crucial for their health and wellbeing. In order to counteract fatigue and overwhelm from daily socialising and camouflaging; sensory triggers, and types of day-to-day or work patterns that felt difficult and unnatural, participants described how they needed regular time where they had control over their own environment. This control might be through being alone, by following self-created routines, or by being in nature where sensory information was felt to be less triggering and more soothing.

> *This is OK, a survivable [work] mask. But when I get home I'll be like [waves] to husband, headphones in, binaural beats in, I have a nap.*

All participants stressed how regularly spending time alone was vital to recover from the stresses of socialising and to generate resilience for times when socialising was necessary or desired. This time might be spent reading, having a creative practice, meditating, napping, or just 'being'. The emphasis was on not having to communicate with anybody else for a time.

> *I loved the silence, I just loved lying in bed in silence.*

Being alone also gave some of the participants a chance to follow their own self-established routines, which were felt to reduce the amount of mental processing they had to do and give a sense of internal peace. Morning routines and after-work routines were described in detail by some, and included washing and dressing routines, eating the same breakfast each day, and daily movement or exercise routines. One participant mentioned a preference for sameness, another that following her routine gave her a sense of peace, another that practising her own programme helped reassure her that she was coping.

> *All my little schedules were very much to do with planning it myself, doing it on my own, not doing what anyone else was doing.*

All participants sought out places in nature where they could retreat to frequently, with two participants moving to the countryside in order to escape overwhelm from the sensory bombardment of living in urban environments; and another retreating to a solitary outdoor existence for several weeks. Those that had moved house felt calmer, more in control and more productive in rural environments with less chance of socialising, less noise and more control over their day-to-day life. Those that still lived in urban environments thrived on the 'buzz' and convenience but still needed regular access to escape routes in green or coastal environments for a few hours or days.

> *I have this one favourite tree, and I'm going to sit under it for a few hours... I think that would help all of us. To remember that it doesn't always have to feel bad to hear everything and see everything and smell everything.*

The home environment was talked about as being crucial to the experience of being autistic. Half of the women noted that having control of the environment around them supported them in feeling less disabled.

> *I build my life around how I work. So, being autistic, when I am in my safe environment, is not in any way a negative thing because I don't feel any of the problems that it can cause.*

Commonly mentioned negative environmental influences included noises generated by other people (talking, eating, breathing, typing etc.), traffic or electric humming; electric lighting and extremes of temperature. These influences were felt to cause distress and fatigue due to them having to be continually processed and interpreted.

> *I'm very perceptive, I see patterns, I'm always thinking and connecting the dots. It's just that, put me in a social environment and there are too many dots.*

Theme 4: creativity and stimming

> *Creativity is probably one of the most important things... I will usually be doing at least one thing a day... It really helps bring my brain back. Tangle it into one thing so I'm not all over the place.*

All the participants discussed how having a creative practice was important to them. Traditionally recognised creative practices such as painting, writing, dancing and playing an instrument were mentioned but participants also talked about how creative projects which involved creative thinking and/or learning skillsets from scratch such as computer coding, interior design and building; and planning social projects were beneficial for health and wellbeing. While the range of creative practices was wide, the benefits related were similar: grounding, relaxing, focussing, resetting.

Participants tended to be completely absorbed by the process. One participant noted that creativity helped her to accept and integrate her autistic differences; another that it settled her, another that it was compulsive.

> *The emotional pain was so bad inside that the paper wasn't enough for me. I got charcoal and chalk and I wrote across the whole wall of the stairs, poetry, imagery. It was just across the whole wall.*

Using creative practices appeared to be key for managing fatigue and overload, mental health and physical health inasmuch as mitigating anxiety lessened digestive symptoms and chronic pain. Such creative practices were frequently (although not exclusively) combined with time alone, became part of daily routines and might be the focus of the participants' livelihoods.

Stimming was also mentioned by some of the participants in similar terms to creative practices, in that they needed to be done frequently in order to help ground, relax or focus. In some cases, the line between stimming and creative practices appeared to be blurred, such as when practising a musical instrument or doing repetitive craftwork. Sometimes stimming was used unconsciously and sometimes it was an intentional, planned practice, particularly since diagnosis or identification.

> *I have stim jewellery... I very intentionally give myself these things to have and to touch and I'm finding that there's this certain synergistic factor where when you let yourself stim... it's almost like a reset.*

Both creative practices and stimming were used to alleviate feelings of overwhelm and sensory overload; and were also felt to support and magnify positive moods, thus enhancing overall feelings of wellbeing.

Discussion

Health and wellbeing outcomes for autistic women, while traditionally overlooked, have received an increasing amount of attention in recent years. However, this is the first study designed to explore how autistic women self-manage their own health and wellbeing. The study was designed to explore how a sample of late-diagnosed autistic women had actively sought out and practiced nutrition and/or other lifestyle strategies in order to manage their health and wellbeing. Analysis of the data from the six, qualitative interviews generated four main themes which explored autistic self-awareness, the development of appropriate strategies, control over the environment and having a creative practice.

An identification or diagnosis of autism was pivotal for the all the participants in understanding their health and wellbeing needs. This finding is consistent with Lory's assertion in Spectrum Women (Cook & Garnett, 2018): that autistic people can find assessing and managing their own wellbeing difficult because they often have different needs to non-autistic populations; but that evaluating a sense-of-self is vital in implementing self-care routines (Lory, 2018). Some of the participants described how losing a blame-and shame mind-set was instrumental in developing holistic practices. This was also reported in Leedham *et al.*'s findings while exploring the experiences of women receiving a late diagnosis of autism: that a diagnosis gave many of the women an increased sense of agency, permission to meet their own needs and to make adaptions which caused them to experience less anxiety and depression. (Leedham *et al.* 2019).

Similarly, Webster and Garvis's study shows how autistic self-awareness can be helpful in overcoming obstacles, achieve desired outcomes and experiencing success (Webster & Garvis, 2017). These benefits are evident in the health and wellbeing improvements experienced by participants when practising the strategies that they developed for themselves. While they were unaware that they were autistic they found it difficult to prioritise practices that enabled them to feel well, such as spending time alone and incorporating creative practices into their daily lives. Self-awareness gave them the knowledge and validation they needed to develop practices that positively impacted their health and wellbeing.

