Understanding Autistic Adults' Relational and Vocational Experiences.

A thesis submitted in partial fulfilment of the requirements for the Doctorate in Clinical Psychology

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Declaration

This thesis has been submitted for the award of Doctorate in Clinical Psychology at the University of Sheffield. It has not been submitted to any other institution, or for the purpose of obtaining any other qualifications.

Structure and Word Counts

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Lay Summary

Researchers have begun to recognise the importance of asking autistic people about their first-hand experiences to enable understanding and person-centred intervention for difficulties faced by the population. Autistic people experience high levels of discrimination and disadvantage. As such, autistic people experience inequalities within multiple areas, including social marginalisation (e.g., interpersonal victimisation) and employment difficulties (e.g., higher prevalence of un/underemployment). This thesis allows for an in-depth exploration of lived experiences.

Literature Review

A literature review was conducted to identify and evaluate qualitative literature about autistic adults' experiences of interpersonal victimisation. Four databases were searched, and eight studies met criteria for the review. Thematic synthesis was used to analyse the data which revealed three superordinate themes. Results illustrated that autistic people feel they are the problem and being autistic gives perpetrators an excuse to victimise. Themes also revealed the consequences of victimisation, and hopefulness for a future where autistic people develop healthy relationships and keep themselves safe. Results highlight the importance of a societal attitudinal shift around difference, alongside the need for better formal education (e.g., sex education) for autistic people to feel more aware and equipped to manage potential risks within relationships.

Empirical Project

A research study was conducted to investigate autistic adults' experiences of unemployment and underemployment. Eight autistic adults undertook semi-structured interviews with a researcher, which were analysed using Interpretative Phenomenological Analysis (IPA). Four themes were generated. Participants felt paralysed by previous traumatic workplace experiences and employment processes. They felt misunderstood, judged, and powerless within systems surrounding employment, which impacted their mental health and ability to progress with their aspirations. Most participants were discovered autistic in adulthood which enabled increased self-understanding, awareness of employment needs, and the importance of managing their well-being. Autism related anti-stigma interventions within the workplace are required to reduce the stigmatising attitudes of non-autistic colleagues and employers, alongside a commitment to inclusivity and diversity from employers. Finally, it is important for clinicians working with autistic adults to be aware of employment inadequacies and the impact on their mental health, opening up conversations about employment challenges and possible accumulated trauma, to support them to make sense of these experiences through a lens of self-compassion. This may support the shift from feeling stuck to moving forward with their career aspirations.

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Firstly, I would like to express my gratitude to the eight people who took the time to share their experiences with me. I am thankful for your willingness and courage to speak so openly about your experience. I hope I was able to offer a space to have your voice heard, and I have captured your narratives honourably. Thank-you also to the people who offered their time and guidance to develop the study materials; it was an honour to learn from you and make this research the best it could be for autistic adults.

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Table of Contents

Declaration ii

Structure and Word Counts iii

Lay Summary iv

Section One: Systematic Literature Review 1

Abstract 2

Introduction 4

Method 7

Results 11

Conclusion 37

References 38

Appendix A: ENTREQ guidelines (Tong et al., 2012) 51

Appendix B: Adapted CASP qualitative research checklist (Long et al., 2020) 53

Appendix C: Line by line coding example (NVivo) 54

Appendix D: Descriptive theme development (NVivo) 55

Appendix E: Analytic themes development (NVivo) 56

Appendix F: Reflective Comments Examples 57

Appendix G: Quality Appraisal Results 58

Appendix H: Additional Supporting Quotes by Theme 59

Section Two: Empirical Project 64

Abstract 65

Introduction 67

Methodology 70

Results 77

Discussion 87

Conclusion 97

References 98

Appendix A: University of Sheffield Ethics Approval Letter 112

Appendix B: Interview Schedule 113

Appendix C: Research advert 115

Appendix D: Participant information sheet 116

Appendix E: Participant consent form 119

Appendix F : Example reflective diary entry 121

Appendix G: Example participant conceptual map 123

Appendix H : Examples of each stage of analysis 124

Appendix I: Audit 137

Appendix J: Participant contribution to themes and additional quotes 139

Section One: Systematic Literature Review

Autistic Adults' Experiences of Victimisation in Interpersonal Relationships: A Thematic Synthesis

Abstract

Objectives

Autistic people are at higher risk of being victimised across the lifespan, settings, and relationships. Research investigating victimisation has generally focused on prevalence and risk factors, with limited focus on understanding the lived experience among autistic adults. Therefore, this qualitative evidence synthesis aimed to synthesise available qualitative research into autistic adults' experience of victimisation by a known perpetrator.

Design and Method

A systematic search for qualitative research on autistic adults' interpersonal victimisation experiences was conducted across four databases. Eight studies were included, critically appraised, and analysed using Thomas and Harden's (2008) approach to thematic synthesis.

Results

Three superordinate themes were identified: '*Victim as the problem'* (An inevitable experience, Blaming ourselves, Us vs. them, Systemic disbelief), '*Consequences'* (Distrust, Distress, Identity conflict), and '*Navigating the aftermath'* (Keeping safe, Finding hope in healthy relationships).

Conclusions

This review supports quantitative reviews demonstrating that victimisation is apparent across relationships, settings, and time for autistic adults. Barriers to support were highlighted at multiple levels (e.g., relationally, systemically) continuing the perpetuation of distrust and distress. On the positive, healthy relationships are possible following victimisation experiences, and safety was recognised as essential for moving forward. There is evident need for better education for both the general population (e.g., autism awareness) and autistic people (e.g., sex and relationships).

Practitioner Points

- A societal attitudinal shift is required to disable the permissibility of victimisation toward autistic people.
- Autistic people highlight a need for better sex and relationship education to help navigate and avoid high risk situations.
- For autistic adults to disclose their experiences, it is essential that their experiences with systems are positive. Further autism awareness training is required.
- Autistic people may benefit from access to trauma focussed interventions (e.g., stabilisation, Trauma Focused-CBT) following victimisation experiences.
- Future research is required to investigate the efficacy of trauma focused interventions for the autistic population.

Keywords: Autism; Bullying; Victimisation; Qualitative Evidence Synthesis; Meta-Synthesis

Introduction

Victimisation is classified as involving acts whereby an individual is subject to cruel or unjust treatment, including bullying, maltreatment (neglect, physical and emotional abuse), sexual harm (rape, sexual assault), and crime (theft, robbery, assault; Trundle et al., 2022). Bullying, also known as peer victimisation, has been categorised as deliberate and recurring physical, verbal and/or relational harm wherein there is an imbalance of power (Monks & Smith, 2006; Olweus, 1993). Interpersonal victimisation includes the presence of an interpersonal relationship between the preparator and victim; as such, the perpetrator is known to the victim (e.g., family, friend, peer; Fardella et al., 2018; Thomas, 2011).

Autism is a life-long neurodevelopmental condition associated with difficulties processing and interpreting social information from others (American Psychological Association, 2013). Such traits can increase autistic individuals'[1] vulnerability to harm (Portway & Johnson, 2005). Autistic individuals experience a higher prevalence of bullying, sexual and crime victimisation, and child abuse than non-autistic individuals (Paul et al., 2018; Sreckovic et al., 2014; Weiss & Fardella, 2018). Specifically, research suggests that 66% of autistic adults experience victimisation (Trundle et al., 2022). Autistic adults are also more likely to experience victimisation in the workplace, with 51% reporting instances of bullying, harassment, or unfair treatment by colleagues or managers (National Autistic Society, 2016). Disturbingly, it is evident that autistic individuals experience multiple forms of victimisation, known as 'poly-victimisation' (Finkelhor et al., 2005).

Researchers have identified multiple factors that may increase the likelihood of victimisation among autistic individuals. Traits such as challenges with identifying and articulating emotions (Bird & Cook, 2013), misunderstanding non-verbal communication and

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[1] "autistic individual/adult" is identified as the preferred term autistic adults want to be identified by; therefore, "autistic adult/individual" will be used throughout this literature review (Kenny et al., 2016).

inappropriately responding in conversation (Hellstrom, 2019), and repeated and repetitive behaviour (Sreckovic et al., 2014); may increase risk of victimisation. Moreover, reduced social inference skills (Sedgewick et al., 2019), low self-esteem (Nguyen et al., 2020) and limited sexual knowledge (Brown-Lavoie et al., 2014) may limit an autistic individuals' capacity to recognise and manage dangerous situations (Pecora et al., 2016). Essentially, personal and systemic factors appear to exacerbate the risk of victimisation.

There have been several systematic reviews within this area, focussed on a specific type of victimisation, such as bullying (Beckman et al., 2020; Maiano et al., 2016). Such reviews have highlighted high prevalence estimates for general and specific (physical, verbal, relational) bullying victimisation (Humphrey & Hebron, 2015; Schroeder et al, 2014). Reviews that narrow the focus to a single victimisation type may underestimate the affect the variety of these experiences have on autistic people and limit our understanding of the impact of this multifaceted risk faced by autistic people. As such, Trundle et al.'s (2022) meta-analysis considered multiple victimisation experiences, including bullying, sexual victimisation, crime, and child abuse. They found significant victimisation in autistic individuals across the lifespan (44%), highlighting victimisation in multiple forms as a substantial issue for autistic people.

Victimisation experiences have been associated with significant difficulties for autistic people (Rose et al., 2011), affecting their self-esteem, mental health, educational attainment, and relationships (Dombeck, 2014). Bullying has been associated with anxiety and depression (Mayes et al., 2013), low self-esteem (Reid & Batten, 2006), and suicide attempts (Carter, 2009) in autistic individuals. Similarly, risk of suicidal ideation and attempts can increase following physical and sexual abuse (Richa et al., 2014) and victimisation among autistic people is associated with stress and Post-Traumatic Stress Disorder (PTSD) symptoms (Paul et al., 2018). Specific to autistic adults, Botha and Frost

(2020) found poorer emotional well-being and heightened psychological distress in those experiencing victimisation. Notably, those victimised are more likely to be re-victimised (Pfeffer, 2016), perpetuating the impact of such experiences.

As outlined, a high percentage of studies investigating victimisation among autistic people have utilised quantitative methodologies to understand the prevalence and risk factors (Cappadocia et al., 2012; Paul et al., 2018; Weiss & Fardella, 2018), with few attempting to look in detail at the victimisation experience. To date, the review evidence base is predominantly literature reviews and meta-analyses of quantitative data to assess the state of already available literature to advance the field of knowledge (Linnenluecke et al., 2020). Existing reviews generally focus on children and adolescents combined with limited adult literature, highlighting the continuation of the need for high quality research on autism in adulthood (Howlin et al., 2015). Positively, there is a developing evidence base aiming to explore the experiences of autistic people (MacLeod, 2019) rather than focusing solely on quantitative outcomes.

Qualitative data allows for understanding *how* victimisation is experienced (Austin & Sutton, 2014). This approach acknowledges the need to address autistic people's daily realities, recognising their needs in the here-and-now (Pellicano et al., 2014). Thus, research is expanding to explore autistic adults' experience of interpersonal victimisation, evident in the recent increase in research studies exploring the issue (Fardella et al., 2018; Pearson et al., 2022a; Pearson et al., 2022b). However, to the author's knowledge, there have been no qualitative evidence syntheses focussing on the experience of victimisation within interpersonal relationships amongst autistic adults. Considering the prevalence and risk factors of victimisation are relatively well known within an autistic adult population (Trundle et al., 2022), it is important that a deeper understanding of such experience is explored

(Hellstrom, 2019) and aggregating and synthesising such literature can enable more tailored prevention and intervention (Carroll, 2017).

This review aims to complete a qualitative evidence synthesis of the findings within the literature on victimisation experiences, including bullying, maltreatment, sexual victimisation, violence, and crime, perpetrated by someone known to the person from the perspective of autistic adults. Specially, the review aims to synthesise and appraise literature considering what are autistic adults' experiences of interpersonal victimisation, how are they affected by interpersonal victimisation, and how do they cope with such experiences.

Method

This systematic review was registered on the international prospective register PROSPERO (reference: CRD42022375775) and followed the enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (Tong et al., 2012; Appendix A).

Search Strategy

The SPICE (Setting, Perspective, Intervention/Interest, Comparison, Evaluation) mnemonic was used to develop and refine the review question and search strategy (Table 1), a recommended framework for qualitative systematic reviews (Booth, 2004).

The search strategy, search terms (Table 2), and databases were identified in consultation with a librarian and the author's research supervisor. Searches were completed in February 2023 across four databases: Web of Science, PsycINFO, Medline, and Scopus. No restrictions were made on date limits to ensure all relevant articles were obtained and there have been no previous reviews. Searches were limited to articles written in or pre-translated into the English language.

Table 1

SPICE Tool (Booth, 2004)

Criteria	**Description**
Setting	Any country / setting
Perspective	Autistic adults
Intervention / Interest	Experiences of bullying, victimisation, and/or violence within interpersonal relationships
Comparison (If relevant)	Not applicable
Evaluation	Experiences, feelings, perspectives, perceptions, attitudes captured in themes

Table 2

Search Syntaxes

Construct	**Search Terms**
Autism	"Autis*" OR "Autis* Spectrum" OR "Asperger" OR "Pervasive Developmental Disorder"
Victimisation	"Peer victimi*" OR "Interpersonal victimi*" OR "Bully*" OR "bullie*" OR "Conflict" OR "Mate crime" OR "Discrim*" OR "Aggres*" OR "Abuse" OR "Interpersonal violence" OR "Exploit*"
Interpersonal Relationship	"Friends*" OR "Peer*" OR "relation*"
Evaluation	"Lived Experience*" OR "Perception*" OR "Feeling*" OR "Understand*"

Note. Individual search terms for each construct were combined with the Boolean operator 'OR', and broad constructs were combined with 'AND'. Search syntaxes were inputted into Web of Science, Medline, and Scopus; MeSH[2] terms were inputted into PsychINFO.

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[2] Medical subject headings are standardised keywords that are used to search on certain databases (e.g., PsychINFO). Articles on PsychINFO are assigned a MeSH term to give information on the content of the articles; thus, are found by searching these terms.

Study Selection

Papers found via searches across all databases were extrapolated into the Mendeley reference manager, and duplicates were removed. Titles and abstracts were screened against the inclusion and exclusion criteria (Table 3). The remaining studies were subject to full-text review, and those that did not meet eligibility criteria were removed. Forward and backward reference searches of included papers were conducted. A secondary reviewer[3] screened nine papers during full-text review to increase the reliability of the study selection process.

Table 3

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Samples include autistic adults aged 16[4] and above	Studies utilised solely quantitative research design
Studies specifically focus on and explore the experience of victimisation (including bullying, peer victimisation, interpersonal victimisation, violence, sexual victimisation, conflict, mate crime, exploitation, and maltreatment) by someone known to the victim (e.g., friend, family relation, peer)	Systematic review, book chapters, or non-peer reviewed articles (e.g., conference papers).
Studies employed qualitative methodology and analysis, including mixed method studies with a qualitative element	Studies which only explored parent/caregiver or professionals account/experience of interpersonal victimisation and violence.
Studies are written or translated in the English language	

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[3] A Trainee Clinical Psychologist independent of this review

[4] Despite 18 years being considered the legal age of adulthood in England (HMRC, 2011) some countries, including Scotland (HMRC, 2011), Cambodia (Youth Policy, 2014a) and Cuba (Youth Policy, 2014b) consider 16 years to be a legal adult. Moreover, 16-year-olds have legal rights associated with adulthood in some countries – for example being able to vote (ACE Electoral Knowledge Network, 2018), have sex and become a parent (Age of Consent, 2023), or be enlisted in the military (CIA, 2019). To ensure inclusivity of different cultures, this study uses 16 years as the cut off for inclusion.

Data Extraction

Data relevant to the review question was extracted and collated, including author, year of publication, country of study, available sample characteristics, data collection, methodology, and a summary of key themes or findings (Table 4).

Assessment of Quality

The quality of included studies was assessed using an adaptation of the Critical Appraisal Skills Programme qualitative research checklist (CASP, 2018; Long et al., 2020; Appendix B). Long et al. (2020) modified the tool to optimise its value for appraisal in qualitative evidence synthesis and proposed an additional question to the original checklist (CASP, 2018). A secondary reviewer appraised a random selection of papers (50%, *n*=4). Discrepancies were found on four of 44 checklist questions, and these were resolved via discussions.

Data Synthesis

Data was analysed following Thomas and Harden's (2008) thematic synthesis approach to meta-synthesis of qualitative literature. The process involved extracting relevant findings, including authors' descriptions and interpretations, and verbatim quotes from the results section of included studies (Thomas & Harden, 2008). Some articles included quantitative data or data from non-autistic populations; only qualitative data from autistic populations reflecting victimisation experiences within interpersonal relationships were extracted. Relevant data was transferred into NVivo software (QSR International, 2018) to undertake 'line-by-line' coding (Appendix C). Data included participant quotes and the authors' descriptions and interpretations, as suggested by Thomas and Harden (2008). Initial codes were generated for each study to highlight key content and meanings, which were clustered together via this inductive process. A comparison of themes across studies was then undertaken to generate descriptive themes (Appendix D). Finally, the themes were further interpreted, producing analytical themes (Appendix E) and a list of superordinate and subthemes. Discussions were held between the lead author and their research supervisor throughout the synthesis.

