

RUNNING TITLE: AUTISTIC EXPERIENCES OF RETIREMENT

**“Retirement is one hell of a change”: Autistic people’s
experiences of retiring**

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Abstract

Background: Limited research has examined autistic people's experiences of aging. While the significance of retirement in the context of aging has been highlighted by autistic people themselves, there is a dearth of research in this regard, with only one study focusing on the retirement experiences of one autistic man.

Methods: In this study, we conducted semi-structured interviews with eight older autistic people (mean age = 63 years, range = 56 – 70 years) who had retired or semi-retired in the last 10 years, and four who were planning to retire in the next five years. We aimed to generate some of the first insights regarding autistic people's retirement experiences. We analyzed the data using reflexive thematic analysis.

Results: Experiences were diverse. Challenges in retirement planning and adjustment were reported by some, while others viewed retirement as a positive respite from challenging work environments. The availability of more leisure time was appreciated by some, while others encountered ongoing responsibilities and obstacles hindering desired activities. A common theme was the inadequate support available for autistic people during retirement. Concerns about the aging process, including concerns about health decline and the possibility of entering residential care, were also common.

Conclusion: Future research should examine the suitability of residential care for older autistic adults, consider alternative autistic-led group living arrangements, and explore avenues for improved support during and after the retirement transition.

Community brief

Why was this study done?

Very little research has looked at autistic people's experiences of getting older. One aspect of getting older that autistic people have said is important is retirement.

Retirement is a transition that many people experience and are challenged by, but autistic people may be especially impacted. However, only one study has looked at retirement – and that study focused on one autistic man only. This means we don't know much about what retirement is like for autistic people.

What was the purpose of this study?

We wanted to know more about autistic people's experiences of retirement, including what made their experiences good or not so good, and how their experiences could be improved.

What did the researchers do?

We spoke to eight autistic adults (aged 55 or above) who had already retired and four autistic adults who were planning to retire in the next five years. We asked them questions about if (and how) they planned for their retirement, what the transition to retirement was like, and how they felt now they had retired. We created written versions (transcripts) of the interviews and read these as a group. We analyzed the transcripts using a technique called thematic analysis to identify patterns in the transcripts.

What were the results of the study?

We found that retirement experiences were different for each person. Some people faced challenges in planning for, and adjusting to, retirement. Other people said retirement was a welcomed break from difficult work experiences. Some people enjoyed having more free time. Other people still had lots of responsibilities, or faced barriers to doing the things they wanted to do, such as not having enough money. A

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common finding across all the people we spoke to was the lack of support for autistic people during retirement. Lots of people were also worried about getting older and becoming ill or going into residential care.

What do these findings add to what was already known?

These findings give us some of the first information about the experiences of autistic people navigating retirement.

What are potential weaknesses in the study?

We only spoke to people who had retired in the last 10 years or were planning to retire soon. This means we still do not know much about how people's experiences change over time, or how older autistic people feel about being retired. Second, we did not speak to anybody whose romantic partner had died. This means we do not know anything about the impact of losing a key connection on the retirement experiences of autistic people.

How will these findings help autistic adults now or in the future?

By understanding autistic people's experiences of retirement, we hope that policymakers, support organizations, and healthcare professionals can develop tailored interventions and resources to better support autistic people as they transition into retirement.

“Retirement is one hell of a change”: Autistic people’s experiences of retiring

Very little research has examined the experiences of older autistic people.^{1,2} Yet, autistic adults have identified a series of barriers and challenges that they face as they age. Notably, only around 3.5% to 7.9% of autistic people aged 50 years and above have a formal autism diagnosis, which results in significant unmet physical and mental health needs.³ Even with a diagnosis, autistic people report facing a slew of barriers when accessing healthcare.^{4–6} Yet, access to appropriate healthcare becomes increasingly important in later life. One aspect of autistic aging that has been seemingly neglected within the literature, however, is retirement. This is despite the fact that autistic people have identified the topic as a research priority,⁷ and that retirement is an experience that many autistic people who work will go through. Addressing the gap in knowledge around retirement experiences is essential to ensure autistic people can thrive and lead meaningful, fulfilling lives as they age.

The current study focused on the retirement experiences of autistic people living in the United Kingdom (UK). In the UK, older adults are supported to retire through the state pension, which provides financial support for retirees of up to £10,600 per year. Those who have made mandatory tax (National Insurance) contributions throughout their working life, or who have received certain state benefits, for example carer’s allowance or Universal Credit (i.e., low-income benefit), are eligible to receive the state pension. Upon reaching the state pension age (~66 – 67 years), individuals become eligible to receive their state pension, which is distributed as a monthly payment. In addition to the state pension, some people contribute to private pension funds throughout their careers. Private pensions are voluntary savings plans that can be set up by an individual or provided by an employer outside the Government-run state pension scheme. Those without a private pension fund may be eligible for additional benefits and tax-reductions, which are designed to assist retirees in maintaining a reasonable standard of living and navigating the financial aspects of retirement.

For many people, retirement marks a period of significant change. Indeed, retirement has long been considered one of the most significant readjustments in

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life.⁸ Traditionally, it involved a complete withdrawal from employment, signifying a shift toward a life of increased freedom and relaxation for those who were affluent, and a descent into poverty for those without access to adequate financial resources.^{9,10} In contemporary society, however, retirement has taken on a more multifaceted and dynamic nature, and people now approach it through various pathways.^{11,12} For example, people may gradually reduce their work hours and responsibilities and/or embark on new careers or voluntary pursuits, rather than leaving the workforce entirely. Irrespective of the path taken, retirement often involves simultaneously navigating multiple transitions across financial, psychological, social, and emotional domains.¹³ This is in line with *Multiple and Multidimensional Transitions Theory (MMT)*, which suggests that transitions are rarely one-dimensional, instead involving multiple transitions across multiple life domains.¹⁴ Though, to our knowledge, MMT has not yet been applied in the context of retirement.