Autistic women have statistically higher rates of psychiatric and medical conditions than non-autistic populations and autistic men. However, health services for such conditions, where available, are under accessed by the autistic population. Recent research has been designed to understand barriers to health-care access and exploring how the needs of autistic people might be better met. In the meantime, autistic women, such as those in the current study, have needed to research and develop self-managed strategies to suit their own needs. The motivation behind this phenomenon could be understood as meeting three main, intrinsic needs as identified by Deci and Ryan (Ryan & Deci, 2000); those of competence, autonomy and relatedness. The participants became competent in researching and developing strategies that positively impacted their health and wellbeing and so take ownership of their health and wellbeing; and they were able to discuss and share these strategies with other autistic women. Meeting the needs of competence, autonomy and relatedness are described by Deci and Ryan as psychological necessities; as demonstrated in this study.

While the diagnostic criteria frames autistic 'traits' as deficits there is an argument for some of these deficits to be understood as benefits. For instance, many autistic individuals will experience highly restricted or perseverated fixated interests (American Psychiatric Association, 2013) which may be of benefit when learning about a subject of interest. Baldwin and Costley (2015) noted that just under half of 82 ASD adult female participants surveyed were undertaking some form of education or study at the time and that this implicated a group with a strong interest in and aptitude for learning. Similarly, Leedham *et al.*'s (2019) findings in which research and connections provided relatable information and autonomy, many of the participants found learning about their health within the concept of autism an intense and empowering process.

Demonstrating high performance on tasks requiring detail-focussed processing has been acknowledged as an autistic characteristic (Happe & Frith, 2006). The participants had invested time and effort in learning about health and wellbeing in some depth. Firstly, learning about psychological and physiological systems; therapeutic interventions and autism itself was necessary. Secondly, the participants integrated these concepts with their knowledge of how they, as individuals, were impacted by autism and co-occurring conditions such as fatigue, executive dysfunction, chronic pain and sensory sensitivities. Finally, they developed practices that fit their needs and requirements. For some, this route was demonstrated in how they had learned about the impact of diet on heath; combined this knowledge with their own experiences of anxiety and burnout; and then found ways to prepare food that didn't trigger sensory sensitivities or require energy resources that they didn't have. For others, fatigue and pain might prompt research on the endocrine system, which then lead to self-experimenting with food and supplement combinations until an improvement in overall health and wellbeing was reached.

The participants talked of needing time alone and for following self-created routines, particularly in times of stress. Similar findings were found in Milner *et al.*'s exploration of the female experience of ASD in which the participants needed alone-time and routines so as not to become overwhelmed (Milner *et al.* 2019) and Muller *et al.*'s study on social challenges and supports from the perspective of autistic adults, in which participants stressed that time spent alone was a legitimate coping strategy (Muller *et al.* 2008).

The participants found that the effects of spending time alone and/or in nature and following routines (limiting the effects of 'decision fatigue') regulated feelings of stress and anxiety. The diagnostic criteria outline hyper or hypo reactivity to sensory inputs, and to an insistence on sameness (American Psychiatric Association, 2013). These behaviours or traits may be better framed as natural responses to stress. Sensory sensitivities can cause pain and distress, and a lack of, or change to a routine can be highly destabilising for autistic people. A growing body of evidence suggests that autistic people may have irregular patterns of cortisol release. Frequent release of cortisol, a regulatory hormone implicated in arousal or stress patterns, can have deleterious implications for other physiological processes such as immunity, metabolism, wound healing, digestion and sleep. When people do not have the ability and freedom to moderate their environment both mental health and physical health is negatively impacted.

Beardon (Beardon, 2017) offers the model *autism + environment = outcome* to explain how the autistic individual is impacted by the environment. An autistic person in a chaotic environment filled with sensory or social triggers may find themselves in a meltdown or shutdown situation. Meanwhile, that same individual might thrive in an environment that didn't trigger a stress response. Beardon's model was reflected in how the participants described their health and wellbeing needs for natural spaces, creative spaces, time alone and spaces where they could be themselves without masking. When they were not able to regularly access these states then meltdowns, burnout and physical ill-health were likely.

Studies of benefits of creative therapies, such as regulating emotions, non-verbal communication and calming of the sympathetic nervous system are largely focussed on autistic children and autistic adults with high support needs. However, self-directed creative practices may also be valuable for other autistic individuals. In line with the Monotropic theory of autism (Murray *et al.* 2005) which describes how the monotropic mind is aroused by very few interests at any time but requires more processing resources, it may be that the level of absorption in one, focussed activity required is therapeutic in itself, blocking out other distractions.

While stimming is generally recognised as using repetitive movements or actions, participants did not always see stimming practices and creative practices as exclusive to each other, particularly if they elicited a regulatory sensory experience or, as with practising a musical instrument, required repetitive movement rather than creative thought. Some of the participants described the process of stimming almost as an antidote to masking, and others as something they did publicly to more easily process the environment that they were in. This is consistent with findings in recent participatory research that identified stimming as a useful coping mechanism; a self-regulating function in situations when the individual experienced overwhelming environments, sensory overload, 'noisy thoughts' or uncontainable emotions (Kapp *et al.* 2019).

Strengths and limitations

Whilst this study contributes to improved understandings of how late-diagnosed autistic women develop and self-manage strategies to improve their health and wellbeing, some methodological factors limit generalisability of the findings. Firstly, the small sample makes it difficult to explore how ethnicity, social status, additional disabilities or background might affect findings. Recruiting a larger sample size may better reflect the female autistic population and give further insights into how they self-manage their

health and wellbeing. Secondly, the criteria, in specifying participants who actively managed health and wellbeing strategies necessitated a recruitment bias. Although findings may not be representative of all late-diagnosed autistic women, the themes raised suggest an interesting basis for future research. Additionally, it is not certain whether similar findings would arise from interviews with autistic adults who are not female; future research may wish to consider whether the findings are transferable to other genders.