Researcher Reflexivity

Recognising the attitudes, values, assumptions, and beliefs of the researcher and how these may influence the way they understand and relate to others is important in qualitative research (Berger, 2013; Dodgson, 2019). The lead author identifies as a neurotypical white British female. They have worked in autism assessment, and mental health services accessed by autistic individuals. They are interested in the social challenges faced by neurodiverse individuals and how this may impact their mental health and well-being. To increase trustworthiness, transparency, and reduce bias (Dodgson, 2019), reflective comments were made by the researcher throughout the analysis (Appendix F).

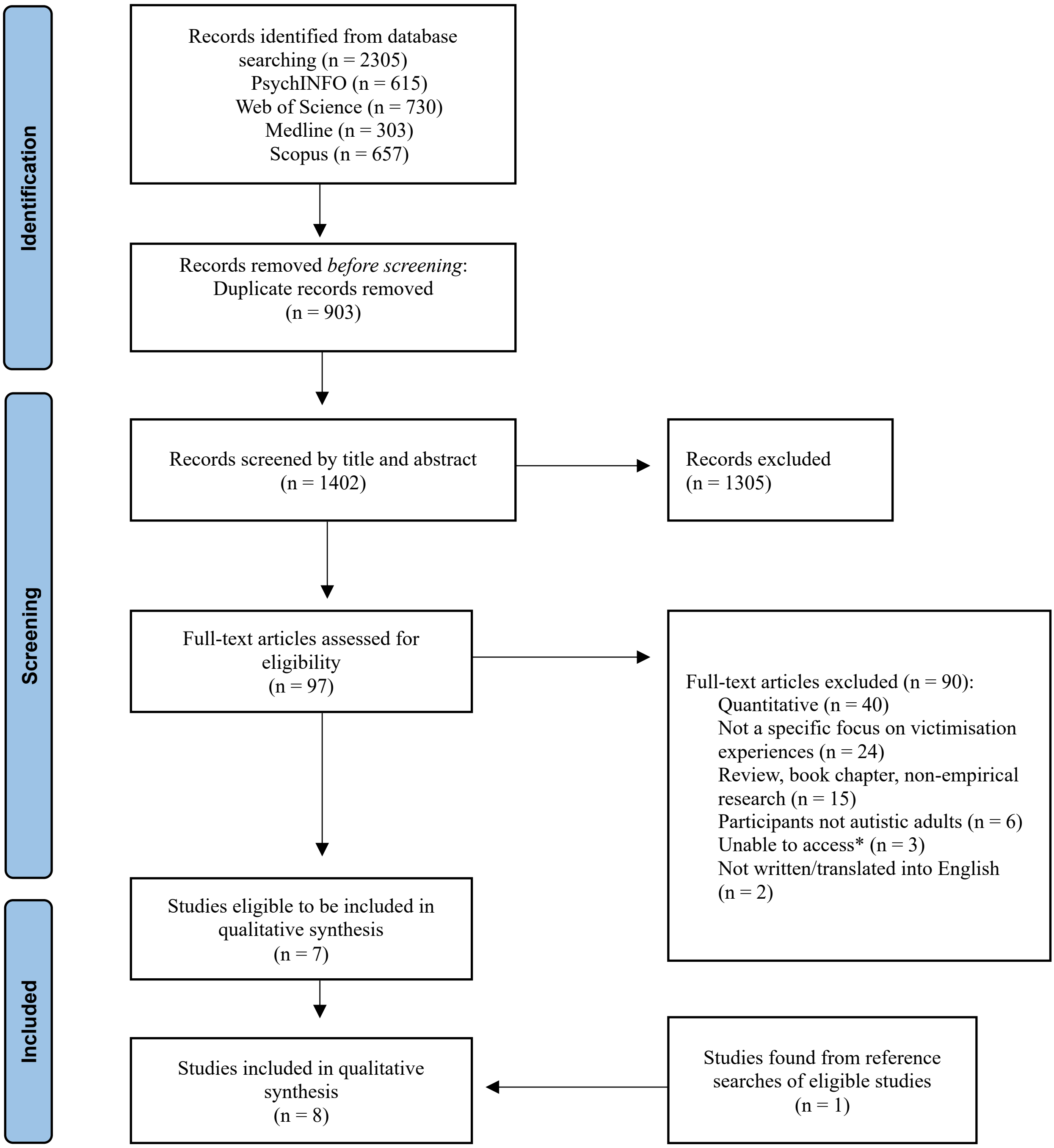
Results

Summary of Included Studies

Searches across databases yielded 1402 studies following de-duplication. After screening titles and abstracts, a further 1305 studies were removed, and 97 papers were subject to full-text review. One ambiguous study was discussed in supervision in relation to the eligibility criteria, and a unanimous decision was made. Seven papers met the inclusion criteria, and one further paper was discovered from reference searches. Overall, eight studies met inclusion criteria for the final review. The screening and identification process is shown in the PRISMA diagram (Figure 1; Moher et al., 2009).

Figure 1

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) Diagram of Study Selection Process.



**Note*. Contact to authors were made; however, no responses were received.

Studies ranged in publication dates from 2016 to 2023 and were conducted across the United Kingdom (UK; n=4), United States (US; n=2), Australia (n=1), and Canada (n=1). A total of 254 autistic individuals participated in studies whereby data was predominantly collected via semi-structured interviews (n=5). Analysis methods included thematic analysis (n=5), interpretative phenomenological analysis (n=1), and content analysis (n=2). Seven papers described the experiences of autistic adults exclusively; the eighth paper included easily identifiable data relating specifically to the autistic individuals' experience. From the studies that reported age (n=6), participants ranged in age from 16-73 years. Gender demographics were available for 224 participants, with 124 females, 75 males, 21 non-binary, and four identifying as other or preferred not to say.

Table 4

Table of Study Characteristics and Quality Appraisal Rating

Author (Year)	Country	Participant Characteristics	Recruitment	Data Collection & Methodology	Key Findings, Themes	Quality Appraisal
DeNigris et al. (2018)	United States	N=37 (22 autistic undergraduates) Aged 16-38 years (mean age = 20.7) 19 men, 3 women	Recruited during pre-test assessments used within a peer-mentorship program for autistic students at College.	Semi-structured interviews and 6-word autobiography task Thematic Analysis	"Double empathy problem" contributes to the bullying of autistic people. Autistic participants felt they were bullied because they were different / disabled. Autistic participants recommended strategies for others experiencing bullying including seeking help, ignoring the bully, and retaliating.	Poor
Fardella et al. (2018)	Canada	N= 22 autistic adults Aged 18-53 years (mean age = 30.0) 10 women, 12 men	Through notices to community-based programmes and organisations offering service to autistic adults in Canada.	Semi-structured interviews Thematic Analysis	Lack of intuition and need for connection increased vulnerability to victimisation. Need for awareness of limits in social situation and better understanding of how to identify negative relationships. A trusted person is important for support, knowledge, and protection, and society's awareness of autism needs to improve.	High
Fisher & Taylor. (2016)	United States	N= 30 autistic adults Aged 17-19 years (mean age = 18.19)	Through local clinics and other autism related research studies, support	Semi-structured interview using ADOS-4 "Social	Types of peer victimisation (verbal, physical, relational & unspecified bullying); reasons for bullying (personal attributes, others' opinion of them);	High

			groups, services providers & autism organisations	difficulties and annoyance” module Content Analysis	reactions to victimisation (in the moment, after, retaliation and intimidation, minimising, changes in relationships)	
Forster & Pearson. (2020)	United Kingdom	N= 5 autistic adults Aged 22-25 years 2 women, 3 men	Via personal networks and social media (twitter, Facebook)	Semi-structured interviews Interpretative Phenomenological Analysis	All participants had experience of bullying and victimisation within different relationships close to them. Participants shared that others make assumptions that they will not pick up on manipulation or bullying. Participants shared feelings of shame and embarrassment. Participants had developed strategies to reduce their vulnerability.	High
Gibbs & Pellicano. (2023)	Australia	N= 22 autistic adults Aged 19-57 years 13 women, 4 men, 5 non-binary	Via social media, personal networks and emails sent to autistic specific organisations	Semi-structured interviews Reflexive Thematic Analysis	IPV is commonplace for autistic people, experiencing multiple and repeated victimisation. IPV had an impact on participants’ mental health, self-concept and subsequent relationships. Participants felt easy targets and felt unable to trust their own judgement due to narratives received through childhood. Participants gave recommendations for improving autistic people’s personal safety.	High
Huxter. (2021)	United Kingdom	N = 8 autistic adults 5 women, 3 men	Searches for autobiographies written by autistic	Content Analysis of autobiographies	Manifestations of bullying were discussed including types of bullying and settings they occurred. The internal and external	Poor

			adults, containing details of bullying experiences.		effects of bullying were outlined, and the authors spoke of the mitigating circumstances of finding alternative activities or space, and having supportive relationships (friends, teachers) as useful.	
Pearson et al. (2022)a	United Kingdom	N= 43 autistic adults 27 women, 13 men, 2 non-binary	Via social media	Online survey (open ended questions) Reflexive Thematic Analysis	Participants spoke of repeated and sustained acts of victimisation, across the lifespan and within multiple relationships. Poly-victimisation led participants to see self as the problem. Participants shared difficulties trusting own instinct, recognising victimisation, and how compliance pervaded their situation.	High
Pearson et al. (2022)b	United Kingdom	N = 102 autistic adults Age range = 19-73 (Mean age = 37.8) 64 women, 21 men, 14 non-binary, 4 other/prefer not to say	Via social media and researchers' personal networks	Semi-structured questionnaire; written (n=100) or in person interview (n=2) Thematic Analysis	Victimisation described as an expected experience for autistic people, which continued from childhood into adulthood. Victimisation impacted emotionally and socially. Survival strategies included masking. Autistic people with a pre-existing support network and connections could access support more easily.	High

Note. IPV = Interpersonal Violence

Quality Appraisal Results

An overview of the critical appraisal can be found in Appendix G. A scoring strategy was implemented to give a general indication of each study's rigor. This is not a reliable or statistical indicator of rigour and is augmented by written analysis to highlight specific strengths and limitations of the studies. Overall, six studies were rated as high and two as poor quality.

All studies explicitly stated the aims of the research and selected qualitative methods appropriately, but DeNigris et al. (2018) did not clearly explain/justify the study design. One study did not clearly outline the recruitment strategy (Huxter, 2021), and two did not adequately describe the data collection methods (DeNigris et al., 2018; Huxter, 2021). Three studies did not adequately report on ethical considerations (DeNigris et al., 2018; Fisher & Taylor, 2016; Huxter, 2021). The same three papers did not outline the data analysis methods sufficiently; however, all but one provided clear findings (Huxter, 2021). Only two of the eight studies discussed the theoretical underpinnings of the study (Forster & Pearson, 2020; Pearson et al., 2022a). Four studies discussed the relationship between researchers and participants (Fardella et al., 2018; Gibbs & Pellicano, 2023; Person et al., 2022a; Pearson et al., 2022b); however, only two described ways of managing their potential biases (Fardella et al., 2018; Pearson et a.,.2022a). All studies described the findings in relation to previous research; however, the quality of the description of clinical and theoretical implications, and critique of the research varied.

Qualitative reviewers recommend not to exclude studies based on quality appraisal (Hannes & Mecaitis, 2012; Thomas & Harden, 2008); thus, no studies were excluded. The quality assessment was utilised to support the analysis and support the reader to interpret the papers in the context of their methodology.

Thematic Synthesis

Analysis of the studies identified three superordinate and several subordinate themes (Table 5). These themes are not an exhaustive list of experiences; instead, they encapsulate the dominant narratives described across the data, with some experiences overlapping within themes. See Appendix H for additional quotes.

Table 5

Themes and Subthemes

Theme	Subtheme
Victim as the Problem	An Inevitable Experience
	Blaming Ourselves
	Us Vs. Them
	Systemic Disbelief
Consequences	Distrust
	Distress
	Identity Conflict
Navigating the Aftermath	Keeping Safe
	Finding Hope in Healthy Relationships

Victim as the Problem

This theme encapsulates the narrative that those that have been victimised are the problem. Participants internalised a feeling that they are wrong based on experiences of being othered in society, and having their feelings and experiences invalidated and dismissed. Participants looked inward and assigned blame to themselves based on personal traits they felt were responsible and recognised the experience as inevitable amongst their autistic peers.

An Inevitable Experience. Participants described multiple victimisation experiences (poly-victimisation) across their lifespan, in education, employment and health settings, and within multiple interpersonal relationships (Gibbs & Pellicano, 2023; Pearson et al., 2022a; Pearson et al., 2022b). Participants shared *"I was bullied a lot growing up and victimised during my teenage years by people I thought of then as friends"* (Pearson et al., 2022a; p.145*) and "for the past 50 years . . . Some have robbed me; some have battered me. I learned that damn few people reciprocate kindness"* (Pearson et al., 2022b; p.504).

Most studies discussed how victimisation was accepted as a standard experience for autistic people, given such high levels of exposure to victimisation throughout childhood into adulthood. They reported *"not really knowing any different… and not realising it's not normal"* (Gibbs & Pellicano, 2023; p.5), and *"I think my experiences are pretty standard"* (Pearson et al., 2022b; p.504).

Moreover, when attempting to seek support from others, this was met with minimisation and dismissal, stating it as something they must "*put up with*" (Gibbs & Pellicano, 2023; p.6). As such, others tended to view victimisation as an inevitable thing that autistic people should and will experience.

> *"they [family/friends] say 'what did you expect would happen' so you learn not to even try [seeking help]"* (Pearson et al., 2022b; p.505)

Blaming Ourselves. Throughout studies, participants seemed to experience victimisation as their fault, predominantly because of their autistic traits. Participants assigned blame across various aspects of their difficulties, including difficulties with social skills both in initiating interactions and reading social cues and others' intentions (DeNigris et al., 2017; Fisher & Taylor, 2016; Forster & Pearson, 2020; Gibbs & Pellicano, 2023; Huxter, 2021). Participants stated, *"I take things literally and miss so much of some people's* *manipulative behaviour, I'm oblivious"* (Pearson et al., 2022a; p.145) suggesting they felt that their difficulties blocked their awareness that they were unsafe.

Messages from others telling participants that something is *"wrong with them"* (Gibbs & Pellicano, 2023; p.8) further perpetuated the narrative that they are to blame for their lack of insight and ability to manage interpersonal relationships without being victimised. One participant reflected *"I believe there is something wrong in the way I introduce myself to friendship which makes people feel I am worth nothing beyond physical resources"* (Pearson et al., 2022a; p.145).

Despite socialising being acknowledged as a challenge for participants they shared a desire for social connection and friendships, which increased their risk for victimisation. Participants specifically spoke of their need for connection impeding their need to be safe and as such they would *"please them [friends] to try to make them like me"* (Pearson et al., 2022b; p.505).

> *"doing what other people want, that people pleasing and compliance, makes you a really good target for people who want someone subservient and who like to exercise power and control"* (Gibbs & Pellicano, 2023; p.7)

Participants blamed themselves for *"being too trusting"* (Pearson et al., 2022a; p.145), and wanting to see the *"good in people"* (Gibbs & Pellicano, 2023; p.7). They expressed that the assumption that others operate in the same way can lure people into thinking "*people are our friends when they're not*" (Gibbs & Pellicano, 2023; p.7) and leave them vulnerable to victimisation.

Finally, a common experience amongst many participants was the internalisation of shame following victimisation experiences. Participants felt as though "*it was my fault*" (Gibbs & Pellicano, 2023; p.6) and they were to blame, which had implications for the likelihood of seeking help and left them with feeling "*traumatised and humiliated*" (Huxter, 2021; p.8).

> *"there's an element of shame that I should have known better, like, that was a dumb thing to do"* (Gibbs & Pellicano, 2023; p.5)

Us Vs. Them. Many participants indicated that they experienced victimisation because they were different from the majority (DeNigris et al., 2017; Fisher & Taylor, 2016; Gibbs & Pellicano, 2023; Pearson et al., 2022b). Participants appeared angry and frustrated that they were "*socially excluded*" (Huxter, 2021; p.8) and not accepted for who they are, whilst neurotypical people are. One participant shared how spending their entire life being invalidated and rejected by others led them to internalise a feeling that *"I'm wrong*" (Gibbs & Pellicano, 2023; p.5) which appeared to give others a free pass to take advantage.

Participants felt society perpetuates an out-group mentality, and this allows for behaviours of discrimination toward those that are different to be excused. One participant said *"It seems okay to discriminate against people with ASD and because of that people have license to do whatever. What we need to do is we need to change that attitude"* (Fardella et al., 2018; p.1471). They felt that unless they fell in line with western society constructed norms they will always be subjected to being made to "*feel othered*" (Pearson et al., 2022b; p.507).