In the general population, outcomes of retirement vary widely. Some research indicates that retirement can have positive effects on physical and psychological health, especially for people who have had to endure poor working conditions, or whose jobs had a negative impact on their wellbeing.¹⁵⁻¹⁹ Yet, other studies suggest there is no significant effect of retirement on health and well-being²⁰⁻²² or, further still, that retirement can have a detrimental effect.^{23,24} Indeed, a literature review of 32 longitudinal studies concluded that “retirement produces heterogenous outcomes” with different groups having different experiences, based on their situational and personal characteristics.^{25(p235)}

Two key theories have been utilized to explain such: *Role Theory* and *Continuity Theory*.²⁶ According to Role Theory, employment provides people with a meaningful way to define themselves.^{27,28} As such, retirement marks a period of adjustment as people navigate the shift from an active working life to a new phase of post-employment existence.²⁸ For those whose identity is deeply entrenched in their work, retirement can therefore evoke a range of negative emotions, including feelings of uncertainty, loss, and even a sense of identity crisis.^{26,28,29} Continuity Theory, on the other hand, purports that identity is defined through multiple sources, and, as such, retirement may not *necessarily* result in losses in well-being.^{30,31} Instead, people may adapt to retirement by seeking continuity in their lives, either by

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undertaking bridge employment (paid work following the end of professional or full-time employment³²) or by finding alternative pursuits aligned with their values and interests.^{30,31,33} Those who fail to successfully adapt (e.g., because they do not have the resources to retain a sense of continuity during their retirement) may therefore be susceptible to more compromised well-being.²⁵

Amongst this heterogeneity, one group for whom retirement may present unique opportunities and challenges are autistic people. First, many autistic people have poor employment experiences, including – but not limited to – underemployment, bullying, exploitation, and discrimination.^{7,34,35} In such cases, retirement may offer a sense of relief from the challenges of navigating unsupportive working environments. Further, retirement typically affords a reduction in enforced social interaction, and an increase in free time to spend on focused interests – two factors that may be especially pertinent to autistic people.^{36,37}

Yet, retirement may also pose particular challenges for autistic people. First, retirement necessarily involves the disruption of established routines and structured environments that employment provides. Such disruption is in direct conflict with the preference for predictability and routine that many autistic people report.³⁸ Second, autistic people can experience difficulties with executive function, including planning and organizing,³⁹ which may make planning for retirement especially challenging.⁴⁰ **Third, half of autistic people are considered as having ‘poor’ outcomes when using traditional markers of success, defined by non-autistic people, such as having competitive employment, having friends and romantic relationships and living independently.**⁴¹ **Indeed,** as few as 29% of autistic people are thought to be employed in the United Kingdom and, of those who *are* employed, many are underemployed.^{42–45} **Consequently,** autistic people may be less likely to have adequate pension provision and/or savings for a financially comfortable retirement and financial concerns may be particularly salient.⁴⁶ **Poor outcomes regarding friends and romantic relationships may also mean that autistic people are less likely to enter retirement with adequate social support. Indeed,** autistic people may be more vulnerable to social isolation and feelings of loneliness than non-autistic people,⁴⁷ and the impact of the loss of structured socialization through work may therefore be greater for autistic retirees.

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Despite evidence suggesting that retirement may pose unique opportunities and challenges for autistic people, there is a dearth of research on the topic. To our knowledge, only *one* study has specifically examined autistic people's experiences of retirement: a single case study of one autistic person in 2004.⁴⁸ This lone study documented the retirement transition support that Bradley, a 55-year-old autistic man, received during a three-year period. Support included working with a recreation therapist to develop a retirement plan and attending retirement day centers. While the study provided positive conclusions, the broader retirement experiences of autistic people remain largely unexplored. Addressing this gap, the current study sought to generate the first insight regarding autistic people's experiences of retirement using a qualitative approach. By understanding first-hand lived experiences, we can identify examples of good practices when it comes to supporting autistic people during retirement, as well as areas for improvement.

Method

Participants

To take part in this study, participants had to (1) be autistic (including people who self-identified as autistic); (2) be aged 55 years or above, and (3) have retired in the last ten years or be planning to retire in the next five years. We advertised the study by circulating a poster from the social media pages of the research team in March 2023. In total, 24 people responded to the call for participants. All participants were invited to participate. Of those, 10 were identified as being scammer participants (see ^{49,50}) and two participants failed to arrange an interview. Scammer participants were identified using several of the factors identified by Pellicano and colleagues.⁴⁹ Specifically, (1) email addresses were often identically configured; (2) emails were short, curt, and similar in format; (3) booking data suggested participants were not based in the UK, despite confirming they were UK residents; (4) several participants claimed to be from underrepresented groups, and (5) participants appeared to have unlimited availability and were keen for the interviews to happen quickly. In total, 12 participants were deemed to be genuine participants (i.e., did not raise the above suspicions) and took part in an interview.