Few studies to date have explored autistic women's experiences and even fewer have matched female autistic interviewers with female autistic participants. In terms of reflexivity, future research may benefit from an increase in matching the neurotypes of interviewers and interviewees. Firstly, because there is likely to be increased understanding of what might trigger a stressful response for participants, and secondly because of subtle differences in communication styles between autistic and non-autistic people (Milton, 2012).

In order to mitigate participant stress leading up to the interview, a participant guide outlined key questions so that, where desired, the participants could plan their answers in advance. Some of the participants used the questions in the guide to prepare themselves and 'script' to an extent and others just to refer to the administrative details; however, all of the participants appreciated the provision of the guide. One participant stated that in past interviews with people who were not autistic she had she had tried to plan her answers in advance even without a guide which added a level of anxiety; but knowing I was also autistic meant she trusted the process and was comfortable answering questions 'off the cuff'.

Verbal and non-verbal communication between autistic people may be more effective than between autistics and non-autistics (Milton, 2012; Crompton & Fletcher-Watson, 2019). Participants noted that they were relieved being able to use a 'short hand' in their answers, knowing that I would be likely to empathise with certain concepts and understand vocabulary not often used outside autistic culture. Additionally, some mentioned that they felt comfortable stimming, not trying to make eye contact and not worrying about falling into more natural speech patterns.

Implications

The discussions highlighted important themes about how autistic women self-manage their health and wellbeing, which have several potential implications. Firstly, that a timely diagnosis of, or identification of autism is crucial in order for autistic women to

understand and appreciate that their health and wellbeing needs may not reflect those of the general population.

Secondly, some deficit criteria could be reframed as strategies used by autistic individuals to support their health and wellbeing, such as spending time alone, following routines and the avoidance of sensory triggers. This could have clinical significance in terms of the diagnostic procedure and the support given to autistic people. I anticipate that a participatory research approach would be suitable in exploring how health and social services might support individuals from this standpoint; an area which a few independent autistic-led teams and organisations are already focussing on.

Finally, autistic women have explored a wealth of health and wellbeing strategies that improve and enrich their lives. While the development of these strategies was undertaken by the individuals, the knowledge and support offered from other autistic women through online communities was invaluable. On the basis of this I plan to create an online resource where autistic women can share their experiences and strategies in the future.

Conclusion

The purpose of this study was to explore how late-diagnosed autistic women manage their health and wellbeing. All the participants demonstrated detailed research into their own conditions and showed similar self-managed strategies to alleviate these. A striking finding was that spending time alone, seen as a deficit in diagnostic criteria (American Psychiatric Association, 2013), was a vital strategy for the participants in understanding and managing their own health and wellbeing. When time spent alone enables an individual to think and 'be'; to self-educate about health, exercise, follow helpful routines and soothe an overstimulated nervous system with creative and stimming practices, then it is difficult to see how this particular coping strategy can be seen as a persistent deficit, any more than meditation, for example, could be described in the same terms.

While there was a lack of confidence in services offered by health organisations, participants felt empowered from owning their identification or diagnosis of autism and using that knowledge to research and develop their own strategies. Until recently, autistic women's voices have not been heard and so the participants were keen to share their strategies in the hope that future research and practice might be influenced; improving the lives of those in the autistic population. It is my hope that these

qualitative accounts of autistic women's experiences and self-developed strategies contributes to a wider understanding of how autistic individuals' health and wellbeing may be better supported.

Appendices

Appendix A: Language

While person first language (i.e. person with autism) is often used within healthcare settings I have opted to use identity first language (i.e. autistic person) as this is the most highly endorsed preference by the autistic community (Kenny *et al.* 2016) and is preferred by myself, an autistic person.

As autistic-led research tends not to consider autism to be either a disorder or a condition I do not refer to the terms Autism Spectrum Disorder (ASD) and Autism Spectrum Condition (ASC) unless I am citing a paper that does so.

The terms Asperger's Syndrome (AS) and High Functioning Autism (HFA) have historically been used to describe a subset of autism in which the individual is more readily able to use verbal communication skills and tends to require less support than those referred to as having classic autism or severe autism. These terms are no longer used in clinical diagnoses as an autistic individual's support needs are necessitated by co-occurring disabilities, physiological conditions and psychological conditions, and may fluctuate during their lifespan.

Appendix B: Codes

- Managing my diet and supplements
- Beneficial environments
- Having a sensitive nervous system
- Depression / anxiety
- Intuition
- Disassociation / alexithymia
- Extensive research
- Needing to manage sleep
- Masking / camouflaging
- Fatigue / overload
- Routine
- Spending time alone / withdrawing
- Creativity
- Accepting and understanding my autism
- Stimming
- Meditation / visualisation / breathing practice
- Sensory sensitivities
- Chronic pain
- Exercise and movement
- Digestion