> *"There are a couple of people who get it, but the majority don't, nor do they try. Why would they? They are the dominant society and we are not part of it"* (Pearson et al., 2022b; p.505)

Additionally, participants highlighted that society generally has learning to do about autism and how people who are different deserve to be treated, but that this should not be "*teaching the minority to be the same as everyone else*" (Gibbs & Pellicano, 2023; p.8).

> *"The public has to learn more about ASD and learn that it's not okay to discriminate against us. The public must learn that it is okay to be different. Just because we're not like them doesn't mean that we are any less"* (Fardella et al., 2018; p.1471)

Systemic Disbelief. Participants spoke of attempting to seek help from family and peers but their experiences being dismissed and minimised. One participant said *"I often told my mom what happened. Sometimes she would not do anything"* (Fardella et al., 2018; p.1470). Disclosing their experience to family members and peers sometimes resulted in being accused of being "*dramatic… a way for me to get attention*" (Gibbs & Pellicano, 2023; p.6) or "*too sensitive*" (Pearson et al., 2022a; p.145) which had implications for these relationships. For example, *"[there was a] whole year of my life in which my dad would not talk to me because he did not believe me"* (Gibbs & Pellicano, 2023; p.6).

Some shared that the denial, dismissal, and lack of concern from family and friends was the *"most traumatising part"* (Gibbs & Pellicano, 2023; p.6). This invalidation also precipitated thoughts that they were the "*horrible person*" (Pearson et al., 2022a; p.145) for thinking they were being victimised when others were saying they were not. Participants reflected on this as being "*gaslit*" (Pearson et al., 2022a; p.145).

Others shared specific examples of seeking support from services, such as the police, victim support, and mental health services; but were not taken seriously, ridiculed by them, or their incompetence exacerbated the problem.

> *"I was told I should admit myself to a mental health ward and they made my mental health so much worse and invalidated my pain and expression of pain even further . . . it only made things worse"* (Pearson et al., 2022b; p.506)

Reflections from childhood experiences also indicated limited ways of accessing support for bullying. One participant explained that *"there was no-one to approach"* (Huxter, 2021; p.9) and another explained that their school *"introduced a way of making it hard to snitch on people"* (Fisher & Taylor, 2016; p.406) presenting as a barrier to seeking help.

Consequences

This theme encompasses the shared narratives about the impact of being victimised. Participants discussed the consequences that victimisation had on their daily functioning, future relationships, and their sense of self.

Distrust. Not feeling able to trust their own intuition or gut feeling was a common narrative expressed by participants. Participants explained that they had often been told from childhood that they do not have instinct and therefore would doubt themselves when trying to distinguish whether they were in a safe or unsafe situation. Moreover, as mentioned in a previous subtheme, "*not being able to trust our feelings and trust our own thought processes*" (Gibbs & Pellicano, 2023; p.7) was perpetuated by not being believed by others. Despite this, one participant stated, *"I wish there were services where you could go and check whether how you were being treated was normal"* (Pearson et al., 2022b; p.507). Highlighting the need to have their gut feeling validated by others.

Experiences of victimisation had consequences for future relationship building. These experiences extinguished the desire to connect with people at all for some participants, sharing "*I no longer do relationships or friendships"* (Pearson et al., 2022b; p.506).

Others highlighted the hypervigilance required if initiating friendships following difficult experiences. As such the sense that participants no longer felt safe within relationships was evident and had an impact on "*security for all of my relationships*" (Gibbs & Pellicano, 2023; p.6) and feeling as though "*everyone is out to get you*" (Huxter, 2021; p.8).

> *"Really try to get to know people as best you can because you start to learn whom you can trust and whom you can't. And if you can't trust them, stay away from them"* (Fardella et al., 2018; p.1468)

Distrust in authority or assumed supportive figures was deepened via negative help-seeking experiences. Participants shared these negative experiences can *"lead to a lack of trust in the advice offered by others"* (Huxter, 2021; p.8).

> *"I felt I couldn't trust adult figures which was further compounded. I didn't feel safe with authority figures, nor did I trust they actually meant it when they said I could reach out to them for help"* (Pearson et al., 2022a; p.145)

Distress. Following victimisation experiences, participants spoke of immediate distress, having a "*breakdown*" and "*going on stress leave for a month*" (Gibbs & Pellicano, 2023; p.5). Participants reported "*anxiety, stress, and a huge lifetime of depression*" (Gibbs & Pellicano, 2023; p.5) and living with a "*constant sense of dread*" (Pearson et al., 2022b; p.505) which was accompanied with low self-worth and at times self-harming behaviours. Participants described their experiences as traumatic, and how they were left with being "*a unit made up of trauma responses"* (Gibbs & Pellicano, 2023; p.5).

The impact on participants' mental health had wider consequences for their daily functioning. Participants were stressed, uncomfortable, and their sense of safety in the world had been destroyed. Participants were frightened, and as such one participant shared that they felt "*terrified of catching the bus alone*" (Huxter, 2021; p.8) and another became so isolated they did not leave the house, "*I wasn't comfortable going for a walk or anything*" (Gibbs & Pellicano, 2023; p.5).

Identity Conflict. As a consequence of their victimisation, participants felt the need to change themselves to fit in with society's version of normal, which left them with no sense of self. It was identified that those around them appeared to encourage such change in both appearance and personality to enable them to "*fit in*" (Gibbs & Pellicano, 2023; p.7) and feel like they belong. Participants spoke of the implications of not being permitted to be their authentic self, such as not having a *"sense of self"* (Gibbs & Pellicano, 2023; p.5) and being *"robbed of so many opportunities to fully develop as a person"* (Pearson et al., 2022b; p.505).

One study highlighted having to hide their identity by masking, as a "*survival skill*" (Pearson et al., 2022b; p.505), to reduce the likelihood of being further victimised. However, the process of masking their true self was described as "*exhausting*" and "*identity-denying*" (Pearson et al., 2022b; p.505). Furthermore, the process of masking seemed to have longer-lasting consequences on recovery.

> "*masking my entire life either for safety reasons or to enable myself to keep a job. Over time It has caused massive burnout . . . I haven't fully recovered*" (Pearson et al., 2022b; p.505)

Navigating the Aftermath

This theme encompasses the narratives shared around navigating moving forward with their lives including how their victimisation experiences have shaped their ability to keep themselves safe, what is needed for autistic people to feel better informed of the dangers they may encounter, and ways that healthy and accepting relationships can offer a hopeful future.

Keeping Safe. This theme encapsulates participants' reflections about risk from others, and what is needed for them to keep themselves safe as they start to rebuild their life following victimisation. Participants described prior difficulties with recognising *"dangerous relationship's"* and understanding *"when abuse is abuse"* (Gibbs & Pellicano, 2023; p.6) which meant they found themselves in *"dangerous situations"* (Gibbs & Pellicano, 2023; p.7). Compliance and ignorance were noted across multiple studies as a way of navigating their safety (DeNigris et al., 2017; Fisher & Taylor, 2016; Huxter, 2021; Pearson et al., 2022a). One participant stated *"I knew I had to do what they told me and be their 'friend' or else they would make my life hell" (Pearson et al., 2022a; p.146).* However, this strategy was not always successful, and at times increased perpetrators' persistence and violence (Fisher & Taylor, 2016; Huxter, 2021).

Given such exposure to victimisation experiences, participants spoke of needing to remain hypervigilant to threat. As such, one participant advised other autistic people to *"always be aware of your surroundings. The worst thing you can do in public is to zone out"* (Fardella et al., 2018; p.1466). Further, participants shared a narrative of learning from their victimisation experiences and putting measures in place to ensure their safety in the future. For example, a participant shared "*when I meet up with friends, I stay away from the city centre*" (Forster & Pearson, 2020; p.1116) to avoid perpetrators. Other participants looked inward and initiated a change in their reactions to others, learning "*to be more non-confrontational and just mellow out"* and paying closer *"attention to what came out of my mouth."* (Fisher & Taylor, 2016; p.406). Furthermore, having such negative experiences allowed participants to *"recognise the red flags"* and *"never make the same mistakes I made with that past partner again"* (Pearson et al., 2022b; p.507).

Participants also highlighted that better education is required to teach ways of recognising danger and to prevent further victimisation experiences amongst autistic individuals. Participants felt sex education was particularly poor as *"it does not cover the red flags that lead up to it [abuse]"* (Gibbs & Pellicano, 2023; p.7) and how to evade dangerous situations.

> *"When teaching about sexual violence you could say 'Keep an eye out for this, these are risk factors, these are things you want to avoid'. These things may be obvious to a neurotypical person but might not be obvious to someone with ASD"* (Fardella et al., 2018; p.1468)

Finding Hope in Healthy Relationships. Having someone acting in the participant's best interests (a healthy relationship) helped them to seek clarity during and following victimisation experiences (Fardella et al., 2018; Forster & Pearson, 2020; Gibbs & Pellicano, 2023; Huxter, 2021). Participants spoke of family or friends who were able to point out when they were being taken advantage of (Forster & Pearson, 2020) or were there to ask questions about situations they were unsure of.

> *"I am from a big family so I always have people I can ask because if something doesn't feel right ... like say 'they did this and this ... what does that mean?' My family knows me well enough to say that person is not your friend"* (Fardella et al., 2018; p.1469)

Understanding and acceptance were highlighted as essential foundations for future healthy relationships following victimisation. Having had such negative experiences within past relationships appeared to enable "*an even better understanding than most what a healthy relationship is"* (Pearson et al., 2022b; p.507) and highlighted the importance of acceptance and having people *"who will actually take your side"* (Fardella et al., 2018; p.1470).

> *"She respects my autistic identity . . . I accept her irritating but socially acceptable neurotypical ways and she accepts me for the human being I am"* (Pearson et al., 2022b; p.507)

Finally, two studies highlighted the importance of having access to the autistic community, to "*learn from each other*" (Fardella et al., 2018; p.1469) and support the recovery process as they feel *"recovering comes from talking to other autistic people and fighting back as a community"* (Pearson et al., 2022b; p.507).

Discussion

This review aimed to identify, critically appraise, and thematically synthesise qualitative literature to provide a more in-depth understanding of autistic adults' experience of victimisation within interpersonal relationships. Three superordinate themes were identified: '*victim as the problem', 'consequences'*, and '*navigating the aftermath'*.

The first superordinate theme, '*victim as the problem',* primarily reflects the narrative perpetuated by society that autistic people are different and, therefore, should expect to be mistreated and victimised by others (Gibbs & Pellicano, 2023; Pearson et al., 2022b). Autistic adults described victimisation as normal for them and their autistic peers, aligning with quantitative research reporting significantly higher rates of peer victimisation, childhood abuse, and violence victimisation in adulthood (Hellstrom, 2019; Trundle et al., 2022; Weiss & Fardella, 2018). Further evidenced across studies, autistic adults shared the experience of victimisation across their lifespan, within multiple settings and relationships. This experience of poly-victimisation is consistent with previous quantitative reviews (Hellstrom, 2019).

Autistic adults felt a causal factor to their increased prevalence of victimisation could be explained by the process of othering. The concept of 'autistic as other' allows for the alienisation of autistic people, which ultimately leads to a discourse of autistic people being dehumanised[5] (Hacking, 2009). Further, when considered in relation to the minority stress

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[5] Dehumanisation is the rejection of 'humanness' to other people, a socio-cognitive phenomenon, showing the bias whereby one see's their own group as better than others (Haslam, 2006).

model (Meyer, 2013), autistic people are contextualised as a minoritized group within a society that marginalises, discriminates against, and victimises them. Thus, being othered by society is perpetuated by their minority status and somewhat appears to permit victimisation.

Studies in the current review highlighted autistic adults' tendency to blame their autistic traits for their vulnerability. Although participants showed an awareness of their personality and actions (Schriber et al., 2014), the lifetime of internalising negative attitudes and reactions of others appears to have increased the likelihood of negative self-appraisal, as outlined by previous studies (Bagatell, 2007; Portway & Johnson, 2005; Punshon et al., 2009; Woods, 2017).

Shame was also highlighted within studies, suggesting that being victimised was shameful, and they should have known better. Shame promotes avoidance and withdrawal to protect oneself from further harm (De Hooge et al., 2010) and has been linked with increased social anxiety (Matos et al., 2013). Shame experienced by the participants in this review is perhaps related to internalised ableism, whereby an unrealistic concept of perfection is ingrained in how we think about ourselves and our actions. Ableism fosters the narrative that having a disability is negative and unfavourable (Campbell, 2019), promoting acceptance of victimisation. Aligned with research conducted with the general population (MacGinley et al., 2019), shame hindered psychological adjustment following victimisation. Further research exploring shame following victimisation amongst autistic populations is indicated.

Furthering the internalisation that they are the problem, autistic people reported a distinct lack of social support. They reported being dismissed by people they disclosed their experience to (e.g., family, friends), which was described by some as worse than the victimisation event itself. The invalidation of autistic people's thoughts, feelings, and experiences by others, coupled with the dismissal of their disclosure, can be understood as epistemic injustice (Fricker, 2007). As such, society's preconceived ideas about autistic people, predominantly based on stereotypes, increase the likelihood of them being perceived as not credible and therefore experiencing testimonial injustice (Fricker, 2007). Structural inequalities were further highlighted as a barrier to help-seeking and recovery. Those who attempted to seek help found systems to be unhelpful, heightening psychological distress. This is consistent with minority group experiences whereby prejudice and bias are evident in services which can trigger further trauma (Kulkarni, 2019).

The second superordinate theme, '*consequences',* encompasses victimisation experiences' impact on autistic adults. The common mental health difficulties documented by autistic adults across studies following victimisation experiences are unsurprising given the research linking traumatic events with increased psychological distress and mood symptomology in the general population (Breslau, 2001; Scheiderer et al., 2015; Yehuda et al., 2001), and autistic populations (Taylor & Gotham, 2016). Psychological interventions are offered to address psychological distress and the impact of trauma (National Institute for Health and Care Excellence, 2018); however, there is a paucity of research examining the efficacy of such interventions for autistic people. Moreover, timely access to trauma interventions to minimise the adverse psychological effects of victimisation is unlikely, given the barriers to mental health treatment experienced by autistic people (Camm-Crosbie et al., 2019).

Autistic adults highlight masking their authentic identity (Forster & Pearson, 2020) as a response to stigmatisation and societal expectations (Han et al., 2022), demonstrating how social prejudice and discrimination play a role in victimisation adversity. Furthermore, aligned with previous research (Cage & Troxell-Whitman, 2019; Hull et al., 2017), masking and trying to 'fit in' with peers was highlighted as a survival strategy to camouflage their differences and attempt to prevent further victimisation. The trauma of experiencing victimisation increased autistic adults masking behaviours which often led to burnout, highlighting its impact on autistic people's mental well-being (Cage et al., 2018). Principally, common coping strategies can exacerbate the impact of victimisation and further destabilise autistic people's mental well-being.

Trust was a dominant theme across studies. Such that autistic adults spoke of the process of becoming untrusting within new relationships, not being able to trust authority figures, and not feeling able to trust their gut instincts. Recognising the broken trust in support systems and services is particularly important as this will make it increasingly difficult for an autistic person to seek support following victimisation (Pearson et al., 2022b). There is an evident lack of autism awareness training among authority figures in support roles (e.g., police) which has been shown to lead to negative help-seeking experiences (Crane et al., 2016; Hepworth, 2017).

The final theme, '*navigating the aftermath',* provides accounts of how autistic adults have generally coped following the experience of victimisation, including reflecting on mistakes they have made in the past and what is needed for them moving forward. Compliance was described as a way of navigating the aftermath of victimisation to avoid further victimisation experiences. However, as described by autistic people, compliance tended to increase their vulnerability and enable re-victimisation. These findings highlight the importance of emphasising that compliance training interventions aimed at autistic people may be unhelpful and could increase the risk of victimisation (Bottema-Beutel & Pavlopoulou, 2021; Davison, 2018). Autistic adults also spoke of learning that retaliation and confrontation did not afford them safety, highlighting how retaliation may halt the victimisation at that moment and encourages the perpetrator in the longer term (Cowie & Berdondini, 2002).

The findings of this review highlight a shared consensus that better education is needed to teach autistic people how to recognise and avoid danger. There was a particular negative narrative around formal sexual education, or lack of, for autistic people in education settings. Challenges related to victimisation experienced by autistic people are situated within the broader context of discrimination and disadvantage (Dowse et al., 2016; Platt et al., 2017). As such, autistic people are afforded fewer opportunities to complete formal education, such as sex education (Brown-Lavoie et al., 2014). These findings are consistent with research suggesting autistic people have lower levels of sexual knowledge (Brown-Levoie et al., 2014; Joyal et al., 2021), less sexual experience (Strunz et al., 2017) and a want for increased opportunity to be educated about sex, relationships, and sexuality (Cheak-Zamora et al., 2019). Though there remains a paucity of interventions aimed at increasing knowledge of healthy relationships and attitudes to stimulate the reduction in interpersonal victimisation for autistic adults, unlike for the general population (Connolly et al., 2015).