Most participants **identified as** semi-retired ($n = 4$, 33.3%) or fully retired ($n = 4$, 33.3%) with the remainder ($n = 4$, 33.3%) **reporting that they were** planning to

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retire in the next five years. All participants who identified as semi-retired engaged in part-time employment and/or voluntary work during their retirement. On average, those who had retired had done so approximately five years before taking part (SD = 2.33), and most ($n = 7$ of 8, 87.5%) retired prior to the UK state pension age. Most participants ($n = 10$, 83.3%) reported having a formal autism diagnosis, while two participants (16.7%) self-identified as autistic. On average, participants first identified as autistic aged 58 years (SD = 5.16) while formal autism diagnoses were received aged 57 years on average (SD = 7.77). Of the eight participants who had already retired, three (37.5%) retired before having received their diagnosis or identifying as autistic, three (37.5%) around the same time as they received their diagnosis or identified as autistic, and two (25%) after having received their diagnosis or identified as autistic. All participants reported co-occurring conditions (see Appendix A). No participants reported having an intellectual disability.

Participants were aged between 56 and 70 years (mean age = 63 years, SD = 4.47). Women were overrepresented ($n = 8$, 66.7%) in the sample, as were participants from a White ethnic background ($n = 11$, 91.7%). Participants were also all well-educated: all completed university education ($n = 11$, 91.7%) or professional qualifications ($n = 1$, 8.3%). See Table 1 for further participant characteristics.

[Insert Table 1 about here]

Most participants ($n = 8$, 66.7%) reported an annual household income between £10,000 and £39,999 and being able to meet their monthly outgoings reasonably well ($n = 5$, 41.7%) or very well ($n = 6$, 50.0%). Participants who were able to meet their monthly outgoings very well reported annual household income ranges between £10,000 and £149,999+, while participants who were able to meet their monthly outgoings reasonably well reported annual household income ranges between £10,000 and £49,999 (see Table 2). One participant reported not being able to meet their outgoings well at all, and they had an annual household income between £10,000 and £19,999. This reported income range of £10,000 to £19,999 may fall below the 2022 relative UK poverty line of £17,700 before housing costs⁵¹ and is well below the Joseph Rowntree Foundation's estimated minimum annual

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income of £29,500 required for a single adult to reach an acceptable living standard in 2023.⁵²

[Insert Table 2 about here]

Materials

First, participants completed a demographic survey, hosted on Qualtrics.⁵³ The survey included demographic questions, such as participants' age, gender, geographical location and annual household income. Next, participants were invited to take part in a semi-structured interview. Two semi-structured interview schedules (see Appendix B) were developed by a neurodiverse group of researchers. One was directed at participants preparing for retirement, while the second was directed at participants who had already retired. Both interview schedules started by asking participants to reflect on their current context (e.g., who they live with, if/when they received an autism diagnosis, their interests) and their career history. All participants were also asked when they started thinking about and planning for retirement (prompting for information about what factors influenced their decision to retire and their initial feelings towards retirement) and what their preparations had involved. In the second interview schedule, focused on those who had already retired, we asked additional questions about (1) participants' experiences of the transition to retirement (prompting for examples of things that went well and not so well); (2) whether retirement had gone to plan, and (3) perceptions regarding whether being autistic impacted on experiences of retirement. Participants could ask questions and add additional information at the end of the interview.

Procedure

We received ethical approval from the Research Ethics Committee at the Institute of Education, University College London's Faculty of Education and Society (REC1744). All participants provided informed consent to take part. Interviews were conducted by JD or RM. All interviews were conducted remotely, via Zoom ($n = 9$, 75%) or Microsoft Teams ($n = 3$, 25%) video call, and lasted approximately 64 minutes (range = 50 minutes – 81 minutes). Participants were offered a £20 voucher following their participation.

Data Analysis

With participants' consent, we recorded the interviews and created an automatic transcript. JD read through each transcript and corrected them as required, ensuring to anonymize them before analysis. Three authors (JD, RM & AMR) undertook the analysis, with support from EP and AR. The authors analyzed the data within a critical realist framework, using reflexive thematic analysis.⁵⁴⁻⁵⁷ The process involved all three authors reading and re-reading a subset of transcripts, before assigning preliminary codes to salient aspects of the data. The authors inductively generated initial codes, without using a pre-existing framework, and identified semantic and latent meanings within the data.⁵⁷ The three authors then reviewed an alternative sub-set of coded transcripts, adding additional insights and/or alternative interpretations. They then met to discuss the findings and generate initial summary themes. When the initial themes had been generated, the authors reviewed the themes against each transcript to ensure no relevant information had been missed. At this stage, the authors also extracted salient quotes from the transcripts before using the quotes to write up the findings. Two authors (JD & RM) wrote up the findings, but all authors reviewed and agreed on the final interpretation of the data.

Positionality

All authors are part of the autism community, either as an autistic self-advocate and activist (RM) or an ally/researcher (JD, AMR, EP & AR) and all view autism within a social model, recognizing that autistic people are disabled by barriers within society that exclude and discriminate against them, as opposed to inherent impairments or deficits.⁵⁸ All authors have varying experience and expertise which contributed to rich and multifaceted interpretations of the data.

Community Involvement

An autistic co-researcher (RM) was involved in developing the interview schedule, interviewing participants, interpreting the findings, writing the manuscript, and making recommendations on how to improve autistic people's experiences of retirement. RM did research training as a lecturer in the mid 1990s. They changed career in the early 2000s and started doing research again as a community

researcher after their autism diagnosis in 2018. RM was paid for their time as a co-researcher on this project.