Appendix C: Map of Potential Themes

Not understanding autism

Masking

Disassociation

Anxiety

Digestion

Depression

Insomnia

Fatigue & overload

Pain

Understanding autism

Beneficial environments

Stimming

Routine

Creativity

Alone time

Reset, clear, calm, soothe

Developing practices

Diet and exercise

Learning styles
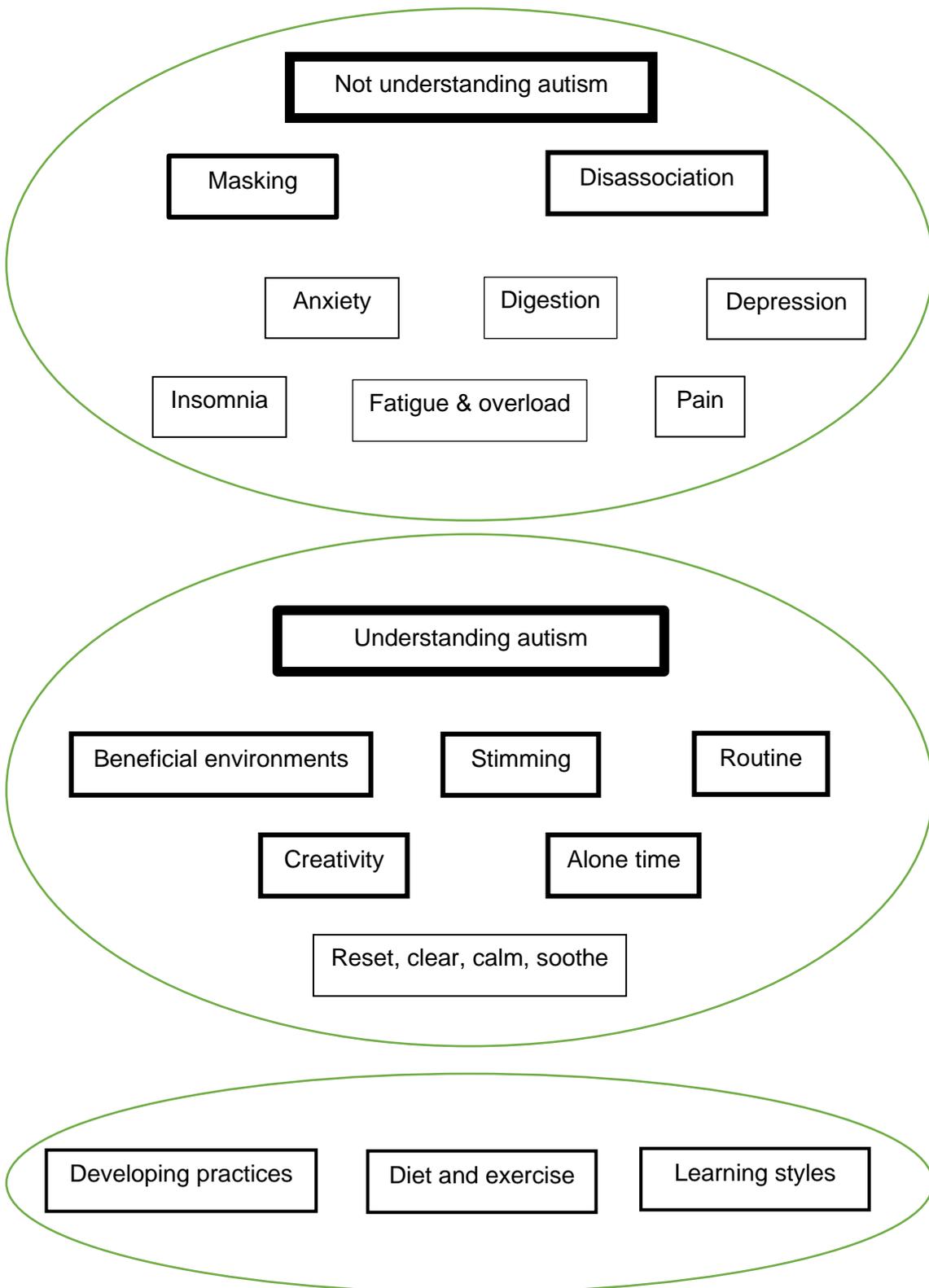
Appendix D: Research Ethics Form

APPLICATION FOR ETHICAL REVIEW OF RESEARCH INVOLVING HUMAN PARTICIPANTS

This application form should be completed by members of staff and PhD/ Prof Doc students undertaking research which involves human participants. Undergraduate and Masters level students are required to complete this application form where their project has been referred for review by a supervisor to a Faculty Research Ethics Committee (FREC) in accordance with the policy at **http://www1.uwe.ac.uk/research/researchethics**. For research using human tissue, please see separate policy, procedures and guidance linked from **http://www1.uwe.ac.uk/research/researchethics/policyandprocedures.aspx**

Please note that the process takes **up to six weeks** from receipt of a valid application. **The research should not commence until written approval has been received from the University Research Ethics Committee (UREC) or Faculty Research Ethics Committee (FREC).** You should bear this in mind when setting a start date for the project.

APPLICANT DETAILS

Name of Applicant*	Florence Neville		
Faculty	FET	Department	
Status: Staff/PG Student/ MSc Student/ Undergraduate	MRes student	Email address	Florence2.Neville@live.uwe.ac.uk
Contact postal address	25 Southside, Congresbury BS49 5BS		
Name of co-researchers* (where applicable)			

*This form must include the name of the UWE Project Manager (normally the budget holder and PI)

FOR STUDENT APPLICANTS ONLY

Name of Supervisor/Director of Studies	Stuart McClean
Detail of course/degree for which research is being undertaken	MRes Social Research (Health and Wellbeing)
Supervisor's/Director of Studies' email address	Stuart.Mcclean@uwe.ac.uk
Supervisor's/ Director of Studies' comments	***Please note the supervisor must add comments here. Failure to do so will result in the application being returned.***

For student applications, supervisors should ensure that all of the following are satisfied before the study begins:

- The topic merits further research;

- The student has the skills to carry out the research;

- The participant information sheet is appropriate;

- The procedures for recruitment of research participants and obtained informed consent are appropriate.

PROJECT DETAILS

Project title	Autistics, autodidacts and autonomy: exploring how late diagnosed autistic women in the UK and US self-manage their health and wellbeing through dietary and other lifestyle measures.		
Is this project externally funded?	~~Yes~~/No		
If externally funded please give PASS reference			
Proposed start date for the research	14/5/2019	Anticipated project end date	12/9/2019

Fieldwork should not begin until ethics approval has been given

DETAILS OF THE PROPOSED WORK

1. Aims, objectives of and background to the research
This should provide the reviewer of the application with sufficient detail to allow them to understand the nature of the project and its rationale, and the ethical context, in terms which are clear to a lay reader. Do not assume that the reader knows you or your area of work. You may provide a copy of your research proposal in addition to completing this section. Please try to keep within 500 words.
It has been my personal observation that many autistic women who have not received an autism diagnosis until adulthood have sought relief for multiple co-occurring health and wellbeing challenges in the form of dietary or lifestyle strategies. While autism itself is not a curable condition, successful management of physical and mental health conditions can help alleviate challenges commonly associated with autism such as chronic anxiety, sensory sensitivities, sleep disorders, digestive disorders and chronic pain. Such distressing conditions may have existed for an individual a long time before autism is identified or diagnosed, leading to a sense of impairment or disablement. When these challenges are reduced the experience of being autistic changes; autism itself can feel less disabling   While the physical and mental effects and the comorbidities of autism are well established there is a gap in the academic literature concerning how adult autistic females experience and self-manage their own conditions. There is a need to generate evidence of the nutrition and lifestyle practices that autistic women develop to self-manage their health and wellbeing. The proposed study will explore common themes in these nutrition and lifestyle practices within a perspective somewhat aligned with critical theory; holding that autistic

values and experiences shape reality in the field of autistic health and wellbeing. In turn, this approach may contribute towards a greater understanding of health and wellbeing autonomy for autistic individuals across ages and genders.