Positively, participants reflected on their newfound ability to understand what a healthy relationship is following victimisation experiences. There was a shared sense that healthy relationships were based on mutual understanding and acceptance. Considered in relation to the 'double empathy problem'[6] (DEP; Milton, 2012), which describes how neurotypical and autistic individuals commonly misunderstand one another, the current review highlights the need for both parties to make adjustments to enable a mutually empathetic relationship. Although recent research has found neuro-mixed relationships to be of lower quality (Morrison et al., 2019), this does not have to be the case, as outlined by participants in this review.

Critique of Included Studies

Half of the studies did not clearly comment on the relationship between the participants and the researchers. Reflexivity should be an integral process within qualitative

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[6] DEP (Milton, 2012) suggests that when interactions between people with very different experiences of the world occur, they will find it challenging to empathise and understand one another. Likely exacerbated by differences in comprehension and language use.

research, given how biases and views may influence interpretations (Flemming & Noyes, 2021). It is a methodological limitation of the studies that did not acknowledge reflexivity. Positively, two studies (Fardella et al., 2018; Pearson et a.,.2022a) reported on the potential biases held by the authors given their experiences working with autistic individuals or being an autistic individual themselves and stated how they implemented ways to offset potential biases (e.g., team discussions, reflexivity rumination). This enabled increased trustworthiness and clarity for the reader to understand how particular conclusions were developed.

Three studies (DeNigris et al., 2018; Fisher & Taylor, 2016; Huxter, 2021) did not adequately describe ethical considerations. Of the three studies, two mentioned informed consent; however, they did not give clear information about how ethical standards were maintained or how the participants were informed of ethical considerations. Two studies did not state whether ethical approval was obtained. Perhaps as Huxter (2021) analysed data involving information freely available in the public domain, they may not have needed ethical approval (Harrison & Lyon, 1993); however, this needed to be made clear. As the protection and safeguarding of participants is essential as a researcher (Sutton & Austin, 2015), unclear reporting of ethical considerations is therefore a significant weakness of these papers.

All studies stated clear aims and described data collection methods. Seven studies utilised multiple researchers during analysis and/or data collection to improve credibility and rigour, which is a significant strength of those papers. Furthermore, the involvement of autistic people was attained in three studies (Gibbs & Pellicano, 2023; Pearson et al., 2022a; Pearson et al., 2022b). Experts by experience involvement is particularly important in autism research given the concept of the ‘double empathy problem’ (Milton, 2012). This could potentially pose problems throughout all stages of qualitative research.

Limitations of the Review and Future Directions

The volume of literature on interpersonal victimisation experiences amongst autistic adults is limited and emerging. All studies are relatively recent, suggesting the topic is a new yet significantly important area of interest to further understand autistic people's adversity. Given such paucity of research, two aims of the review could not be explored in full as not all papers focused on affect or ways of coping. Positively, this review addressed a gap in the literature and is the first review of this topic which contributes considerably to the autistic adult research on victimisation. Given this gap, the researcher used broad search terms to attempt to yield as many studies as possible whilst maintaining consideration for the eligibility criteria to ensure the included studies specifically explored the experience of victimisation. It was a strength that attempts were made to ensure all relevant papers were found, including forwards and backward citation searches of all included papers.

The same research group undertook several of the included papers as experts in the field, which can create a bias in the findings. However, across papers, the authors collected data from different samples, had distinctive research questions, and produced different themes based on participants' responses.

The review excluded grey literature and papers not published in the English language. Despite appropriate reasons for this, potential bias (e.g., cultural bias) remains. Future reviews may benefit from the inclusion of grey literature and papers not written in the English language.

Furthermore, the review excluded articles that did not explicitly focus on the participant's victimisation experiences as the main aim. Given the search terms the papers had to have victimisation in their keywords or titles to be captured, the review may have missed articles exploring phenomena such as friendship conflicts that may have themes relating to victimisation experiences. Future reviews may therefore wish to consider the inclusion of any study that yielded a theme relating to victimisation to broaden the understanding of contextual factors relating to victimisation experiences.

The definition of interpersonal relationships differs within research. Papers were included in this review if the victimisation was experienced at school or college by peers. This decision was made via discussions within supervision and based on the premise that the perpetrator (school or college peer) was known to the victim (autistic person; Fardella et al., 2018). Future research could consider whether there are differences in the impact of victimisation experiences based on the closeness of the relationship (e.g., peer versus familial relationship) and whether differing recovery interventions are required based on the relationship type.

An adapted version of the CASP (2018) qualitative checklist was utilised to critically appraise the quality of the included papers based on its wide use and accessibility across differing analysis approaches. However, as the questions are answered with a “yes”, “no” or “can’t tell” there is the possibility of significant rater variation. Within this review, a second rater was used to increase reliability; however, perhaps a tool with better sensitivity would better highlight the variance of study quality.

Clinical Implications

This review highlights the societal attitudinal change required. There needs to be a recognition that developing resilience in autistic individuals is not a resolution, as this may shift the accountability from the perpetrator to the victim (Pearson et al., 2022a). Autism services, community psychologists, and educational settings could provide educational initiatives to the public with accurate and de-shaming information to increase acceptance of autism and decrease stigma. Considering equality and diversity, providing this physically and electronically may help reach a wide range of individuals of differing demographics to encourage a broader societal attitudinal shift.

In line with autistic adults' recommendation within the review about their desire for better sex and relationship education, it would be useful for this content to be taught within schools. For example, the role of Education Mental Health Practitioner (EMHP), supervised by clinical psychologists, within school could support psychoeducation on sexual development, the foundations of healthy relationships, and potential relational dangers. Furthermore, safety programmes are available for autistic youth and young adults, focusing largely on practical aspects of safety such as crossing the street (Josman et al., 2008). This review further highlights the need for such programmes to broaden their understanding of safety and include interpersonal victimisation safety awareness.

Moreover, for victimised autistic adults to report and disclose their experiences, it is essential that their experiences with systems intended to support are positive. As highlighted, an inadequate understanding of autism within public and mental health services likely facilitates inadequate support (Crane et al., 2016). Better autism awareness training is required to ensure the fair treatment of autistic people across settings.

This review highlights that some autistic individuals may benefit from evidence-based trauma interventions following victimisation experiences. Considering the three-stage trauma model (Herman, 1998), re-establishing safety following victimisation may be indicated for those whose sense of safety has been destroyed. Trauma stabilisation can be offered as a standalone intervention or before therapy focussed on processing trauma memories and working toward reintegrating values and goals into their lives. Moreover, Trauma-Focused Cognitive Behavioural Therapy is recommended for the general population, and adaptations have been recommended for the autistic population (Peterson et al., 2019). Research is required to investigate the efficacy of such approaches for autistic people. Tailored approaches by clinicians are essential for autistic people to have better mental health help-seeking experiences.

Finally, as desired by autistic people, clinicians could facilitate, advocate for, and promote autistic support groups to enable a sense of community and support with the recovery process following victimisation.

Conclusion

This review supports previous quantitative meta-analyses highlighting the increased prevalence of victimisation experienced by autistic adults across their lifespan, settings, and relationships. The results show the internalised stigma of holding a minority status and the excuse this affords perpetrators, alongside how a lack of support and negative help-seeking experiences present as barriers to recovery. Distrust, distress, and identity conflict followed victimisation experiences. Positively, some autistic adults established post-victimisation healthy relationships. Autistic adults highlighted a need to keep themselves safe, with the acknowledgement that some strategies do not allow for safety and can increase mental health difficulties. A societal attitudinal shift, better sex and relationship education, and trauma-focused interventions are indicated to prevent and reduce the impact of victimisation.

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Appendices

Appendix A

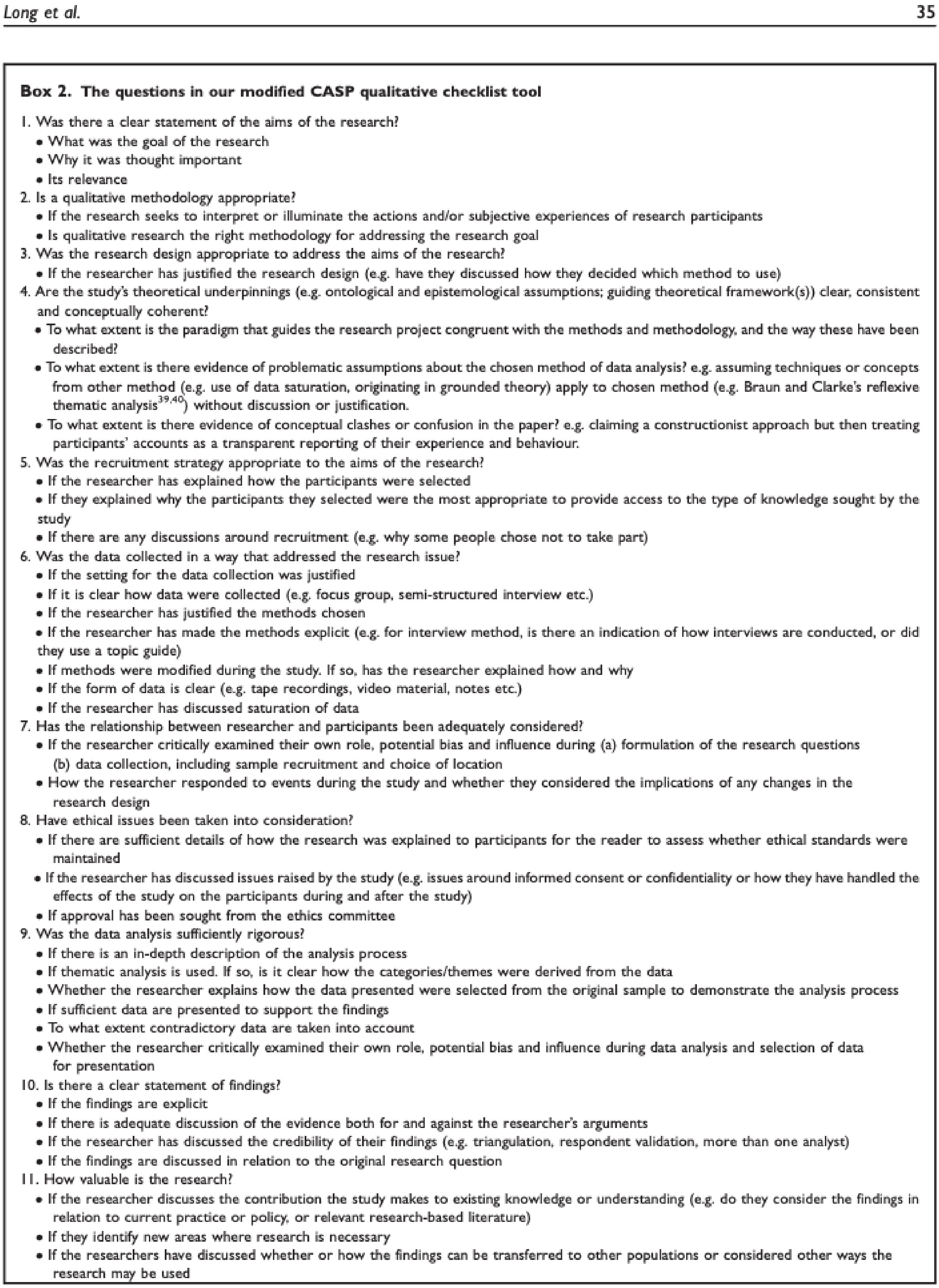
Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) Guidelines (Tong et al., 2012)

No.	Item	Guide and Description	Page Number
1	Aim	State the research question the synthesis addresses	pp.7
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology (e.g., meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	pp.7, 11
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	pp.7
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g., in terms of population, language, year limits, type of publication, study type).	pp.9
5	Data sources	Describe the information sources used (e.g., electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	pp.7
6	Electronic search strategy	Describe the literature search (e.g., provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	pp.8
7	Study screening methods	Describe the process of study screening and sifting (e.g., title, abstract and full text review, number of independent reviewers who screened studies).	pp.8, 11, 12
8	Study characteristics	Present the characteristics of the included studies (e.g., year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	pp.13, 14
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g., for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).	pp.11, 12

10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	pp.10, 17
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	pp.10
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	pp.10
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	pp.14-16, 17
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	pp.10-11
15	Software	State the computer software used, if any.	pp.10
16	Number of reviewers	Identify who was involved in coding and analysis.	pp.11
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts)	pp.10, Appendix C-E
18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	pp.10
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	pp.10
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation	pp.18-27, Appendix H
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	pp.18-32

Appendix B

Adapted CASP Qualitative Research Checklist (Long et al., 2020)



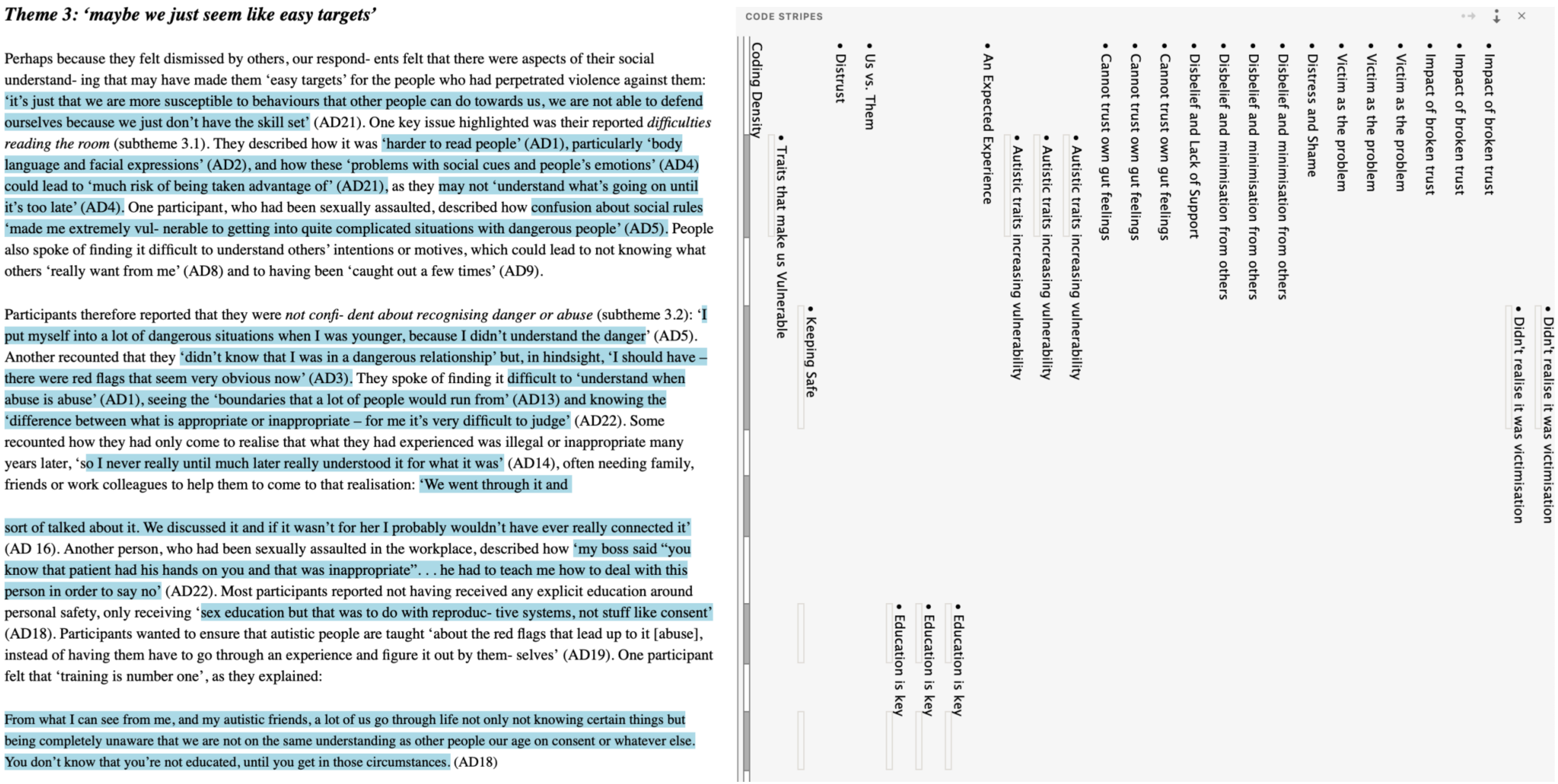
Long et al. 35

Box 2. The questions in our modified CASP qualitative checklist tool

1. Was there a clear statement of the aims of the research?
   - What was the goal of the research
   - Why it was thought important
   - Its relevance
2. Is a qualitative methodology appropriate?
   - If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
   - Is qualitative research the right methodology for addressing the research goal
3. Was the research design appropriate to address the aims of the research?
   - If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)
4. Are the study's theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?
   - To what extent is the paradigm that guides the research project congruent with the methods and methodology, and the way these have been described?
   - To what extent is there evidence of problematic assumptions about the chosen method of data analysis? e.g. assuming techniques or concepts from other method (e.g. use of data saturation, originating in grounded theory) apply to chosen method (e.g. Braun and Clarke's reflexive thematic analysis[39,40]) without discussion or justification.
   - To what extent is there evidence of conceptual clashes or confusion in the paper? e.g. claiming a constructionist approach but then treating participants' accounts as a transparent reporting of their experience and behaviour.
5. Was the recruitment strategy appropriate to the aims of the research?
   - If the researcher has explained how the participants were selected
   - If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
   - If there are any discussions around recruitment (e.g. why some people chose not to take part)
6. Was the data collected in a way that addressed the research issue?
   - If the setting for the data collection was justified
   - If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
   - If the researcher has justified the methods chosen
   - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
   - If methods were modified during the study. If so, has the researcher explained how and why
   - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
   - If the researcher has discussed saturation of data
7. Has the relationship between researcher and participants been adequately considered?
   - If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
   - How the researcher responded to events during the study and whether they considered the implications of any changes in the research design
8. Have ethical issues been taken into consideration?
   - If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
   - If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
   - If approval has been sought from the ethics committee
9. Was the data analysis sufficiently rigorous?
   - If there is an in-depth description of the analysis process
   - If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
   - Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
   - If sufficient data are presented to support the findings
   - To what extent contradictory data are taken into account
   - Whether the researcher critically examined their own role, potential bias and influence during data analysis and selection of data for presentation
10. Is there a clear statement of findings?
    - If the findings are explicit
    - If there is adequate discussion of the evidence both for and against the researcher's arguments
    - If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
    - If the findings are discussed in relation to the original research question
11. How valuable is the research?
    - If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
    - If they identify new areas where research is necessary
    - If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix C