Results

We developed five themes, based on the interview data: (1) the unexpectedness of retirement; (2) the autistic experience of retirement; (3) inadequate retirement support; (4) “an awful lot of extra hours to have”, and (5) a shift in identity and purpose. See Figure 1 for a thematic display of these themes. Illustrative quotes are used to demonstrate participants’ rich and diverse perspectives. Quotes are accompanied by a unique ID which indicates whether a participant was planning for retirement (P) or considered themselves semi-retired (SR) or fully retired (FR).

[Insert Figure 1 about here]

Theme 1: The unexpectedness of retirement

For several participants, retirement seemed to come out of the blue and many felt they had woken up to the reality of it too late: “*I’ve never actually thought about planning for retirement... people go off to retirement courses and all that and I just don’t get it, because I only exist now*” (01-SR). Participants often assumed that they would stay in employment until state pension age [Note: The state pension age is the earliest age at which a state pension can be claimed in the United Kingdom, and is based on one’s date of birth and gender]. As such, if something happened to bring forward their retirement, they were left feeling unprepared, and without plans in place: “*I hadn’t been building up to it ... [I] thought that I would carry on working ... [and] stop at my state pension age ... I hadn’t got a big vision of my retirement, because it all happened so quickly*” (09-FR). For some participants, retirement was unexpected because they felt forced into it, either, because of unexpected changes or disputes at work, or a deterioration in their health:

My supervisor took me out for coffee [and] said: ‘Well, the way things have been ... you’ve not been well ... what are you going to do about it?’ and I

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said: 'Well, I just can't take it anymore.' So, she said: 'Well then, you need to hand in your notice.' (08-FR)

Many participants also spoke of unexpected disruptions to their retirement plans. For example, one participant explained that their long-standing dream to retire to Europe had been “*kiboshed*” by Brexit [Note: Brexit refers to the withdrawal of the United Kingdom from the European Union] (04-SR). Retirement could also be a catalyst for unexpected changes in relationships. For one participant, the prospect of relocating somewhere remote and spending more time with their partner prompted the decision to separate: “*I was supposed to be retiring to [location] with my ex ... it dawned on me that it wasn't a good [idea]. The last thing I needed was to be alone in the middle of nowhere with [them]*” (06-P). Even where retirement had been well planned for, the reality of being on the brink of it could hit hard: “*I thought when I got to retirement, I would say 'hallelujah. Isn't this wonderful?' And, actually, after being a tax lawyer for 35 years, I really don't know what for. It's quite a strange, unsettling feeling*” (07-P).

Theme 2: The autistic experience of retirement

Sub-theme 2.1: The impact on retirement planning

Some participants felt that being autistic made them particularly well-equipped to plan for retirement: “*Maybe the [autistic] attention to detail is what allowed me to set up a fairly obscure pension fund type, which has done me very well and gives me great flexibility*” (04-SR). Indeed, autistic logic was seen as a motivation for putting things in place and investing more than the required amount so “*retiring would never be a problem financially*” (10-SR). This contrasted with the view expressed by other participants that being autistic made them *less* aware: “*I think that it's [being autistic] made me unaware of things like planning for retirement. I haven't thought about it*” (05-P). Specific challenges in this regard included finding the time and energy to plan (“*because I'm so focussed on my work and tired with the work [and] worried about burnout ... I haven't got time naturally in my life schedule to do that planning*”; 11-P) dealing with pension-related paperwork (“*whether it's the autism or, definitely, the ADHD, me and forms [don't get on]... it's like my brain just freezes*”; 04-SR) and navigating the administrative challenges of claiming benefits around the time of

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retirement: *“The thing I think I wish was different was that having received an autism diagnosis is that you wouldn't then [have] to continually be assessed by Government departments to be classed as suitable to get the benefits”* (02-FR).

Sub-theme 2.2: Poor employment experiences

Participants often had relatively poor employment experiences, which resulted in work-related stress, exhaustion, and burnout. Such experiences led some participants to have ‘patchy’ career histories (*“my career path hasn't been a career path it's been... I've done this, and then I've done that”*; 05-P), with some describing the decision to retire being *“something that was forced on me because of my mental health”* (02-FR) or accelerated by their experiences. For many participants, receiving their autism diagnosis later in life was seen as a key contributor to career problems, which ultimately precipitated retirement: *“One of my biggest regrets is that I didn't get my diagnosis earlier... it would have made a massive difference if I'd known and could've asked for reasonable adjustments earlier in my career. I might have continued working”* (12-SR).

Given their experiences, many participants would have preferred to retire early. Yet, this depended quite crucially on financial circumstances: *“I looked into getting the pension from the previous company, and so I took it very early, really, 7 years early, and that enabled me to stop work”* (09-FR). As a result, some participants faced a gap before reaching the state pension age which they were struggling to bridge, with one participant explaining: *“I'm kind of at a horrible impasse”* (05-P). Others continued to work for longer than they really wanted to (*“it's balancing that huge human need [to retire] with making sure I get the financial side of things OK. That is my challenge really”*; 11-P), while some retired early and were struggling financially: *“If I had been able to work, and [get] a decent pension from work, I could do stuff like having my house fixed, [getting] my car upgraded ... whereas [recently]... I had to go to the food bank”* (08-FR).

Participants who had good pensions as a result of career success described the price they had paid for this. For example, one participant stated, *“burnout is my price for actually having a relatively secure and less stressful retirement”* (12-FR) while another explained that *“to achieve what I have in my career, I've always been*

focused on it, to the exclusion [of other things]. I had never considered getting married or having a family or whatever” (10-SR). Yet, even financially secure participants were anxious about slipping into poverty post-retirement, and a healthy pension pot was not necessarily a defence against anxiety: “I think I am going to starve, and if I don't starve it will be because of charity, you know? And that's nonsense... but it still feel[s] very, very strange” (07-P).