I am particularly interested in this research area as I have observed first-hand how my own autism-related challenges have been lessened with nutrition and lifestyle strategies including reductions in chronic anxiety, depression, social anxiety, insomnia, digestive distress, thermoregulation, joint pain, sensory sensitivities, brain fog and compromised immunity. Meanwhile, my own professional health and nutrition coaching practice with autistic individuals is based on the framework that Autism + Environment = Outcome (Beardon, 2017); that while autism itself is a fixed state, the environment, both external and internal, of the autistic person can be improved to create best possible outcomes in terms of health and wellbeing for that individual.

The aims and objectives of this study are to contribute to knowledge about the health and wellbeing experiences of autistic women by interviewing late-diagnosed autistic women to explore:

1. What dietary and lifestyle self-managed strategies have been used by late-diagnosed autistic women to improve their health and wellbeing?
2. Which (if any) of these strategies did they feel changed their experience of being autistic?
3. To explore if there are any differences between how autistic women from the UK and autistic women from the US self-manage their health and wellbeing?

2. Research methodology to be used

You should explain how you plan to undertake your research. A copy of the interview schedule/ questionnaire/observation schedule/focus group topic guide should be attached where applicable.

On completing a review of existing papers in autism research journals on the themes listed above (medical approaches, Critical Autism Studies and the lived experiences of autistic women) and books I will carry out in-depth qualitative interviews with 8 – 10 late-diagnosed autistic women in the UK and the US asking what dietary and lifestyle interventions they have voluntarily made to improve their wellbeing (both before and after diagnosis) and which of these they found improved their experience of being autistic, particularly in the areas of depression, anxiety, sensory sensitivities and day-to-day functioning.

Rather than beginning the study with set themes in mind (a priori) I will transcribe and make an initial analysis of each interview before the next takes place as these themes will help to generate additional questions. However, my existing understandings of the research area mean that I anticipate certain thematic links between particular restrictive diets and symptomology patterns; and moderating sensory home/work environments and anxiety levels.

In order to improve reliability of data analysis a selection of transcripts will be analysed by both myself and my supervisor to reflect on coherence, consistency and clarity of themes.

3. SELECTION OF PARTICIPANTS

You must indicate if any of the participants in your sample group are in the categories listed. Research involving adult participants who might not have the capacity to consent or who fall under the Mental Capacity Act must be reviewed either by an NHS Research Ethics Committee or the [National Social Care Research Ethics Committee](#).

If your proposed research involves contact with children or vulnerable adults, or others of the specified categories below, you may need to hold a valid DBS check. Evidence of a DBS check should take the form of an email from the relevant counter signatory confirming the researcher has a valid DBS check for working with children and/or vulnerable adults. It is the responsibility of the applicant to provide this confirmation.

Members of staff requiring DBS checks should contact Human Resources hr@uwe.ac.uk.

*DBS checks for students are usually organised through the student's faculty, but students in faculties without a DBS counter signatory should contact **Marisa Downham** (Marisa.Downham@uwe.ac.uk).*

Will the participants be from any of the following groups? *('x' as appropriate)*

☐   Children under 18*
☐   Adults who are unable to consent for themselves
☐   Adults who are unconscious, very severely ill or have a terminal illness
☐   Adults in emergency situations
☐   Adults with mental illness (particularly if detained under Mental Health Legislation)
☐   Prisoners
☐   Young Offenders
☐   Healthy Volunteers (where procedures may be adverse or invasive)
☐   Those who could be considered to have a particularly dependent relationship with the investigator,   e.g. those in care homes, medical students
☐   Other vulnerable groups
☒   None of the above

* If you are researching with children please provide details of completed relevant safeguarding training.

If any of the above applies, please justify their inclusion in this research.

4.	**Please explain how you will determine your sample size/recruitment strategy, and identify, approach and recruit your participants. Please explain arrangements made for participants who may not adequately understand verbal explanations or written information in English**

In this section, you should explain the rationale for your sample size and describe how you will identify and approach potential participants and recruit them to your study.

I will be running 8-10 interviews. While this number will allow for a range of participant experiences, perspectives and practices, I expect to see many common themes generated and do not anticipate that further interviews would substantially increase the breadth of data required to generate and explore common themes.

Recruitment would be via snowballing through my own autistic networks to reach a homogenous demographic. I have a number of interviewees in mind already and will ask them for additional potential participant contacts.

The inclusion criteria:

- Participants to have gained a formal diagnosis of autism or Asperger's in adulthood or to self-identify as autistic
- Participants to have been assigned female gender at birth or self-identify as female
- Participants to have actively sought out and practiced nutrition and/or other lifestyle strategies in order to self-manage their health and wellbeing

All participants will understand verbal explanations and written information in English

5.	**What are your arrangements for obtaining informed consent whether written, verbal or other? (where applicable, copies of participant information sheets and consent forms should be provided)**

Informed consent is an ethical requirement of most research. Applicants should demonstrate that they are conversant with and have given due consideration to the need for informed consent and that any consent forms prepared for the study ensure that potential research participants are given sufficient information about a study, in a format they understand, to enable them to exercise their right to make an informed decision whether or not to participate in a research study.

You should describe how you will obtain informed consent from the participants and, where this is written consent, include copies of participant information sheets and consent forms. Where other forms of consent are obtained (eg verbal, recorded) you should explain the processes you intend to use. If you do not intend to seek consent or are using covert methods, you need to explain and justify your approach. Please consider carefully whether or not you need to seek consent for archiving or re-use of data.