Line-by-Line Coding Example (NVivo)



Theme 3: ‘maybe we just seem like easy targets’

Perhaps because they felt dismissed by others, our respond- ents felt that there were aspects of their social understand- ing that may have made them ‘easy targets’ for the people who had perpetrated violence against them: ‘it’s just that we are more susceptible to behaviours that other people can do towards us, we are not able to defend ourselves because we just don’t have the skill set’ (AD21). One key issue highlighted was their reported *difficulties reading the room* (subtheme 3.1). They described how it was ‘harder to read people’ (AD1), particularly ‘body language and facial expressions’ (AD2), and how these ‘problems with social cues and people’s emotions’ (AD4) could lead to ‘much risk of being taken advantage of’ (AD21), as they may not ‘understand what’s going on until it’s too late’ (AD4). One participant, who had been sexually assaulted, described how confusion about social rules ‘made me extremely vul- nerable to getting into quite complicated situations with dangerous people’ (AD5). People also spoke of finding it difficult to understand others’ intentions or motives, which could lead to not knowing what others ‘really want from me’ (AD8) and to having been ‘caught out a few times’ (AD9).

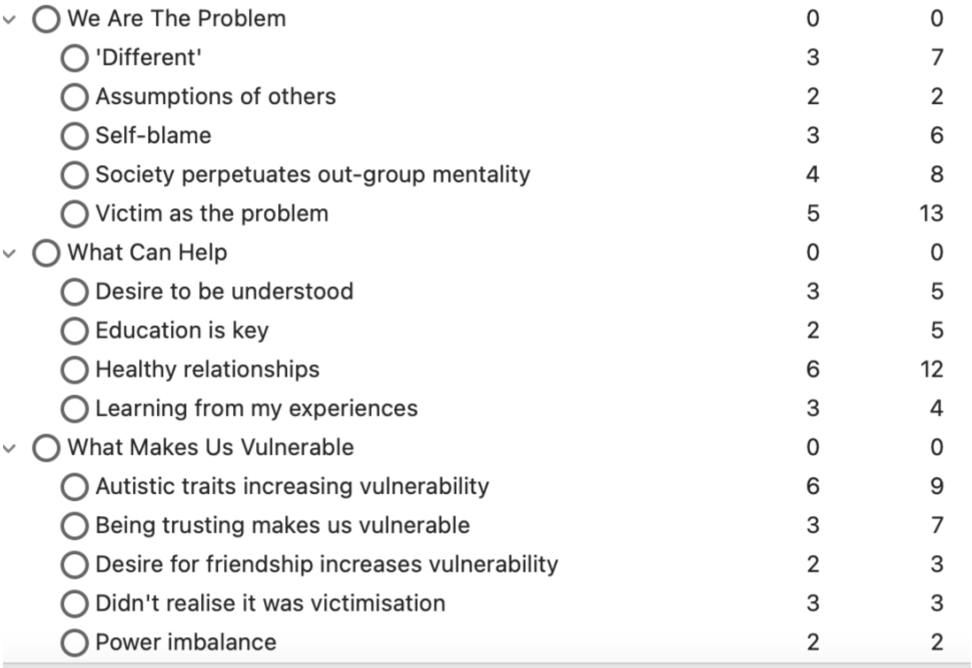
Participants therefore reported that they were *not confi- dent about recognising danger or abuse* (subtheme 3.2): ‘I put myself into a lot of dangerous situations when I was younger, because I didn’t understand the danger’ (AD5). Another recounted that they ‘didn’t know that I was in a dangerous relationship’ but, in hindsight, ‘I should have – there were red flags that seem very obvious now’ (AD3). They spoke of finding it difficult to ‘understand when abuse is abuse’ (AD1), seeing the ‘boundaries that a lot of people would run from’ (AD13) and knowing the ‘difference between what is appropriate or inappropriate – for me it’s very difficult to judge’ (AD22). Some recounted how they had only come to realise that what they had experienced was illegal or inappropriate many years later, ‘so I never really until much later really understood it for what it was’ (AD14), often needing family, friends or work colleagues to help them to come to that realisation: ‘We went through it and sort of talked about it. We discussed it and if it wasn’t for her I probably wouldn’t have ever really connected it’ (AD 16). Another person, who had been sexually assaulted in the workplace, described how ‘my boss said “you know that patient had his hands on you and that was inappropriate”. . . he had to teach me how to deal with this person in order to say no’ (AD22). Most participants reported not having received any explicit education around personal safety, only receiving ‘sex education but that was to do with reproduc- tive systems, not stuff like consent’ (AD18). Participants wanted to ensure that autistic people are taught ‘about the red flags that lead up to it [abuse], instead of having them have to go through an experience and figure it out by them- selves’ (AD19). One participant felt that ‘training is number one’, as they explained:

> From what I can see from me, and my autistic friends, a lot of us go through life not only not knowing certain things but being completely unaware that we are not on the same understanding as other people our age on consent or whatever else. You don’t know that you’re not educated, until you get in those circumstances. (AD18)

Appendix D

Descriptive Theme Development (NVivo)

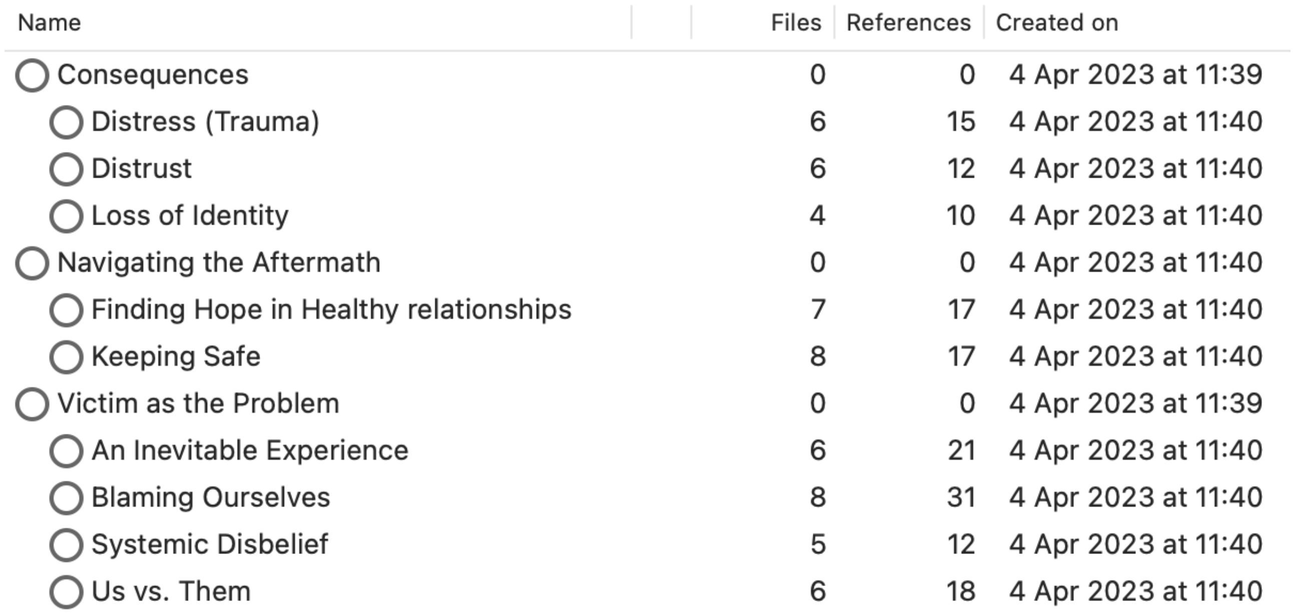
Name	Files	References
Consequences	0	0
Cannot trust own gut feelings	3	3
Impact of broken trust	4	7
Isolation	4	5
Long-term consequences	2	3
Loss of identity	3	4
Psychological impact of victimisation	4	9
Victimisation is expected	4	6
Not Believed	0	0
Disbelief and minimisation from others	3	6
Disempowered by systemic support	4	7
Survival Strategies	0	0
Autistic community support	2	2
Avoiding confrontation	4	8
Masking	1	5
People pleasing	3	5
Retaliation	2	6
Seeking advocacy	1	2
Victimisation Types and Situations	0	0
Physical bullying	2	5
Sexual bullying	1	1
Verbal bullying	2	2
Victimisation across lifespan	4	6
Victimisation isn't always obvious	4	5
Victimisation within multiple relationships	3	4



We Are The Problem	0	0
'Different'	3	7
Assumptions of others	2	2
Self-blame	3	6
Society perpetuates out-group mentality	4	8
Victim as the problem	5	13
What Can Help	0	0
Desire to be understood	3	5
Education is key	2	5
Healthy relationships	6	12
Learning from my experiences	3	4
What Makes Us Vulnerable	0	0
Autistic traits increasing vulnerability	6	9
Being trusting makes us vulnerable	3	7
Desire for friendship increases vulnerability	2	3
Didn't realise it was victimisation	3	3
Power imbalance	2	2

Appendix E

Analytic Theme Development (NVivo)



Name	Files	References	Created on
Consequences	0	0	4 Apr 2023 at 11:39
Distress (Trauma)	6	15	4 Apr 2023 at 11:40
Distrust	6	12	4 Apr 2023 at 11:40
Loss of Identity	4	10	4 Apr 2023 at 11:40
Navigating the Aftermath	0	0	4 Apr 2023 at 11:40
Finding Hope in Healthy relationships	7	17	4 Apr 2023 at 11:40
Keeping Safe	8	17	4 Apr 2023 at 11:40
Victim as the Problem	0	0	4 Apr 2023 at 11:39
An Inevitable Experience	6	21	4 Apr 2023 at 11:40
Blaming Ourselves	8	31	4 Apr 2023 at 11:40
Systemic Disbelief	5	12	4 Apr 2023 at 11:40
Us vs. Them	6	18	4 Apr 2023 at 11:40

Appendix F

Reflective Comments Examples

- Feeling a real sense of sadness considering autistic adults' narrative around just accepting that this is expected based on them being autistic. Considering a person's identity, personality and their likes and dislikes is something I have always been passionate about – looking past a person's differences and generally seeing people as human beings. It is distressing to have it highlighted that society generally does not view people equitably, although I already knew this deep down, reading the papers sparked such anger at times.
- Reading the paper around autistic people's experiences of attempting to seek help by systems intended to support like the police was upsetting, yet unsurprising. Despite being a neurotypical individual I too have had difficult help-seeking experiences with the police in my local area, being made to feel like the person in the wrong, when this was not the case. I was mindful of my own experience whilst reading the papers, however, it clearly highlights a wider issue and made me think about how it would be possible to conduct an evaluation around help-seekers experiences of accessing police support.
- Gaslighting really interests me as a concept both personally and professionally. Although gaslighting is not something I have experienced, I wondered how it would feel to be uncertain of your own thoughts and feelings and then be told you are wrong. Validation of emotional experiences is so important and something I am mindful of within my role as Trainee Clinical Psychologist. Who is anybody else to say that the way you have experienced something is wrong? No one else is able to feel what you feel, or process things in the same way that you do. I have never been told the way I think, feel, or act is wrong, and this is something I will hold in mind when moving forward and liaising with client's wider context throughout my career.
- Sex education and perceptions others have of people with disabilities is a long-standing interest of mine. Having completed an undergraduate dissertation about students attitudes toward people with intellectual disabilities (ID) having sexual relationships. Noting that although this review is exploring autistic people's experiences and not those with ID, it still seems apparent almost 10 years later that disabled people are not receiving adequate sex education. Is this based on other's perceptions that autistic people should not be having sex? Or taboo nature of sexual relationships in general?

Appendix G

Quality Appraisal Results

Author (Year)	**Clear aims**	**Qualitative methodology**	**Research design**	**Theoretical underpinnings**[a]	**Recruitment strategy**	**Data collection**	**Relationship & reflexivity**	**Ethical Issues**	**Rigorous data analysis**	**Clear statement of findings**	**Value of research**	**Quality rating**
DeNigris et al. (2018)	Yes	Yes	Can't Tell	No	Yes	Can't Tell	No	Can't Tell	Can't Tell	Yes	Findings were discussed in relation to previous research. Limitation discussed. Sentence discussing future research. Clinical implications not discussed.	Poor
Fardella, at al. (2018)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research. Limitations discussed. Future research areas identified. Clinical implications discussed at multiple levels using ecological model.	High
Fisher & Taylor. (2016)	Yes	Yes	Yes	Can't Tell	Yes	Yes	No	Can't Tell	Can't Tell	Yes	Findings were discussed in relation to previous research. Future research identified. Clinical implications discussed in brief detail.	High
Forster & Pearson. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Findings were discussed in relation to previous research. Limitations discussed. Clinical implication discussed in brief detail re: targets for interventions needing to change.	High
Gibbs & Pellicano. (2023)	Yes	Yes	Yes	Can't Tell	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research. Limitations discussed. Future research identified and discussed extensively, including widening the research to involve further marginalised autistic groups. Clinical implications discussed.	High
Huxter. (2021)	Yes	Yes	Yes	No	Can't Tell	Can't Tell	No	Can't Tell	No	No	Findings discussed, briefly discussed in relation to existing research. No strengths or limitations of study included. Some recommendations for practice outlined.	Poor
Pearson, Rees, & Forster. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research. Limitations discussed. Future research areas identified. Some clinical implications discussed in brief detail.	High
Pearson, Rose, & Rees. (2022)	Yes	Yes	Yes	Can't Tell	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research. Limitations discussed. Future research identified. Clinical implications discussed in brief detail.	High

[a] Long et al. (2020) added question: are the study's theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?