Theme 3: Inadequate retirement support

The scale and complexity of changes associated with retirement were considered vast, which was felt to be particularly challenging for autistic people: *“retirement is one hell of a change isn't it? You know it's a great big change of pace, of gear, of where you fit in the world, how the world sees you, how you see yourself” (04-SR). As a result, many participants felt they needed more time, and support, to prepare. Few participants received support with the transition from their employer, leaving them feeling unappreciated: “I got a very nice e-mail from them telling me to print off my P60 because they'd charge me if I wanted them to send it out later ... So, it's just a soldier's farewell, frankly” (7-P). Where employers had provided support, this was seen as focussing too heavily on financial needs, neglecting social and emotional aspects of retiring: “I did do the courses that [my employer] offered... They were quite focused on the financial side. I don't think there was enough focus on reassessing who you were, what your priorities were, what's meaningful for you” (12-FR). As a result, some participants were left feeling unprepared: “What I don't have is an emotional plan for retirement” (04-SR).*

The absence of realistic portrayals of retirement on TV, in films, and in adverts, also made it harder for participants to imagine what being retired would be like. While there were advantages in knowing people who had already retired as they could sometimes offer advice and support and assist with planning (*“I had friends who have retired before me. So, I've obviously talked to them about what it's like, the pitfalls... And they've been very helpful and supportive”*; 07-P) most participants lacked such support, making retirement more difficult to plan for: *“When you haven't got anyone to talk to about any of it. You just kind of push it away and think I'll think of that later and then later might be too late.” (05-P).*

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Regarding other, more formal forms of retirement support, participants were reticent about discussing their pension provisions with professionals, which exacerbated issues with preparation. Specifically, participants shared concerns about being on the receiving end of a 'hard sell' of pension products ("*you occasionally get [people saying] 'Oh, come and talk to me about your retirement planning'. But you know that they've got an ulterior motive because they'll be on commission*"; 05-P) and sharing personal details about their finances with 'strangers'.

Yet, having a trusted person to give advice and support was seen as important: "*Being able to sit down with somebody [to say] this [pension] is here ... What do I do with this stuff? How do I use it? How do I make best use of it? [would be useful]*" (04-SR). To that end, many participants welcomed the prospect of autism-specific support that focussed on adjusting to change, managing the transition, and maintaining social contact:

If there's any psychoeducation to be done for autistic people around retirement, I think what would make it different to [education for] people generally is focusing on that change element and on the changes in connections as well. For some autistic people, their work colleagues might be the only social contact they have. I think that thing is probably the biggest area. (04-SR)

Theme 4: "An awful lot of extra hours to have"

Some participants felt that demands on their time had not diminished during retirement, with one participant explaining: "*I feel in no sense have I been retired, really... if it means having a life of leisure*" (02-FR). Nonetheless, for many participants, retirement afforded a significant increase in free time. Indeed, one participant explained: "*We work 30/35/40 hours a week or whatever, and that is an awful lot of extra hours to have*" (10-SR). For some, this increase in free time provided a sense of liberation and flexibility, and they were able to embrace their newfound freedom: "*I like the fact that there is nothing [in my diary]... I can do what I want with my time and I have no problem whatsoever with filling my time*" (12-FR). However, others struggled with the lack of a defined schedule, feeling adrift without

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the structure that employment once provided: *"I have had no routine, and I continue to have no routine, and that's a great lack... [because] routine is something that [autistic people] love"* (02-FR).

Several participants were able to reconnect with long-lost interests and passions during their retirement, with the transition providing a chance to be unapologetic about pursuing activities they had set aside during their working years: *"I took out an ancestry membership [and] I love it! It's just so wonderful to have the time to do the things I'm passionate about and not have to do the stuff that other people dictate, you know, at work"* (12-FR). Yet, others encountered barriers that hindered their engagement in meaningful activities. For example, financial constraints impeded some from fully indulging in hobbies, with the costs proving prohibitive: *"I think I'd like to get involved in more things, but it's that thing, if you get involved in more things, you've got to be able to afford to get involved in more things"* (05-P). Unfortunately, some participants faced discrimination, exploitation, and abuse (*"I've been bullied in church several times. In fact, I'm in the process of making a complaint about my former rector. I don't expect it to succeed, in fact, it's been turned down once... it's all quite nasty"*; 03-SR) while others felt unable to complete complicated application processes to join new activities or groups (*"I'd like to do bowls... but the thing of applying, you have to be vetted. Christ sake, what does that mean?"*; 01-SR) and/or found the sensory environment and/or social demands of group activities too overwhelming:

I find myself, you know, wanting to withdraw from the LGBT+ Christian group, not because I don't want to support it, or because I don't like it... it's just that the planning meetings and the chit chat before and after services. I just can't cope with it. (03-SR)

The complex interplay between retirement and family caring responsibilities was also evident, as participants grappled with balancing newfound free time and the need to attend to elderly parents and/or the demands of children or grandchildren: *"When you get to this age, they don't call it middle-aged for nothing, you're sort of in the middle between, you know, all the challenges that your kids bring... And then you've got the worries about elderly parents, too"* (11-P).