Information sheets and consent forms (which will be transparent and clearly defined in terms of responsibility and accountability) will be emailed in advance of scheduled interviews. Participation in interviews is voluntary and all participants will be given the opportunity to ask questions before giving informed consent.

6.	**What arrangements are in place for participants to withdraw from the study?**

Consent must be freely given with sufficient detail to indicate what participating in the study will involve and how they may withdraw. There should be no penalty for withdrawing and the participant is not required to provide any reason.
Please note: allowing participants to withdraw at any time could prejudice your ability to complete your research. It may be appropriate to set a fixed final withdrawal date.

Both the information sheet and the consent form make clear that participants are free to withdraw at any point with no requirement for a reason given.

7.	If the research generates personal data, please describe the arrangements for maintaining anonymity and confidentiality (or the reasons for not doing so)

You should explain what measures you plan to take to ensure that the information provided by research participants is anonymised/pseudonymised (where appropriate) and how it will be kept confidential. In the event that the data are not to be anonymised/pseudonymised, please provide a justification.

Please refer to the [UWE Data Protection Guide](#).

All data collected will be treated sensitively, with full confidentiality and anonymity maintained.
Interviews will be audio-recorded and will be destroyed as soon as I have completed the transcripts. All information used will be treated as fully confidential and I will ensure anonymity of identity and identifying information. If extracts of the interview transcripts are quoted then pseudonyms will be given. All participant data and the transcripts themselves will also be destroyed one year after completion of the study.

8.	Please describe how you will store data collected in the course of your research and maintain data Security and protection.

Describe how you will store the data, who will have access to it, and what happens to it at the end of the project, including any arrangements for long-term storage of data and potential re-use. If your research is externally funded, the research sponsors may have specific requirements for retention of records. You should consult the terms and conditions of grant awards for details.

It may be appropriate for the research data to be offered to a data archive for re-use. If this is the case, it is important that consent for this is included in the participant consent form.

UWE IT Services provides data protection and encryption facilities - see
http://www.uwe.ac.uk/its-staff/corporate/ourpolicies/intranet/encryption_facilities_provided_by_uwe_itservices.shtml

Audio records will be destroyed once they have been transcribed. My transcriptions, to be stored on UWE Bristol OneDrive, will be anonymised. Access to the data will be limited to myself and my supervisor. A year after completion of the study all hard copies and electronic data will be erased

9.	What risks (eg physical, psychological, social, legal or economic), if any, do the participants face in taking part in this research and how will you AddRESS these risks?

Describe ethical issues related to the physical, psychological and emotional wellbeing of the participants, and what you will do to protect their wellbeing. If you do not envisage there being any risks to the participants, please make it clear that you have considered the possibility and justify your approach.

I do not envisage there being any risk to the participants and have stated this in the information sheet with the proviso that if talking about their autism and their health makes

them feel emotional, I will do whatever I can to mitigate this, including terminating the interview.

10. Are there any potential risks to researchers and any other people impacted by this study as a consequence of undertaking this Research that are greater than those encountered in normal day to day life?
Describe any health and safety issues including risks and dangers for both the participants and yourself (if appropriate) and what you will do about them. This might include, for instance, arrangements to ensure that a supervisor or co-researcher has details of your whereabouts and a means of contacting you when you conduct interviews away from your base; or ensuring that a 'chaperone' is available if necessary for one-to-one interviews. Please check to confirm you have carried out a risk assessment for your research ☐
I do not believe that there are any risks or dangers for either the participants or myself.

11. How will the results of the research be reported and disseminated?
Please indicate in which forms and formats the results of the research will be communicated.

(Select all that apply)

☐ Peer reviewed journal

☐ Conference presentation

☐ Internal report

☒ Dissertation/Thesis

☐ Other publication

☒ Written feedback to research participants

☐ Presentation to participants or relevant community groups

☐ Digital Media

☐ Other (Please specify below)

12. WILL YOUR RESEARCH BE TAKING PLACE OVERSEAS?
If you intend to undertake research overseas, please provide details of additional issues which this may raise, and describe how you will address these. Eg language, culture, legal framework, insurance, data protection, political climate, health and safety. Please also clarify whether or not ethics approval will be sought locally in another country.

Some of the interviewing will take place via video calling from my home in the UK to participants in the US. I do not anticipate that this will cause additional issues.

13. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of the Faculty and/or University Research Ethics Committee?
This gives the researcher the opportunity to raise any other ethical issues considered in planning the research or which the researcher feels need raising with the Committee.
Particular ethical consideration needs to be given to my prior experience and qualifications as a health and nutrition coach. It will be made clear to participants that I will not be giving any advice, looking for business or interviewing anyone who is or has been a client of mine. Failing to address these points could shift the power relationship between researcher and participant, put the key-informers that are helping to recruit in a difficult position, and potentially affect the data collected

CHECKLIST

Please complete before submitting the form
Please note: supporting documentation should include version numbers and dates

	Yes/No
Is a copy of the research proposal attached?	Yes
Have you explained how you will select the participants?	Yes
Is a participant information sheet attached?	Yes
Is a participant consent form attached?	Yes
Is a copy of your questionnaire/topic guide attached?	No
Have you described the ethical issues related to the well-being of participants?	Yes
Have you described fully how you will maintain confidentiality?	Yes
Have you included details of data protection including data storage?	Yes
Where applicable, is evidence of a current DBS (formerly CRB) check attached?	n/a
Have you considered health and safety issues for the participants and researchers?	Yes

DECLARATION

The information contained in this application, including any accompanying information, is to the best of my knowledge, complete and correct. I have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my obligations and the right of the participants.

Principal Investigator name	Florence Neville
Signature	Florence Neville
Date	20/5/2019
Supervisor or module leader name (where appropriate)	Stuart McClean
Signature	
Date	

The signed form should be submitted electronically to Committee Services: researchethics@uwe.ac.uk and email copied to the Supervisor/Director of Studies where applicable together with all supporting documentation (research proposal, participant information sheet, consent form etc).