Note. The researcher implemented a scoring template. Scoring strategy: 'No' = 0, 'Can't tell' = 0, 'Yes' = 1. Total score ratings: <3 = poor quality; 4-6 = moderate quality; 7-11 = high quality

Appendix H

Additional Supporting Quotes by Theme

Theme	Subtheme	Additional Support Quotes
Victim as the Problem	Us vs. Them	“I think telling people your diagnosis will absolutely lead to them taking advantage because it gives people an excuse” (Fardella et al., 2018; p.1471) “To get a reaction out of me, that’s what they were after ... thought it was funny seeing my re- seeing me react ... Cause I was different like my disability. They took advantage of it.” (Fisher & Taylor, 2016; p.406) “difference or disability . . . opens up an individual to receiving verbal and physical abuse from people who don’t like difference” (Gibbs & Pellicano, 2023; p.5) “It’s also hard to believe people don’t see me as subhuman, as I’ve often been treated that way due to my disabilities” (Pearson et al., 2022b; p.505) “Some of the participants expressed feeling like the ‘odd one out’, ‘How come if we’re all different, how come everybody else apart from me seems to get on with each other and socialize?” (Pearson et al., 2022b; p.505) “Society in general is all about making people feel othered until they fall in line with what’s considered ‘normal’“ (Pearson et al., 2022b; p.507)
	Blaming Ourselves	“If I am bullied, or taken advantage of... the person gets to do it for a while because it takes me a long time to realize what they are doing... it takes me a while to make the connection that they are behaving in a way that somewhere in my brain is saying to me is ‘unsafe’” (Fardella et al., 2018; p.1467) “that desperation for contact can sometimes lead you to do things you wouldn’t normally do or people you wouldn’t normally associate with” (Fardella et al., 2018; p.1467)

		“I’m easy to aggravate, pretty much. At times, at least. Um, yeah. I was way too easy to target, I was easy pickings is the word (Fisher & Taylor, 2016; p.406) I’m not exactly approachable,” “I haven’t exactly made an attempt,” and “[it was an] awk- ward phase of early teens.” (Fisher & Taylor, 2016; p.406) “People who are more vulnerable are more likely to be victims of crime if they have less social skills and are less able to interact with people and then you are more likely to be a victim of crime anyway” (Forster & Pearson, 2020; p.1115) These included not understanding group dynamics (Willey, 2015, page 21), not knowing how to join in (Purkis, 2006, page 12) or being alone (Fleisher, 2003, page 13). Some described being naive which made them a target (Mór, 2007, page 71), while another felt they were deceived easily as they were not able to understand the intentions of others (Gerland, 2003, page 117). Similarly, others found they did not know they were being set up as they found it difficult to read social cues (Hadcroft, 2005) or found it difficult to distinguish between meanness and playfulness (Gerland, 2003, page 77; Purkis, 2006, page 39). (Huxter, 2021; p.7) “being too trusting could be taken advantage of by perpetrators” (Pearson et al., 2022a; p.145)
	Systemic Disbelief	“they deny everything, you end up looking like the idiot, and now not only have you experienced sexual assault but now no one believes you” (Gibbs & Pellicano, 2023; p.6) “Victim Support were unbelievably useless. Psychologists, likewise . . . The Police, they – amazingly – believe my body language says I am lying” (Pearson et al., 2022b; p.506) “both of them essentially lecturing me about how I was ‘too sensitive’ and that I was being selfish and that this was just how this friendship worked .‘being honest’ with me ‘for my own good’. This lead to me thinking I was a horrible person for questioning them they gaslit me several times” (Pearson et al., 2022a; p.145) “The policed laughed at me, forced me to look into their eyes” (Pearson et al., 2022b; p.506)

	An Inevitable Experience	“anywhere you go, you’ll have that” (Fisher & Taylor, 2016; p.407)
		“‘around it most of my life - verbal and physical abuse - that it was almost normal that this type of stuff happened” (Gibbs & Pellicano, 2023; p.5)
		“victimized every day in their situations in employment, education and health” (Gibbs & Pellicano, 2023; p.5)
		“every relationship that I have had with someone has been open to abuse and physical violence” (Gibbs & Pellicano, 2023; p.4)
		“every single one of my autistic friends has been abused in some way shape or form and they are usually not little things, they are usually huge things like sexual abuse, abuse from support workers and financial abuse, domestic violence relationships” (Gibbs & Pellicano, 2023; p.5)
		“I don’t believe victimization ends for us. It’s kind of an ongoing thing in a neurotypical world”. (Pearson et al., 2022b; p.507)
		“experienced near constant victimization by parents, teachers, class- mates, co-workers, bosses, strangers, etc. from the time I was very young” (Pearson et al., 2022b; p.504)
		“Bullied at school, ganged up on, bullied at work, stolen from” (Pearson et al., 2022a; p.145)
		“A male friend raped me and sexually assaulted me for over four hours and he kept trying to pull my hearing aids. My mam has mentally emotionally and financially abused me throughout the years. My brother regularly took his anger out on me in many ways such as mentally emotionally and physically. I have been bullied throughout growing up and was even cyber bullied at college” (Pearson et al., 2022a; p.145)
		“Taken advantage off by male mates when incapacitated. Stalked by ex. Abused by friend I wouldn’t date. Suspect friend stole from me.” (Pearson et al., 2022a; p.145)
Consequences	Distress	“feeling unlovable, feeling that I’m wrong, I’m broken” (Gibbs & Pellicano, 2023; p.5)
		“I self-harm a lot” (Gibbs & Pellicano, 2023; p.5)

		“I don’t think I even considered telling anyone else, because I felt shame, you know, I felt like it was my fault” (Gibbs & Pellicano, 2023; p.6)
	Distrust	“It’s harder for me to rely on instinct because in my childhood I was often told that I don’t have instinct so I was told to always doubt my gut” (Fardella et al., 2018; p.1466)
		“I am not very trusting of people most of the time”. (Fisher & Taylor, 2016; p.407)
		“spending ‘a lot of time by myself after that, as trusting other people was very, very, very difficult” (Gibbs & Pellicano, 2023; p.6)
	Identity Conflict	“trying to fit in, trying to feel like you belong . . . because you are brought up to believe that’s the way it is” (Gibbs & Pellicano, 2023; p.7)
		“(Masking) is a survival skill I have adapted and cannot turn off” (Pearson et al., 2022b; p.505)
		“But it is very exhausting nevertheless. And sometimes it even feels embarrassing and demoralizing” (Pearson et al., 2022b; p.505)
		“I’m trying to be more accepting of myself and of the fact that other people’s reactions etc. are theirs- not mine to manage . . . It was a survival mechanism for the majority of my life and is hard to unlearn” (Pearson et al., 2022b; p.505)
Navigating the Aftermath	Keeping Safe	" ... a general course that kids or teens or young adults can take on staying safe” (Fardella et al., 2018; p.1468)
		“knowing the difference between what is appropriate or inappropriate – for me it’s very difficult to judge” (Gibbs & Pellicano, 2023; p.6)

		“just ignore it and just move on with your life and just, just pretend like they’re not even there you know” (DeNigris et al., 2017; p.673) “Um, my responses were at times not the best” (Fisher & Taylor, 2016; p.407)
	Finding Hope in Healthy Relationships	“I was really close friends with a girl but my dad pointed out that I kept doing things for her but I didn’t see it. Like we’d go out for lunch and I’d pay and she wouldn’t pay” (Forster & Pearson, 2020; p.1115) “We went through it and sort of talked about it. We discussed it and if it wasn’t for her I probably wouldn’t have ever really connected it” (Gibbs & Pellicano, 2023; p.7) Tell people that you have ASD so they can work with you and so they can understand you in the workplace. They should be accepting and really it should be a legal requirement” (Fardella et al., 2018; p.1472) “There are people out there who are will help you and just don’t alienate yourself”. (DeNigris et al., 2017; p.673) “My current relationship with my life partner is based on acceptance and mutual respect; such a rare and precious thing” (Pearson et al., 2022b; p.506) “found a partner who seems to get me and is kind” (Peason et al., 2022a)

Section Two: Empirical Project

The Lived Experience of Unemployed and Underemployed Autistic Adults: An Interpretative Phenomenological Study

Abstract

Objectives

Autistic adults are underrepresented in the employment market, and those in work are likely to identify as underemployed. There is a paucity of research exploring the lived experience of un- and underemployment among autistic adults; therefore, this study aimed to gain an in-depth understanding of autistic adults' experiences of unemployment and underemployment.

Design and Method

Interpretative Phenomenological Analysis (IPA) was used to investigate the lived experiences of unemployed and underemployed autistic adults. Eight autistic adults who were unemployed or self-identified as underemployed participated in semi-structured interviews.

Results

Four group experiential themes were identified: '*Feeling paralysed*' (The past weighs heavy; Fragile self-confidence); '*Powerlessness'* (Lack of agency; Systemic support failures); '*Negative perceptions'* (Feeling misunderstood; Fear of judgement; Pressure to meet societal expectations) and '*Recognising our needs'* (Managing mental health difficulties; Importance of self-understanding).

Conclusions

Participants felt paralysed by employment experiences which impacted their confidence to progress with their career aspirations. Autistic people felt misunderstood, judged, and powerless within systems designed to support which had implications for their mental health. Subsequently, participants recognised the importance of managing their mental health needs during times of un- and underemployment via self-care and psychological support. Findings highlight the importance of clinicians working with autistic adults to ask about employment circumstances to explore how systemic factors may be precipitating or perpetuating their mental health difficulties. Advocacy for autistic people's employment needs and reasonable adjustments is required, and anti-stigma interventions are needed to reduce stigmatising attitudes, beliefs, and behaviours of non-autistic people in the workplace.

Practitioner Points

- Clinicians working with autistic adults need to be aware of their potential employment challenges, and how this can impact their mental health to support autistic adults to make sense of their experiences through a lens of self-compassion.
- Clinicians can advocate for autistic people's employment needs, providing strengths and needs based formulations to employers and encouraging reasonable adjustments.
- Autism related anti-stigma interventions are needed in the workplace. Further research is required to investigate their efficacy in changing behavioural intentions.
- A commitment to inclusivity and diversity is needed from employers to help autistic people to feel empowered from the beginning of their employment journey.

Keywords: Autism; Unemployment; Underemployment; Interpretative Phenomenological Analysis; Qualitative research

Introduction

Autism, a life-long neurodevelopmental disorder, is characterised by pervasive difficulties in social communication and interaction; restricted and repetitive patterns of behaviour; and sensory difficulties (American Psychological Association, 2013). Although there has been a shift in diagnostic understanding over time, the needs of autistic adults[7] often continue to be unmet (Howlin et al., 2015). Principally, research remains biased toward understanding and exploring the needs and well-being of autistic children (Nicolaidis, 2019).

Although more limited, research regarding autistic adults demonstrates that they experience a higher prevalence of co-occurring mental health conditions than non-autistic adults, including depression and anxiety disorders (Lugo-Marin et al., 2019; Buck et al., 2014; Croen et al., 2015). Autistic adults also report a lower quality of life (Oakley et al., 2021; Wong & Smith, 2006), inadequate social opportunities (Farley et al., 2018), and increased homelessness (Churchard et al., 2019). Moreover, research has shown high rates of suicidality amongst autistic adults with non-suicidal self-injury, employment difficulties, and high prevalence of mental health difficulties appearing to be risk markers (Cassidy et al., 2018).

Employment is a key determinant of health and life outcomes (Benach et al., 2007). Employment is vital from a personal economic standpoint, and existing literature in autistic and neurotypical populations highlights other benefits, including increased independence, social status, and self-esteem (Chen et al., 2015; Creed & Macintyre, 2001). Outlined by Social Identity Theory (SIT; Tajfel et al., 1979), feeling part of an in-group increases well-being and self-esteem, increasing social functioning (Rosenberg, 1986); hence employment, perception of belonging and social support are positive predictors of autistic quality of life

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[7] Kenny et al. (2016) found “autistic individual” was the preferred term autistic adults wished to be identified by; therefore, “autistic adult” will be used throughout this empirical project.

(Mason et al., 2018; Milton & Sims, 2016). Further, involuntary joblessness and underemployment are associated with common mental health conditions such as anxiety and depression and lower perception of self-worth and self-esteem (Goldsmith et al., 1997; Honkonen et al., 2007; Prause & Dooley, 1997). Essentially, inadequate employment opportunities and social exclusion faced by autistic people have implications for physical and mental well-being.

Data published by the Office for National Statistics (2022) revealed that autistic people are among the least likely to be in employment of any other disabled group in the United Kingdom (UK). Just 29% of autistic individuals aged 16-64 years are in employment compared to 81.6% of non-disabled people. Of those employed autistic people, they are unlikely to be in senior roles, suggesting many in work are underemployed (Office for National Statistics, 2022). The Labor Utilization Framework (LUF; Clogg, 1979; Hauser, 1974; Sullivan, 1978) acknowledges that inadequate employment is multifaceted, and no single indictor can fully define the concept (Sullivan & Hauser, 1979). Subsequently, LUF outlines that 'underemployment' can be defined in three ways: involuntary part-time work (e.g., working fewer regular hours than desired), low-income work (e.g., income unable to meet basic needs), and skill mismatch (e.g., a mismatch of education and occupation). Supporting autistic adults into employment is a current UK government priority. It is outlined as one of the six key areas of the national strategy for autistic children, young people, and adults 2021-2026 (Department of Health and Social Care, 2021). Research indicates that many autistic adults can work, have the desire to be employed and possess strengths workplaces can benefit from, yet a disproportionate number of autistic people remain unemployed or underemployed compared to the general population (Bernick & Holden, 2015; Barnhill, 2007; Foden, 2008).

Research into employment inequalities has typically focussed on the barriers and facilitators to employment for autistic adults globally (Black et al., 2020; Coleman & Adams, 2018; Hurlbutt & Chalmers, 2004), although research within the UK remains limited. Low employment rates may be attributable to autism-specific challenges such as difficulties with communication, social relationships, adverse physical and/or mental health at work, sensory issues, others' lack of awareness, and the recruitment processes (Black et al., 2020; Coleman & Adams, 2018; Harmuth et al., 2018; Hayward et al., 2018; Hurlbutt & Chalmers, 2004). Principally, promoting themselves at interviews and managing behavioural and social norms conducive to good interview performance are skills not easily learned or performed by many autistic adults (Davies et al., 2023; Scott et al., 2017).

Recently, Davies et al. (2023) found autistic adults reported having to mask their authentic selves to gain employment and reflected on the challenges when trying to decode what employers were asking of them, when investigating UK hiring processes. Camouflaging or masking is often reported as a coping mechanism by autistic individuals to hide traits around neurotypical people to attempt to fit in (Hull et al., 2019), sometimes borne out of a fear of discrimination (Romualdez et al., 2021b). In line with the 'double empathy problem (Milton, 2012), communication disconnect around employment processes appear to be a two-way issue; thus, there is a need for both employer and autistic adult to adapt to enable reciprocal understanding.

Moreover, barriers to employment exist at a systemic level, such as societal labelling of autistic characteristics as deficits instead of positive attributes brought to the workplace (Lorenz et al., 2016). Research has shown employer discrimination and unfavourable employer perceptions toward recruiting autistic people, assuming it will increase operating costs and decrease productivity (Scott et al., 2017). However, the sample within such research may not represent the wider population of employers of autistic adults. The social model of disability (UPIAS, 1976) outlines how people are disabled by physical and attitudinal barriers in society rather than their difference, which may somewhat explain the recruitment barriers for autistic people.

There is an evident need for employers to better meet the needs of autistic adults, given the significant underrepresentation in the UK employment market. However, there is currently a paucity of research exploring the lived experience of un- and underemployment among autistic adults. In line with recommendations outlined by Nicholas et al. (2017), there is a need to understand autistic adults' employment challenges, including insight into the impact on well-being and mental health, utilising qualitative methodologies. Adopting a qualitative approach can enable a more in-depth understanding of autistic people's experience, giving them a voice and empowering individuals to be heard (van Schalkwyk & Dewinter, 2020).

This study, therefore, aims to add to the sparse existing literature to better understand and identify themes relating to the lived experience of unemployment and underemployment within an autistic adult population.

Method

Design

Aligned with the study aims that intend to gain an in-depth understanding of individuals' lived experience, a qualitative research design, specifically Interpretative Phenomenological Analysis (IPA; Smith et al., 2009) was utilised.

IPA research values the dynamic process between the participant and the researcher, engaging in "double hermeneutics". Participants assign meaning to their subjective lived experience, following which the researcher attempts to make sense of and interpret the participant's accounts of their experiences (Larkin & Thompson, 2012; Pietkiewicz & Smith, 2014; Smith et al., 2009). Thus, interpretation is the joint reflection of the participant and the researcher (Osborn & Smith, 2015). It has been argued that features of IPA, such as its commitment to equality of voice and researcher's reflexive statements, support a better understanding of autistic adults (Howard et al., 2019). Moreover, IPA has been shown to be an applicable methodological approach for studies with autistic people as research participants, adding to the strength of utilising this approach for this study (e.g., MacLeod, 2019; Dugdale et al., 2021; Treweek et al., 2019; Huws & Jones, 2015).

Ethics

Ethical approval was obtained via the University of Sheffield Research Ethics Approval system (Appendix A).

Participants

As IPA is an idiographic approach, examining a particular phenomenon in a particular context, small and reasonably homogeneous samples are suitable (Smith et al., 2009). Purposive sampling was used to enable a selection of participants with knowledgeable expertise within the interested phenomenon (Tongco, 2007).

Eight autistic adults participated in this study, self-identifying that they met the inclusion criteria, shown in Table 1. Participant demographic information was collected during interviews (Table 2).