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While, for some, retirement provided ample leisure time, such increased leisure time amplified concerns about loneliness and a lack of connectedness: *"I don't like the idea of retirement on my own... but we're back to that autism-thing with relationships, and maintaining friendships, all of that... so, I feel a little fearful of [full] retirement"* (04-SR). On the other hand, some eagerly anticipated fewer social events and the related pressures that came with their working life: *"I'm quite happy with my own company... I perhaps thought that I would miss seeing people and I actually haven't much, you know, it being much less frequent, and much smaller, it's been really good"* (12-FR). Indeed, a distinction between colleagues and friends was drawn, with participants not necessarily missing work-specific social connections: *"I never really had close friends at work. I'd always really get on with people really well, but I could always just move on to the next people because my social life wasn't really interconnected with [work]"* (11-P).

For those who had experienced solitude throughout their lives, retirement was seen as an extension of their comfort with being alone: *"When you've lived a life alone to that degree, you become very self-sufficient... I'm well trained and skilled at being independent"* (10-SR). Yet, concerns were raised about the long-term impact such aloneness may have: *"With the way the autism has influenced my life from the point of view of isolation, I think that could come back to bite me in 10/15/20 years time, if I'm still around"* (10-SR). As such, opportunities for social interaction were valued and sought by many. For example, some participants expressed desires to continue part-time or voluntary work to stay connected socially: *"I'd like to carry on working part-time because I want connection with people"* (05-P). Others sought opportunities for focused socialisation around shared interests, allowing them to form friendships centred on their passions and hobbies: *"I'm studying [a book] and we have a weekly sort of set up group class... which is really nice"* (08-FR). Similarly, some participants highlighted the internet as a valuable platform for connection and participation, particularly for those facing challenges with in-person gatherings due to sensory or social barriers: *"As an autistic person, I don't always want a lot of social interaction. I can manage this online sometimes better than I can in person"* (03-SR). Something that was felt to be lacking, however, was a place for autistic retirees to connect with one another: *"I think it would be really helpful to have kind of, maybe it's*

regional or whatever, like groups of autistic retired people that you knew that you could just have a conversation with” (11-P).

Theme 5: A shift in identity and purpose

Employment gave participants a sense of purpose and self-worth, which was often felt to dissipate during retirement: *“Employment does give you a position or a feeling of worth in your life, and that goes very rapidly. You think, well, now I'm not responsible for all these people or all this work. Why am I, what am I here for?” (10-SR).* Indeed, many participants perceived retirement to be a period of diminished worth (*“If I'm honest, [retirement] sounds a bit like a punishment, you know, your useful life is over, [you're part of] the scrap heap... sitting [in] your house on your own all day, doing nothing”*; 04-SR) and worries about becoming “old and decrepit” (05-P) were common.

Worries about aging were deeply intertwined with the loss of a work identity: *“I always was very much defined by what I did. I was proud of [job role]. I was proud of, you know, being successful in the projects I led... [and I] obviously don't have those anymore” (12-FR).* Many participants also expressed concerns about their increasing frailty and declining overall health as they aged: *“I'm worried about my health as well. I've noticed when we walked on holiday that my legs aren't as strong as they used to be, I tire more easily, you know” (03-SR).* Interviewees raised particular concerns about the growing need for healthcare: *“One of my fears is that as I get older, I might need more medical help [but] systems aren't set up to allow for appropriate care [for autistic people]” (12-FR).* Such concerns were especially salient for those who lived alone, or who had minimal social support: *“[my mum] had Alzheimer's [and] if something like that happens to me, who would be there to support me? Because I haven't got family and close friends. That is actually quite scary” (05-P).* Similarly, many participants were worried about the potential need for residential care, and whether they would be able to find an appropriate provision:

If I end up having to go to a care home, are they going to have rooms that have got, you know, low lights and not too much sound, and not people wearing a lot of perfume and stuff like that? It freaks me [out], it absolutely does. And that's partly why I guess I say I don't really want to particularly live to be old, [or] older. (08-FR)

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Nonetheless, retirement afforded some participants a unique opportunity to reassess their career paths and consider alternative avenues aligned with their strengths and needs. Indeed, several participants moved into more autism-specific work during their retirement: “*I’m now delivering [autism] diagnostic assessments for [organization], and it’s a joy and a privilege*” (02-FR). ‘Career reinvention’ served as a means of reclaiming a sense of purpose and identity beyond the confines of traditional work roles. After years of dedicating themselves to their careers, many participants saw retirement as an opportunity to engage in activities that were driven by a sense of purpose and a desire to make a difference:

I thought one of the nice things I could possibly do would be Ability Net, which is to help elderly or disabled people with access to computers and the Internet. In the pandemic, I felt this huge impulse to try to mitigate the pandemic. I worked for the food bank collecting food, and I ran the website. I also got involved with a local charity distributing hot lunches to elderly disabled people... And then, when the vaccination started, I volunteered as a vaccinator. (03-SR)

Discussion

This study aimed to generate initial insights into how autistic people experience retirement. Our findings revealed diverse experiences. While some participants were able to leverage their attention to detail and logical thinking to craft well-structured retirement plans, others grappled with time management and administrative challenges, leaving them feeling unprepared. Contextual factors such as poor employment experiences, delayed autism diagnoses, and financial circumstances influenced retirement choices, either leading to early retirement or undesired, prolonged employment. The complex relationship between retirement and leisure time was also identified, with some participants able to embrace their newfound time for hobbies, while others felt ‘retired only in name’ and/or experienced barriers to meaningful engagement. Despite these differences, a common thread highlighted inadequate support for autistic retirees, leaving them emotionally and socially unprepared for this significant life change. Here, we discuss how these findings relate to existing research and make suggestions for future research and practice.