For student applications where an electronic signature is not available from the Supervisor we will require an email from the Supervisor confirming support.

Please provide all the information requested and justify where appropriate.

For further guidance, please see http://www1.uwe.ac.uk/research/researchethics (applicants' information)

Appendix E: Participant Information and Consent Form

Autistic women and how they self-manage their health and wellbeing

Participant Information

You are being invited to take part in a research study. It is important for you to understand why the research is being done and what it will involve before you decide whether to take part. Please take time to read the following information carefully and discuss it with others if you wish. Please email me if there is anything that is not clear or if you would like more information.

Who am I?

I am Florence Neville. I am a late-diagnosed, autistic, post-graduate, female student with a background in health and nutrition. I am also a postgraduate student at the University of the West of England. It has been my personal observation that many autistic women who have not received an autism diagnosis until adulthood have sought relief for multiple co-occurring health and wellbeing challenges in the form of dietary or lifestyle strategies.

What is the purpose of this study?

While autism itself is not a curable condition, successful management of physical and mental health conditions may help alleviate challenges commonly associated with autism such as chronic anxiety, sensory sensitivities, sleep disorders, digestive disorders and chronic pain. Such distressing conditions may have existed for an individual a long time before autism is identified or diagnosed, leading to a sense of impairment or disablement. When these challenges are reduced, the experience of being autistic changes; autism itself may feel less disabling.

I would like to find out more about how late-diagnosed autistic women self-manage their own health and wellbeing and how this might change their experience of being autistic

Why have I been chosen?

I would like to interview you if:

- You gained a formal diagnosis of autism or Asperger's in adulthood or if you self-identified as autistic since adulthood

- You were assigned female gender at birth or if you self-identify as female

- You have actively sought out and practiced nutrition and/or other lifestyle strategies in order to self-manage your health and wellbeing

- You currently live in either the UK or the US

After each interview I will be asking participants to recommend and put me in touch with somebody else who fits the above criteria until I have reached my target of 8-10 interviews.

Do I have to take part? What will I have to do?

It is up to you to decide whether or not to take part. If you do decide to take part, I will ask you to sign a consent form and to retain a copy of this information sheet. We will then schedule a video interview (Skype, FaceTime or Whatsapp video) which will take no longer than one hour. During this interview I would like you to outline dietary and lifestyle strategies you have used to improve your health and wellbeing; and to describe for me how these strategies have impacted your experience of being autistic.

Interviews will be audio-recorded only so that I can transcribe them and destroyed as soon as I have completed the transcripts. All information used will be treated as fully confidential and I will ensure anonymity of your identity and identifying information. If extracts of your interview are quoted then pseudonyms will be given. The transcripts themselves will also be destroyed one year after completion of the study.

Please note that you are free to withdraw at any time and without giving a reason.

What are the possible benefits and risks of taking part?

The research will not benefit you directly, however the project hopes to find out information about self-management techniques that improve the lives of autistic people. We don't believe there are any risks to taking part in this study. There is a chance that you may feel emotional if talking about some of your memories around autism and health. Please let me know if this occurs and I will do whatever I can to mitigate any distress, including ending the interview. However, please note that my intention is to make the interview process both enjoyable and interesting. If you have cause for any concern or complaint, please contact my supervisor via the email address below.

How will my details be kept confidential?

Any information collected from you will be strictly confidential. Your personal details will not be shared with anyone outside of the study. Your interview will be made anonymous so you cannot be identified.

What will happen to the results of the research study?

The findings will not be known until the project has been written up as a project dissertation, after which any key findings will be sent to interviewees on request. These findings may be reported in professional publications.

Contact for Further Information

My contact details are: **My supervisor's contact details are:**

Florence Neville   Stuart McClean

University of the West of England, Bristol, UK
Florence2.Neville@live.uwe.ac.uk

University of the West of England, Bristol, UK
Stuart.Mcclean@uwe.ac.uk

Consent Form

Project: Autistic women and how they self-manage their health and wellbeing

Researcher: Florence Neville

Date: _____

I confirm that I have read and understood the participant information sheet for the above research project and have had the opportunity to ask questions.

I agree to take part in the above research project.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving reason and without there being any negative consequences. In addition, should I not wish to answer any particular question(s) or participate in any other way, I am free to decline.

I give permission for the interview to be audio-recorded and for the researcher's supervisor to have access to the researcher's transcripts of the interview. I understand that all data will be anonymised, that any quoted statements from myself will be given under a pseudonym; and that I will not be identified or identifiable in any of the data

I understand that the recordings will be destroyed as soon as they are transcribed and that the transcripts and all other data held will be held until the end of September 2020

_____ _____

_____

Name of Participant   Date   Signature

_____ _____

_____

Name of Researcher   Date   Signature

Appendix F: Participant Interview Guide

Autistic women and how they self-manage their health and wellbeing

Interview Guide for Participants

I know that some participants will feel anxious about being interviewed so I have put this short guide together to explain what will be happening on the day. If you have any questions please do not hesitate to email me in advance.

How will I prepare for the interview?

The interview will take place via a video link so you will need a phone, tablet or computer set up somewhere where you can be comfortable for up to an hour.

You will need to make sure that you have good access to WiFi and that the video link app (Skype, Whatsapp or FaceTime) we are using is open.

How will the interview start?

I will send you a text message (via the app that we are using) at the time we are scheduled to start, to check that you are ready. As soon as you message me back to let me know that you are happy to start I will video-call you.

We will spend a few minutes introducing ourselves and getting the volume levels right. Then, when we feel ready to start, I will let you know that I am going to turn my recording equipment on. Then we can start the interview

What questions are you going to ask me?

This won't be a formal question and answer interview! I would just like you to tell me, in your own words about the following:

- What does being autistic mean to you in terms of your health and wellbeing?

- Can you give me a brief outline of health and wellbeing challenges you currently have or have had in the past, such as anxiety, chronic pain, depression, digestive problems, fatigue, insomnia etc.
- What self-managed strategies – as opposed to products or activities that you have been prescribed by someone else - have you used to improve your health and wellbeing? (Such as diet, exercise, meditation, yoga etc.)
- How did you learn about these strategies?
- Do you feel that using any of these strategies changed your experience of being autistic?