Table 1

Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
Autistic Adult (aged 18 years old and older)	Comorbid diagnosis of an Intellectual Disability (ID) and/or Attention Deficit Hyperactivity Disorder (ADHD)
Formal diagnosis of autism (including differential diagnoses such as Asperger's Syndrome, High Functioning Autism; HFA)	Not actively seeking employment
Completed formal education up to the age of 15-16 years old (UK Year 11; minimum)	Not fluent in English
Actively seeking work but currently unemployed or self-identify as someone who is underemployed	

Table 2

Participant Demographics

Name[a]	Gender	Age Group[b]	Ethnicity	Elapsed Time Since Diagnosis[b]	Highest Qualification	Employment Status	Category of Underemployment
Grace	Female	25-34 years	White British	2-5 years	Undergraduate Degree	Underemployed	Part-time hours (30) Underutilising full skills and abilities
Ashley	Other	45-54 years	White Irish	5-10 years	Undergraduate Degree	Underemployed	Part-time hours (22.5) Underutilising full skills and abilities
Susan	Female	45-54 years	White British	2-5 years	Higher National Diploma (HND)	Unemployed	N/A
Graham	Male	35-44 years	White British	5-10 years	Higher National Diploma (HND)	Underemployed	Part-time hours (22.5) Low-income role unable to meet needs
Zayn	Male	45-54 years	Arab	5-10 years	Undergraduate Degree	Unemployed	*Previous experience of underutilising full skills and abilities*
Alexander	Male	45-54 years	White British	2-5 years	Higher National Diploma (HND)	Underemployed	Part-time hours (24) Underutilising full skills and abilities
Marcus	Male	25-34 years	White British	10+ years	Diploma of Higher Education (DipHE)	Unemployed	N/A
Richard	Male	55-64 years	White British	> 2 years	Higher National Diploma (HND)	Underemployed	Part-time hours (7) Low-income role unable to meet needs

Note: [a]*All names are pseudonyms to protect confidentiality.* [b]*Exact ages and time elapsed since diagnosis are not reported to protect confidentiality.*

Materials

Interview Schedule

The semi-structured interview schedule (Table 3) was developed in collaboration with the researcher's supervisors, in line with the aims of the study, and Smith et al.'s (2009) methodological guidance. Prompts were used for clarity and further information (Appendix B).

Table 3

Main Interview Questions

Interview Questions
1. When you were coming to the end of your school years, what did you want to do for work?
2. Can you tell me about your experience of when you first started applying for jobs?
3. Can you tell me about your current experience of trying to gain the type of job that you want?
4. What has it been like for you during periods of being out of work (unemployed) and/or underemployment?
5. How does being unemployed / underemployed affect your day-to-day life?
6. What sorts of thoughts and feelings have you had about being unemployed and/or not being at your desired level of employment?
7. Is there anything else that you have not had the chance to tell me about today that you feel would be important for me to know about your employment experiences?

Service User Involvement

Two autistic adults were contacted to comment on and provide advice on the ethical considerations, research advert (Appendix C), participant information sheet (Appendix D) and interview schedule. Comments were received on the content, wording and any insufficiently addressed questions. Following feedback, amendments were made to the wording of several interview questions, prompts, and the participant information sheet.

Procedure

Participants were recruited via the Sheffield Autism Research Lab (ShARL) participant database[8], Twitter account, and website. Brief study details were posted online and emailed to people from the database. If interested and eligible, the participant information sheet, consent form (Appendix E), and main interview questions were sent.

Online video interviews took place between the 14th June and 8th August 2022. At the beginning of the interview, the limits to confidentiality (e.g., risk) were discussed. Interviews were recorded using an encrypted Dictaphone obtained from the University of Sheffield. Interviews lasted between 26 and 91 minutes (mean= 55 minutes). A debrief was offered at the end of the interview to check their well-being and remind them of their right to withdraw, and an Amazon e-voucher for participation was sent following the interview. The lead author transcribed all interviews.

Data Analysis

Reflexivity

The participant and their experiences are at the centre of IPA research. However, it is acknowledged that the researcher plays a significant part in the process (Nagel, 1974). Therefore, an IPA researcher needs to be aware of their own beliefs, perceptions, and experiences so that they can enrich their interpretations rather than them presenting a barrier to making sense of the person's experience (Smith et al., 2009). Throughout the study the lead author kept a reflective diary recording emotions, thoughts, and pre-conceptions during each stage, including analysis (Horsburgh, 2003; Appendix F).

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[8] ShARL database includes autistic adult research participants who have previously consented to be contacted about research.

The lead researcher identifies as a white British woman in her late twenties, without a diagnosis of autism. In their role as trainee clinical psychologist, the researcher has worked with autistic children, young people, and adults in various settings and has studied psychological theories and autism research. The researcher discussed in supervision and in their reflective diary how their clinical experience may have influenced their beliefs and assumptions within the research.

Analysis

The data was analysed using IPA principles outlined by Smith et al. (2022). Firstly, the transcripts were read whilst listening to audio recordings to keep the participant's voice in mind. Following this, a detailed line-by-line annotation of the transcript took place using colour coding to highlight descriptive, linguistic, and conceptual aspects of the data. Then the researcher began to generate possible interpretations, noting experiential statements from the exploratory comments to reduce the volume of detail whilst articulating the complexity of the participant's experiences. Individual data was then organised and mapped to see how their Personal Experiential Themes (PETs) fit together (example conceptual map in appendix G). Finally, the researcher identified patterns of similarity and difference across the PETs to create Group Experiential Themes (GETs). Examples of each stage of analysis are presented in Appendix H.

Quality and Rigor

The use of general guidelines, as opposed to rigid guidance, to ensure validity and quality and control is advised (Smith et al., 2009). Yardley's (2000; 2008) guidelines outline four key principles for assessing the quality of qualitative research, which were upheld throughout this study (Table 4).

Table 4

Quality Control

Guideline	Application to Current Study
Sensitivity to context	The researcher recognised and reflected upon their own position, biases, assumptions, and thoughts using a reflexive log (Appendix F). Demographic information for all participants provided to help situate the findings, whilst ensuring anonymity is protected. The researcher remained aware of the specific environmental and emotional impact on autistic adults who may have anxieties and sensory sensitivities and made adaptations where appropriate (e.g., providing interview questions in advance).
Commitment and rigour	Verbatim extracts are included in the results section, with a clear presentation of GETs presented throughout the written report to support the interpretation being made. An audit was completed by the researcher's supervisor (Appendix I) at each stage of analysis to enable a high standard of rigor.
Transparency and coherence	Methods of analysis are presented, and the development from PETs to GETs is outlined clearly (Appendix H). A clear and concise summary of the findings are provided in the results section. GETs are organised clearly in a table for ease.
Impact and importance	The gap in the literature is clearly identified and outlined. The practical and clinical implications and how this may contribute to meaningful change within the employment market and support services for autistic adults are reflected on within the discussion.

Results

Analysis of the data yielded four group experiential themes (GETs) and several group-level subthemes (Table 5). Verbatim participant quotes are provided to illustrate each theme. Themes are not an exhaustive account of participants' experience; they are an interpretation of prominent discourses. Participants' contributions to each theme and additional supporting quotes can be found in Appendix J.

Table 5

GETs and Group-Level Subthemes.

Group Experiential Theme	**Group Level Subtheme**
Feeling Paralysed	The Past Weighs Heavy
	Fragile Self-Confidence
Powerlessness	Lack of Agency
	Systemic Support Failures
Negative Perceptions	Feeling Misunderstood
	Fear of Judgement
	Pressure to Meet Societal Expectations
Recognising our Needs	Managing Mental Health Difficulties
	Importance of Self-Understanding

Feeling Paralysed

This theme encapsulates participants' descriptions of feeling paralysed by the stress and trauma of application processes, paralysed by past experiences of marginalisation and rejection leaving feelings of hopelessness, and paralysed by lack of self-confidence.

The Past Weighs Heavy. Participants shared that the "*stress and the trauma*" (Ashley) begins right at the start of the application process. They spoke of the internal process of contemplating downloading an application taking "*mental energy*" (Marcus) that difficult past employment experiences have diminished. Participants recognised that a key contributor to their lack of energy for employment processes is autistic burnout stating, *"it's always been due to like burnout, so I've absolutely reached rock bottom and have no energy"* (Graham).

Furthermore, participants shared a narrative of feeling a dissonance between wanting to be within a desired and fulfilling role and not wanting to apply for jobs because "*it would put way too much of a mental burden*" (Marcus) on them, thus they remain paralysed within their current un- or underemployed circumstance.

> *"I'll just stick with this job and well I'll just do what I'm doing because I just can't really face the psychic trauma of getting a paper or going on the internet trying to troll jobs and then applying and feeling more debilitating"* (Ashley)

Participants shared severe emotional distress to reminders of the traumatic experiences they have faced within employment. They described the "*terror*" (Susan) felt when considering applying for a job, sharing how it "*really is terrifying to to put yourself out there"* (Susan), and how distressing is it to feel "*that history will repeat itself*" (Susan). When feeling constant threat, participants felt unable to exit that state of mind and thus felt frozen in their current circumstance. Moreover, participants shared a sense of their life being "*defined by failure, or not getting, or knowing what to apply for and then… not getting a job*" (Ashley) and these negative thoughts and experiences present as a barrier to taking a chance and applying for desired roles.

Fragile Self-Confidence. Participants spoke of having limited self-confidence to apply for a role that would mean they were fully utilising their skills and being paid appropriately to do so. Subsequently, participants would elect to apply for or stay within roles that qualify as underemployed sharing *"I know I could probably do it but no, I wouldn't have the confidence to go for it [a higher role] like I have so much self-doubt"* (Grace) and *"I think that's tied in with confidence. I've always gone for jobs lesser than what I know I'm capable of doing*" (Alexander).

Moreover, one participant shared his experience of job advertisements using complex language which appeared to contribute towards an internal narrative of self-criticism and not being good enough for skilled roles. Despite their knowledge and qualifications, any job advertisement that triggered this feeling "*shattered my very fragile confidence and I never bothered applying*" (Alexander).

For some "*the self confidence has always been a problem*" (Ashley) and they have "*never really had a great deal of self-confidence or self-esteem*" (Graham) which appeared to stem from childhood and has consequently impacted their employment experiences. Others spoke of the damage that traumatic experiences of bullying have exacted upon their self-esteem and confidence. These experiences have subsequently been internalised and impact upon their belief in their ability to return to work.

> *"I think I need more one to one support, because to be honest with you, I don't feel very much confident to get back to work, you know, especially with the bullying I had in the past"* (Zayn)

Powerlessness

This theme covers participants' narratives of having limited power and control over their decision making and circumstances within and around employment processes and assumed support systems.

Lack of Agency. From the start of the participants' employment journey, they share a narrative of having no control over their own actions and being "*railroaded into other people's expectations but by accident*" (Graham) and how they *"just kind of drifted into things"* (Richard). Participants described uncertainty, not knowing, and receiving no guidance as to what they were qualified and/or able to do, which seemingly lead to the allowance of things happening to them and a sense that they were passive in decisions made.

For others, their experience of gaining and being in employment was characterised by a lack of power and control. Despite the desire and willingness to work, one participant shared that they previously did not have the appropriate working visa documents to enable them to undertake a sandwich year within their desired field of work which *"actually really affected very negatively for me to get into what I really want"* (Zayn). Another explained that they had been promised a promotion of job title and pay based on current responsibilities he was undertaking multiple times but "*it never happens*" (Graham).

Whilst unemployed and searching for suitable and desired employment, some participants were receiving financial aid provided by the government. However, this decreased participants' agency to make their own employment decisions and perpetuated anxiety around having to apply for unsuitable roles "*just to have a job so I'm not unemployed*" (Alexander). Participants worried that if support were to be retracted, they would be forced to apply for roles within unsuitable environments which they felt would have dire consequences for their mental health.

> *"I can't just go and get any job… if the government turned round to me tomorrow and said we're stopping your benefit you've got to get a job in [supermarket name]… then I would be probably dead within the year"* (Susan)

Systemic Support Failures. Support systems and services for autistic people in either un- or underemployment circumstances were described as "*non-existent*" (Alexander) and "*slim to none*" (Marcus). Participants were unsure or unable to find services that could guide them toward their desired employment, alongside considering and advocating for their needs as an autistic person through the employment processes (application, interview, in-role).

> *"there isn't really a strong support structure there to to guide erm adults and late late diagnosed… so it's really debilitating"* (Ashley)

Moreover, the few services that participants were navigated to were described as unsupportive. Specifically, several participants highlighted their difficulties with the job centre, which is a service set up to help individuals find appropriate employment.

> *"I'd rather lose my house, I'd quite happily live in my tent and wait until the winter takes me in the middle of you know, the Scottish highlands than rely on that [the job centre]"* (Graham)

Participants also described feeling on the edge of support, specifically financial support. One participant explained that their "*wage is low, but then it's not low enough to ever receive any like support or benefits because I do work, so yeah, it's hard especially at the moment*" (Grace) and another described themselves as "*living like a hollow life where I'm just existing*" (Marcus) due to financial insecurity. Subsequently, participants shared the implications of such financial difficulties.

> "*I cannot afford to 'join in' as it would be such a big chunk of my disposable income which I need to save instead for financial security due to underemployment. This does affect friendships that are more activity based.*" (Graham)

Negative Perceptions

This theme encompasses the negative perceptions of others in society, and the workplace; the feared negative perceptions that autistic people worry they will receive; and negative perceptions that participants hold of themselves. All of which have consequences for autistic people's well-being and ability to motivate themselves to progress into or within employment.

Feeling Misunderstood. Bullying experiences in the workplace were highlighted within several participants' narratives. For many these experiences appeared to stem from others showing limited understanding and compassion for autistic people's characteristics. As such, participants were labelled as "*weird*" (Zayn) and "*rude*" (Grace) and assumptions were made about them being "*difficult on purpose*" (Grace). Disclosure of their autism diagnosis also appeared to have some disadvantages with one participant sharing they had to continually "*justify*" (Ashley) their need for reasonable adjustments, and another stated that their diagnosis appeared to place a "*limit on what they [employer] think I can actually do*" (Grace).

In addition, "*gaslighting*" (Richard) experiences were noted, perpetrated by managers, feeling as though they were told to do one thing when they meant something different. Some of these experiences have impacted on individuals' ability to trust others, have the confidence to return to a work environment, and appear to have precipitated mental health struggles that may require *"some kind of psychological help along the way"* (Zayn).

> *"My faith in myself has been decimated. My faith in other people has been (pause) in an employment situation has been horrific. I I I don't trust people"* (Susan)

Moreover, participants shared a sense of seeking increased understanding and compassion from others, including society, colleagues, and employers. Participants felt that it would be "*simple*" (Marcus) for individuals within society and the workplace to make slight adjustments to how they interact, relate to, and involve autistic people including "*just taking time to learn a bit more about autism*" (Grace) and "*embrace it [autism] as opposed to trying to fit us in a box"* (Susan). As such, autistic people would feel less like they need to "*camouflage your way through*" (Alexander) and instead be their neurodiverse authentic self.

> *"Why is it that I'm treated like a neurotypical person. I'd love to be able to talk to somebody who could understand neurodiverse people"* (Alexander)

Fear of Judgement. Despite acknowledgement that some employers were offering reasonable adjustments from the start of employment processes, participants shared that they were "*wary*" (Grace) of accepting or requesting reasonable adjustments, especially before successful appointment of a role. Participants feared that these adjustments would be perceived as "*giving autistic people an advantage*" (Grace) or "*making demands*" (Ashley). There were suggestions that reasonable adjustments could be made for everyone, however, given this is not the case, participants spoke of struggling through the process to escape such judgement.

> *"If people were offering me you know some good employers do now, they say… if you need any reasonable adjustments for the application, like, I'm not sure that I would take them up on it because companies have offered these things because it's the right thing to offer and they have the disability confidence tick, but actually, that really colours their perceptions"* (Graham)

Perceptions of prospective employers felt particularly important, and individuals shared feeling as though their diagnosis and needs relating to this would instantly put them on the backfoot compared to non-autistic applicants. One participant shared *"I have a lot of needs period, and if I tried to get that across like before I'm in a job, then they will choose someone else who doesn't have those needs*" (Marcus). Consequently, individuals felt that they were unable to be open on an application form about such needs, as this would put them at a disadvantage.

Similarly, there was an expressed anxiety around how an application with multiple short-term jobs or long periods of unemployment would be perceived by employers.

> *"You're confronted with your past failures whenever you fill in [an application form]… and you think gosh, what is this going to look like to the employer. I'm always thinking ahead to how is this going to be perceived.*" (Ashley)

Pressure to Meet Societal Expectations. All participants shared a narrative of societal expectations starting from mandatory childhood expectations, such as "*you go to primary* *school, and you go to secondary school*" (Ashley) and leading onto optional but expected transitions for an individual to feel a "*functioning member of society*" (Susan). Participants shared that being unemployed feels as though they are "*worthless… like I'm not meeting people's bare minimum expectations*" (Marcus). These expected transitions were described as putting immense "*pressure*" (Grace) on individuals to get a job, often leading them to apply for inappropriate or underemployed positions to be able to say they were employed and "*not a bum sitting on my own all day*" (Zayn). Consequently, employment would often break down and individuals were left to feel as though it was their "*fault*" (Ashley) for failing to succeed in the expected transitions.

> *"You just made to feel like you're dragging the country down just by being unemployed and being autistic forced into those places you just don't want to be just makes you have a mental breakdown"* (Alexander)

In contrast, one individual spoke of societal pressure to be "*grateful*" (Graham) for being in a job and feeling the "*guilt of when you do feel hard done by for it [being underemployed]*" (Graham) as there will always be people who are in a worse position than themselves. This seems to also have significant implications for their well-being, as it minimises their difficulties with the employment position they are in and reduces their confidence to advocate for themselves and their employment needs.

Recognising our Needs

This theme reflects how participants have found the importance of recognising and understanding both their personal and professional needs, and how this increased understanding could help to support them moving forward into their desired level of employment.