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As identified in previous research, autistic people have particular strengths – such as superior attention to detail – which can be particularly beneficial in an employment context.^{59,60} Some of our participants were able to leverage these skills to craft well-considered retirement plans.⁴⁰ However, many participants reported feeling unprepared for retirement, either because (1) they had not adequately planned for retirement; (2) they felt forced into retirement, or (3) unexpected events changed their retirement plans. Relatedly, participants in this study highlighted an overall lack of retirement support. Indeed, in line with MMT,¹⁴ many spoke of the complex nature of the retirement transition, with it not only entailing a transition in terms of employment, but also in terms of financial status, relationships with others, and identity. To this end, our participants appeared to view retirement as a major life transition, akin to other life transitions such as entering employment, as opposed to the 'end of the line'. Aligning with this perspective, Gambone⁶¹ proposes the concept of 'refirement' which reframes retirement as a new, exciting life chapter rather than an end point. Reframing retirement this way may help shift perspectives and policies to better address the support needs of autistic people during this period. Indeed, our findings highlight that adequate services and guidance are essential at this life stage, just as they are at any other.

Our participants said that navigating so many transitions at once was challenging, especially without support. This paucity of support echoes existing research indicating insufficient support at other employment stages, including entering employment and navigating a career.^{62–64} Yet, support during this period may be particularly pertinent for autistic retirees given autistic people's preference for predictability and routine.³⁸ Indeed, some participants in this study suggested the vastness of change during retirement was in direct conflict with their preference for predictability. As such, tailored support for autistic retirees may be warranted. Participants in this study provided several recommendations in this regard. First, they highlighted a particular need for tailored financial guidance and support, especially around critical moments, such as pension-sharing during divorce settlements or making decisions about cashing in occupational pensions early.⁴⁰ Indeed, such decisions can have lasting financial impacts, and some participants were concerned that autistic people may be more likely to be exploited in such critical periods.⁶⁵ Importantly, participants highlighted the importance of establishing

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reliable pension support schemes, and expressing dissatisfaction with existing schemes. Second, participants recognized the need for emotional support during the transition, emphasizing that concerns and uncertainties persisted even among those who were financially prepared. Third, there was a call for more flexible retirement options, where possible, including gradual retirement or trial periods, which could help autistic people settle into retired life. Finally, participants highlighted a need for more dedicated spaces for autistic older people to connect, allowing them to make connections with others and provide/receive informal support.

Our participants also highlighted the profound impact their employment experiences had on their retirement path. Many faced poor employment experiences, leading to feelings of exhaustion and burnout.^{7,66} Unfortunately, all our formally diagnosed participants received their autism diagnosis in later life, leaving them without workplace adjustments throughout their careers. Together, poor employment experiences and a lack of adjustments were perceived to impact participants' job performance and employment longevity, ultimately impacting their financial preparedness for retirement. Recent research also points toward possible disparities in career progression opportunities for autistic people (Davies et al., under review), which may result in lower pension contributions and reduced retirement savings. These findings are consistent with the concept of cumulative (dis)advantage, which describes how educational, economic, and other (dis)advantages cumulate over the life course.^{9,10,67} In the context of this study, the inequalities autistic people faced during employment translated into inequalities during retirement, highlighting the pervasive inequalities that autistic people face throughout their lives.

Inequalities in retirement experiences were also evident between participants within our study. Indeed, while some participants felt they had to leave their jobs prematurely due to unbearable work conditions^{63,68}, others were stuck in unsuitable jobs because they could not afford to retire early. The persistence of some participants in unsuitable job roles is disconcerting since negative employment experiences are reported to have potentially catastrophic effects on the mental well-being of autistic people (Davies et al., in preparation). However, insights from the general population suggest that retirement can positively impact mental health, particularly when it follows challenging working conditions or occupations detrimental

to health.^{15–19} Future research within the autistic community may be warranted to examine whether these findings are replicated in this population. Nonetheless, some participants in this study described retirement as a welcome break from the difficulties they faced during employment. As such, we assert that consideration should be given to policies regarding reducing – or removing – penalties for autistic people taking occupational pensions early. Indeed, autistic people, on average, face earlier mortality than non-autistic people^{69,70}, potentially limiting the time they have to enjoy their pension benefits.

We also found diversity in the way that retirement impacted participants' identity. In line with *Role Theory*^{27,28}, retirement brought about a shift in many participants' sense of purpose and self-worth, which was previously derived from their employment. As a result, many reported a sense of 'rolelessness', reflecting the difficulty of adapting to a new life phase where their previously defined roles and responsibilities were no longer central.⁷¹ While this finding is not necessarily unique to autistic retirees, work identity may play a unique role in autistic people's lives. Many autistic people face stigma and discrimination.^{72,73} Given that unemployment is also associated with stigma,^{74,75} and that workforce participation is considered important for a 'dignified' existence,⁷⁶ employment identities may offer autistic people a degree of protection against societal stigma. Further, several participants had to reconcile themselves with a late autism diagnosis during their retirement phase, resulting in a dual identity shift. This process of re-definition amid retirement⁷¹ and newfound understanding of being autistic⁷⁷ added layers of complexity, compounding the challenge. Nevertheless, some participants found retirement gave them much-needed time to redefine their experiences and come to terms with their diagnosis. Similarly, some participants found liberation in retirement, as they could dedicate more time to the activities that were important to them, and carve a new, positive, identity around being a retiree.