I will prompt you when I would like you to tell me more about something or when it is time to cover another question.

How long will it take?

We will finish in under an hour. If you would like a break during the interview or would like to terminate the interview altogether, please let me know.

Contact for Further Information

My contact details are:

Florence Neville

University of the West of England, Bristol, UK

Florence2.Neville@live.uwe.ac.uk

Skype: florenceneville

Phone (for the video interview only): +44 7415 358605

Appendix G: Summary of Findings

I am a late-diagnosed autistic woman with a lifelong interest in health and wellbeing. For my Masters in Research study I wanted to explore how other late-diagnosed autistic women manage their own health and wellbeing. This is a summary of my findings. If you would like to read the findings in full please contact me on Florence2.Neville@live.uwe.ac.uk

Over the summer of 2019 I interviewed six women, diagnosed or identified as autistic (hereafter referred to as identified) as adults, about health and wellbeing self-managed strategies they used, how they had developed these strategies, and whether using the strategies changed their experiences of being autistic. Analysis of the data generated four main themes exploring: (1) understanding needs, (2) individual health practices, (3) individual environments, and (4) creativity and stimming. Whilst the findings may be of use to all autistic people and their supporters, all the women had an interest in health and wellbeing so we must be wary of applying the findings to autistic women or other groups.

Theme 1: understanding needs

An identification of autism enabled the participants to more effectively tailor how they supported their own health and wellbeing. Before this time, they had been more likely to try and 'keep up' with non-autistic women (a type of 'masking'); and have more difficulties recognising or expressing emotions or symptoms (commonly known as 'alexithymia'). Masking and alexithymia can lead to a lack of necessary support. An identification of autism led to greater understanding about challenges common for many autistic people such as (1) fatigue and overload, (2) anxiety, burnout and sleep problems and (3) digestive problems and pain.

An identification also enabled peer support from other autistic people (mostly online). This was beneficial in terms of (1) discussing and sharing information sources, (2) increased self-respect and decreased self-blame for exhaustion, stress and not being able to 'keep up', and (3) understanding that a problematic environment was often linked to the physical and mental health problems they were managing.

Theme 2: individual health practices

Participants preferred to learn about practices themselves, rather than relying on recommendations/advice from professional sources. This way they could understand how and why something might work and whether it would work for their own needs. All participants demonstrated a strong interest in self-education, tending towards immersive learning through books, medical journals, websites and podcasts. Participants reported using their pattern-finding abilities to make connections between different health theories, making for novel and deep understandings.

Most reported that in developing structured dietary practices, such as identifying and removing foods to which they were sensitive to, and basing meals around unprocessed foods, to address challenges such as digestive issues and/or chronic pain, they had noted improvements in sleep quality, energy, focus and co-ordination, and reductions in sensory challenges, anxiety and agitation. Some also researched and used herbs and supplements to support their mental health and hormones. Most participants practised a combination of martial arts, yoga, walking or strength training, mostly alone, but some also attended supportive classes. Benefits of these practices included: reducing anxiety, improving co-ordination and mobility; pain relief, increased confidence, improved sleep and avoiding burnout.

Theme 3: individual environments

Everyone described how they needed regular time when they had control over their own environment; through spending time alone, following routines, or being in nature. Time alone spent reading, creativity, meditating, napping, or just 'being' helped them recover from the stresses of socialising and generated resilience for future socialising. It also enabled the participants to create and maintain self-created routines which improved feelings of calm and control. Places in nature were used frequently to escape difficult social and sensory environments, reduce stress and fatigue and increase feelings of calmness, control and productivity. Home environments were very important, some said that control over their home made them feel less disabled. Options ranged from living somewhere remote, arranging things in a personal way, having established household routines and creating a pleasant sensory environment.

Theme 4: creativity and stimming

Creativity and stimming were used to reduce feelings of being overwhelmed by other people, or by sensory sensitivities as well as for encouraging and magnifying positive moods. Words used by participants included: grounding, relaxing, focussing, and resetting. Many participants talked about helpful strategies in terms of creative practices like painting, writing, dancing and playing an instrument; and projects that needed creative thinking such as computer coding, interior design and building; and planning social projects. Twirling pens, practising music, playing with fidget jewellery, dancing and other types of stimming were also helpful. Sometimes the participants stimmed without being aware of it, and sometimes stimming was a deliberate, planned practice. Rediscovering and learning about stim practices from other autistic people were seen as empowering and beneficial for health and wellbeing.

Glossary

Alexithymia: difficulty with recognising and communicating one's own emotions.

Autistic burnout: clinically referred to as autistic regression. Understood in the autistic community as when the mind and body temporarily shut down from exhaustion. This may last for several months and cause issues with cognition, executive function, fatigue and increases in meltdowns or shutdowns.

Disassociation: extreme stress or chronic pain can cause someone to feel a disconnect with their emotions, bodily sensations and/or the world around them.

EDS: common to many autistic individuals, Ehlers Danlos Syndrome (hypermobility type) is a connective tissues disorder that can cause conditions such as hypermobility, bruising, pain, poor wound healing and a range of digestive problems.

Executive dysfunction: difficulties in remembering information, deciding on or carrying out a plan of action; and self-managing impulse control.

Meltdown / Shutdown: involuntary responses to an overload of emotions or sensory sensitivities. Meltdowns tend to be explosive, while shutdowns refer to the individual shutting off from external input.

Proprioception: the perception of the position and movement of the body in relation to itself and the physical space around the individual.

Sensory sensitivities: many autistic people find that certain lighting, sounds, smells, tastes and textures can cause pain and distress.

Spoon Theory: a disability metaphor for explaining mental and physical units of energy that are used up for activities and need to be replaced throughout the day

Stimming: autistic people often employ repetitive movements or actions to soothe or focus, a process called stimming. Actions such as using stim toys, repetitive hand movements or rocking are generally considered to filter out sensory stimuli and relieve emotional distress.

TMJ: temporomandibular joint disorder, common for many autistics, can cause extreme pain and stiffness in the jaw.

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