Finally, retirement was often associated with significant worries about aging-related issues, such as declining health and increased healthcare needs. While such concerns are likely to be common amongst all aging adults, they may be especially pronounced for autistic people, as they face significant barriers to accessing healthcare.^{4–6} Indeed, participants in this study shared concerns about the inaccessibility of healthcare, with specific reference to the sensory environment and

clinicians' perceived lack of knowledge. Such worries extended to the prospect of residential care, where the incompatibility of sensory environments and lack of autism training were pressing concerns². Yet, there is a paucity of research in this domain, meaning very little is known about the suitability of residential care for older autistic adults.⁷⁸ This is despite the topic being identified as a priority research area by autistic people and their allies.⁷⁹ Future research must seek to bridge this knowledge gap.

Limitations

While this study provides valuable insights into the experiences of autistic people during the early stages of retirement, several limitations warrant consideration. First, the participants we interviewed were all at a relatively early stage of their retirement journey: on average, those who had already retired had done so approximately five years before taking part. As such, a gap in our understanding remains regarding the experiences of autistic retirees navigating young-old (e.g., 60-74 years) and oldest old-age (e.g., 74 years and above).⁸⁰ Relatedly, most of our retired participants had retired before the UK state pension age, which may have impacted their experiences. Future research should seek to specifically examine the experiences of autistic people who do not retire early. Second, our sample is small and not representative of the broader autistic or general populations. For example, most of our participants identified as White women, who were highly educated. As such, while this study provides important initial insight into autistic people's experiences of retirement, our findings only speak to the experiences of a specific sub-group of the autistic population. Future work should seek to broaden the scope of the research by including a larger and more demographically diverse sample of autistic people. Third, all our participants identified as being autistic, and most had a formal autism diagnosis. Yet, the overwhelming majority of older autistic people are likely to be undiagnosed and may not be aware they are autistic.³ As such, our participants are in the minority of older people who have been recognized (by themselves or clinically) as autistic, and their experiences may differ from those who have not. Fourth, we did not collect detailed information about participants' marital status, home ownership, or pension income sources. Given that these factors are likely to shape retirement experiences, future research should seek to gather more detailed demographic and financial information

to elucidate potential differences in retirement experiences and outcomes. Fifth, the cross-sectional nature of the study means we are unable to make conclusions about the longitudinal impact of retirement, or how retirement experiences change over time. More longitudinal research will be beneficial in this regard. Finally, while one participant ended their relationship with a romantic partner during retirement, none of our sample had been bereaved of a partner, which raises questions about the potential impact of involuntarily losing key connections in the context of retirement. Considering the challenges some of our participants reported facing in establishing and maintaining long-term social relationships, outside of romantic relationships, the impact of bereavement on this population may be particularly significant. This may be an avenue for future research.

Conclusions

This study highlights diverse retirement experiences among autistic people. The findings underscore the necessity for tailored support, flexible retirement options, and improved access to healthcare and social networks to address the multifaceted concerns raised by autistic retirees. Future research should examine the suitability of residential care for older autistic adults, consider alternative autistic-led group living arrangements, and explore avenues for improved support during and after the retirement transition.

CRedit Authorship Statement

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Supplementary Material

Appendix A. Table of co-occurring conditions

Appendix B. Interview guides

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Table 1.

Participant characteristics

Characteristic	<i>n</i>	%
Age in years M^a (SD) Range	63 (4.47)	56 – 70
Gender		
Woman (including trans women)	8	66.7%
Man (including trans man)	4	33.3%
Ethnicity		
White British / European / Other White background	11	91.7%
Mixed / Multiple ethnic background	1	8.3%
Geographical location		
London	3	25.0%
North West of England	2	16.7%
Scotland	2	16.7%
South West of England	2	16.7%
South East of England	1	8.3%
Wales	1	8.3%
Yorkshire and the Humber	1	8.3%
Highest level of education		
Bachelor's Degree (e.g., BSc, BA, BEd)	3	25.0%
Masters Degree (e.g., MSc, MA, MEd)	3	25.0%
Post Graduate Education (e.g., PGCert, PGDip, PGCE)	3	25.0%
Doctorate	2	16.7%
Professional Qualifications	1	8.3%
Current household annual income		
£10,000 – £19,999	4	33.3%
£20,000 – £29,999	1	8.3%
£30,000 – £39,999	3	25.0%
£40,000 – £49,999	1	8.3%
£100,000 – £119,999	1	8.3%

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£140,000 +	1	8.3%
Prefer not to say	1	8.3%
Perceived ability to meet monthly outgoings		
Not well at all	1	8.3%
Reasonably well	5	41.7%
Very well	6	50.0%
Childcare responsibilities		
Yes	3	25.0%
No	9	75.0%
Other caring responsibilities		
Yes	2	16.7%
No	10	83.3%

^a Rounded to the nearest whole year

Table 2.

Perceived ability to meet monthly outgoings by annual household income range

Perceived ability to meet monthly outgoings	Annual household income range	<i>n</i>	%
Very well (<i>n</i> = 6)	£10,000 – £19,999	2	33.3
	£30,000 – £39,999	1	16.7
	£100,000 – £119,999	1	16.7
	£149,999+	1	16.7
	Prefer not to say	1	16.7
Reasonably well (<i>n</i> = 5)	£10,000 – £19,999	1	20.0
	£20,000 – £29,999	1	20.0
	£30,000 – £39,999	2	40.0
	£40,000 – £49,999	1	20.0
Not well at all (<i>n</i> = 1)	£10,000 – £19,999	1	100.0