Managing Mental Health Difficulties. All participants spoke of how experiencing historical and/or present difficulties within employment has implications for their motivation or confidence to apply for a desired role and their mental health. Participants shared how processes prior to and within employment can trigger "*fear and stress and depression as well*" (Ashley) and has often led to "*burnout*" (Graham, Marcus) and an increase in "*anxiety*" (Marcus). As such, participants shared a narrative of attempting to be proactive in managing their mental health difficulties to "*stabilise my mental health and get into a place where I can build myself back up*" (Marcus).

Participants shared multiple ways in which they were able to proactively manage their mental health needs, including accessing psychological therapy, increasing time spent on hobbies, and increasing physical exercise by going to the "*gym*" (Zayn).

> *"I'm going to try and get back into it [writing] as a hobby, something I do in the evening that makes me feel good about myself"* (Alexander)

This increased understanding of what they might need to manage their mental health was discussed as something they felt would be important to consider when contemplating changing their current employment status.

> *"I've got a lot of time on my hands, but a lot of that time is spent on my allotment. That is the way I feel like the world isn't quite such a bad place. If I don't go I feel it in my mood, my stress levels increase"* (Susan)

Importance of Self-Understanding. Most participants were diagnosed as autistic in adulthood and shared that when they were "*discovered autistic*" (Ashley) this enabled them to reflect on their past and the challenges they have faced within employment through a lens of increased self-understanding. Prior to their diagnosis, or awareness of their needs as an autistic person, they were unable to advocate for their employment, relational, and well-being needs because they "*never thought [they] needed it to be adapted*" (Grace). With this previous lack of awareness was a shared sense of sadness, that their employment and life circumstances could have been different, and they may not have had to endure the traumatic employment experiences they have shared and accessed support earlier.

> *"…and now knowing that I am, because I'm autistic, but not knowing in the past, so then re-thinking about the past and how I went through life and why I have ended up here [underemployed]. It's something that plays on my mind all the time"* (Ashley)

Having an increased awareness of their needs did provide hopefulness to some, with the diagnosis offering empowerment to disseminate a formulation of their needs and advocate for what does and does not work for them, including requesting reasonable adjustments.

> *"As soon as I got diagnosed I went straight to her [manager] and said, right I'm struggling, I've got this diagnosis, you need to know… I said to her look I cannot do nights"* (Alexander)

Ultimately, participants shared a narrative that looking back knowing what they know now, they can show themselves some self-compassion and understanding of what they need moving forward within employment.

> *"I think I think this time I think I'm not going to just accept any job like before, because I really want to want to get into work, I was desperate to get into work. Now obviously there's a condition that I have to work around"* (Zayn)

Discussion

This study aimed to investigate the lived experience of unemployment and underemployment for autistic adults. The analysis yielded four group experiential themes: *'feeling paralysed', 'powerlessness', 'negative perceptions', and 'recognising our needs'.*

The first theme, '*feeling paralysed',* encompasses the intense fear felt by autistic adults when contemplating applying for a job, whether to return to work or progress within their career. Such fear appeared to be triggered by historical unsuccessful and traumatic employment experiences. For example, participants spoke of specific instances of bullying behaviours by both colleagues and managers, which decreased their confidence and motivation to return to work. Autistic people are contextualised as a minority group within a society that discriminates against them. In line with the minority stress model (Meyer, 2013), these difficult social situations, accumulated over time, result in long-term adversity and significantly affect autistic people's well-being and self-esteem (Dombeck, 2014).

Participants shared the experience of feeling of being frozen or stuck, with a desire to stay away from recruitment processes despite their skill set, indicating a trauma response (Gil, 2003). Findings highlight the importance of acknowledging and validating individuals' subjective responses and interpretation of an event when attempting to clinically define and manage trauma (Brewin et al., 2019). Moreover, there is a need to respond to trauma to enable an individual to move forward with employment.

Participants referenced autistic burnout and limited emotional capacity to engage with employment processes. Autistic burnout is characterised by exhaustion, withdrawal, reduced functioning, and heightened autistic traits (Higgins et al., 2021; Mantzalas et al., 2022; Phung et al., 2021; Raymaker et al., 2020). Existing literature highlights implications of loss of vocation, impact on ability to work, quality of life, and increased suicidality (Raymaker et al., 2020; 2023). These findings indicate a need for the emotional loading of job applications to be considered when supporting autistic people into and within employment, which is not currently reflected in the national strategy (Department of Health and Social Care, 2021).

Participants described their significant lack of self-confidence paralysing employment progression. Self-confidence, the belief in one's ability to perform (Bandura, 1977; Clark et al., 2008), is linked with self-esteem and the self-assessment of self-worth or value (Erol & Orth, 2011). Participants shared self-critical narratives of not being good enough and being defined by past employment failures. Self-confidence is understood to be established via positive feedback about one's abilities (Park et al., 2007); thus, participants' lack of self-confidence may be attributable to minimal positive feedback around employment. Principally, participants appeared to get stuck in a cycle whereby their limited self-confidence makes it hard to apply and succeed in gaining desired employment, further shattering their self-worth and confidence. Findings therefore suggest that building self-esteem and confidence is important.

The second theme, '*powerlessness',* describes the lack of power and control felt over decision-making and support around employment circumstances. A person's locus of control (Rotter, 1966) outlines how they perceive that they control situations and outcomes in their lives. Participants spoke of employment outcomes feeling attributable to causes outside themselves (e.g., behaviour of others, environmental factors), suggesting they have an external locus of control (Spector, 1982). Furthermore, early career indecision and uncertainty around what participants wanted or were qualified to do vocationally was evident and seemed to pave the way to underemployment. Early career indecision has resulted in underemployment cycles, further decreasing a person's desirability for higher-skilled roles, as evidenced within a neurotypical population (Feldman, 2003). Participants also described feeling forced into roles unsuited to their needs, aligning with findings that autistic people encounter barriers to support to grow a career (Nicholas et al., 2019). Therefore, indicating a need to ensure employment is aligned with the individual's strengths and interests rather than mould the person to the environment.

Lack of agency also emerged when considering the financial consequences of un- and underemployment. When considering autistic adults' unmet needs, un- and underemployment has consequences at multiple levels of Maslow's (1943) hierarchy of needs. As such, financial instability can affect access to food, drink, shelter, warmth, and sleep (physiological needs) and not fulfil a person's safety needs. Not being able to satisfy these lower-level needs halts the ability to progress and meet high-level growth needs (Maslow, 1943). Participants also spoke of implications for their 'love and belongingness needs' as being financially unstable meant they could not be social and maintain friendships. This aligns with the broader research linking unemployment to reduced social participation (Dieckhoff & Gash, 2015).

Lack of support for autistic adults has been associated with increased suicidality and mental health risks (Cassidy et al., 2018) and post-diagnostic and employment support were noted as lacking within this study. Research has outlined multiple reasons for exclusion from mental health services, including limited services for autistic people without an intellectual disability (ID), long waiting lists, and lack of funding (Camm-Crosbie et al., 2019). Given the lack of vocational and mental health support described in the current study, yet the high prevalence of mental health and employment difficulties experienced by this population, increased service provision for autistic adults must be prioritised. Specifically, participants experienced unsupportive and dismissive vocational support services (e.g., the job centre). The national strategy supporting individuals into employment (Department of Health and Social Care, 2021) recommends ensuring the job centre welcomes and supports autistic individuals by March 2022. However, the results of the current study suggest further consideration may be required given the intensity of hesitation to access such support by the current participants.

The third theme, '*negative perceptions'*, captured the impact of perceived and actual negative attitudes about autistic people. In line with the social model of disability (UPIAS, 1976), participants' desire to feel understood by others, including managers, colleagues, and the wider society, was a dominant discourse. Participants felt they could not be authentic throughout employment processes and within the workplace. These findings align with previous research indicating attempts to fit autistic people into a neurotypical world increase autistic masking, which is exhausting and inhibits autistic people from functioning at their best in the workplace (Djela, 2021). Many participants felt discriminated against and experienced bullying when trying to be authentic. Previous research has highlighted the negative impact of bullying and victimisation on autistic individuals' mental health (Griffiths et al., 2019), and these negative experiences have been found as external drivers of masking behaviours (Chapman et al., 2022). Principally, considering social identity theory (Tajfel et al., 1979), autistic adults are excluded from feeling part of the in-group within and around employment processes and masking to try to be part of the in-group impacts their well-being.

Participants shared a sense that neurotypical people within the workplace need to be more aware of autism-specific struggles and that there would be simple ways to increase their understanding of autism, their compassion, and kindness. Previous research has indicated that employers feel providing autism awareness training would be practical, feasible and implemented without excessive difficulty, and training has the potential to increase autistic people's confidence, job performance, and employer's confidence to recruit autistic people (Dreaver et al., 2020; Scott et al., 2017). Despite this, the current study supports the 'double empathy problem'[9] (Milton, 2012); as such, there remains persistent misperceptions between autistic and non-autistic people and a lack of action of non-autistic people to change this.

Participants described worries about requesting reasonable adjustments based on fear of being judged by prospective or current colleagues and employers. Making reasonable adjustments accessible to everyone throughout employment processes was suggested by

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[9] 'Double empathy problem' (Milton, 2012) outlines how when people with very different experiences of the world interact with each other, there will likely be misunderstanding and difficulties with empathy.

several participants, aligning with research suggesting this approach could reduce perceived unfairness and makes the workplace environment fully inclusive (Flower et al., 2019; Patton, 2019). These findings align with the concept of universal design (Burgstahler & Russo-Gleicher, 2015), meaning workplaces are designed to be useable by all employees, recognise variability in employee's needs and contrasts changes being made based on diagnosis disclosure.

The significance of societal judgement was recognised as detrimental to participants' well-being. Participants identified that being autistic and un- or underemployed added a double layer of societal judgement. Negative attitudes toward autism continue to exist (Treweek et al., 2019; Wood & Freeth, 2016) and stigma for failing to meet societal norms is present and perpetuated by people with the least knowledge of autism (Botha et al., 2022; Milačić-Vidojević et al., 2014). Thus, further highlighting the need for better autism awareness.

The final theme, '*recognising our needs',* highlights the importance of self-understanding and recognising personal and professional needs. Supported by previous research, this study found that autistic un- and underemployed people encounter significant mental health difficulties (Hurlbutt & Chalmers, 2004), described by participants as perpetuated and precipitated by negative employment processes and within employment experiences (e.g., bullying). Common difficulties include depression, anxiety, and anger, which the participants' narratives in this study indicate relate to employment difficulties (Bashe & Kirby, 2001).

Participants spoke of the importance of proactively managing their mental health difficulties. Some utilised therapy to help stabilise their mental health before being able to consider a change in employment circumstances. National Health Service (NHS) Talking Therapies services were set up to improve health and well-being to support staying in or returning to work, and trials have found positive trends towards employment over the course of therapy engagement (Kuhn, 2011). However, participants articulated uncertainty about where they may be able to access such support provided by a professional with specialist autism knowledge. Other participants had spent considerable time figuring out how to independently manage their mental health problems. Participants attempted to ameliorate the effect of workplace difficulties via self-care strategies such as engaging in physical exercise, relaxation, and pleasurable activities (Hansson et al., 2005), which should be further encouraged.

Although autism is now understood as a lifelong condition, there are a population of adults referred to as ‘a lost generation’ (Lai & Baron-Cohen, 2015) as they were most likely missed or misdiagnosed prior to diagnosis. The participants diagnosed in adulthood within this study articulated negative and positive outcomes of their late diagnosis on their employment circumstances. Participants’ narrative of their diagnosis facilitating greater self-understanding and self-compassion is supported by previous research (Jordan et al., 2020) and is aligned with Neff’s (2003) definition of self-compassion, enabling a better understanding of their difficulties through a lens of self-kindness. However, there was a shared sense of sadness and grief about the years of challenge they had faced, which may have been different with an earlier diagnosis. Participants articulated that discovering they were autistic meant they felt more confident to advocate for themselves within the workplace via diagnosis disclosure. There are mixed workplace disclosure outcomes determined by previous research (Lindsay et al., 2019; Romualdez et al., 2021a; Romualdez et al., 2021b). Some have found that disclosure supports autistic people to express their identity, enables reasonable adjustments for legal protection, and increases acceptance (Romualdez et al., 2021a). However, Roumaldez et al. (2021b) also found autistic individuals feared discrimination from others, increasing their reluctance to disclose. Similarly, this study shows that employers' reactions to disclosure are not always positive or enable appropriate support or career progression (Sayce, 2011).

Strengths, Limitations, and Future Directions

This study adds to the paucity of research available exploring the lived experience of unemployment and underemployment among autistic adults. Using IPA methodology enabled voices of autistic participants to be heard and addresses the underrepresentation of autistic adults in research (Howlin et al., 2015; Nicolaidis, 2019).

A strength of this study is the use of reflexivity and audit to reduce bias and increase transparency. The main researcher acknowledged her position as neurotypical and thus the external perspective from which they conducted the research. Consultation with the autistic community during research development was completed to offset this bias, recognised as crucial for this study (Fletcher-Watson et al., 2021), and recommendations were implemented to study materials accordingly.

Open-ended qualitative data collection could overwhelm autistic people, as interview structure and predictability may be preferred (Nicholas et al., 2017). However, using a semi-structured interview enabled the researcher to meet autistic people's needs and sensitivities whilst ensuring data acquisition aims were achieved. Furthermore, the interview questions were sent in advance to allow the participants to prepare if desired and create a comfortable interview environment.

The recruitment of the current sample was predominantly through the ShARL database, and therefore it is likely to have gathered the views of people involved in and interested in research. Further research may seek to recruit those underrepresented in research (e.g., individuals with communication difficulties), approaching a wider pool of participants by reaching out to autism-specific charities and other services.

Moreover, participants were offered a gift voucher for participation. Given the nature of the topic, it could be argued that participants may have participated based on such an incentive. However, offering gift vouchers can reduce some of the power imbalance between researcher and participant, increasing fairness to participants and enabling both in the relationship to benefit directly (Gelinas et al., 2018; Head, 2009).

Participants varied in current employment status, and time elapsed since being unemployed or self-identifying as underemployed may have influenced their narrative and feelings around their experience. Hence time could have impacted the individual’s narrative, and the variability across participants will make it difficult to understand the impact of time. Future research may consider whether the adjustment to employment status experience differs depending on certain time points spent as unemployed or underemployed. Similarly, this study explored both un- and underemployment; all but one participant had experienced both. There may be differing narratives between experiences of these two employment statuses, which may not have been recognised within this research. Further research may wish to separate the two employment statuses and unpick the experience of the specific employment individually further.

Clinical Implications

At an individual level, this study highlights the importance of clinicians working with autistic adults to be aware of their potential employment challenges. Being curious about their employment circumstances, history, and satisfaction can open a conversation around systemic factors that may be precipitating or perpetuating their mental health difficulties. Using a job satisfaction questionnaire such as the Job Description Index (Smith et al., 1969) measuring satisfaction with work, supervision, co-workers, pay, and promotion could enable such a conversation. Liaison and advocacy were also noted as desired; thus, it is important for clinicians working with autistic adults to advocate for their employment needs, providing formulations of their strengths and needs to their employers and advocating for necessary reasonable adjustments in the workplace.

Furthermore, trauma in the context of employment can be significant, as highlighted by the current sample, and has consequences for daily and social functioning. Exploring and supporting autistic adults to make sense of potential multiple accumulated traumatic experiences appears essential for them to even contemplate moving forward with their employment aspirations. Similarly, as the current sample found self-understanding following their diagnosis enlightening, it is important for clinicians working in adult autism diagnostic services to facilitate a non-judgemental space to reflect on their historical employment difficulties where required through a lens which increases self-compassion.

At an organisational level, autism-related stigma in the workplace is evident, with autistic adults reporting stigma and misunderstanding as perpetuating exclusion, stilting career advancement, and reducing the likelihood of being recruited. Specific anti-stigma interventions targeting non-autistic colleagues and employers are required to improve the knowledge and attitudes of neurotypical people toward their autistic colleagues. Although more general autism anti-stigma interventions exist (Dachez & Ndobo, 2018; Morris et al., 2020), further research is required to investigate their effectiveness within a workplace setting and in changing behavioural intentions.

Moreover, as suggested by the current sample, an organisational commitment to inclusivity and diversity is needed. Employers should consider how they can support people with disabilities to feel more empowered from the beginning of their employment journey. For example, considering how job advertisements are presented and ensuring language is accessible.

At policy level, it remains important to monitor whether national guidance is affecting meaningful change for autistic adults and their employment circumstances. The current participants have yet to see the benefits of the national strategy, given that the guidance is in its infancy. Continued research and advocacy by clinical psychologists to ensure the conversation remains on the government's agenda is imperative to support further change.

Conclusion

Autistic participants shared narratives of traumatic employment experiences, pre-recruitment and within roles, and how they impacted their self-esteem, self-confidence, and well-being. There was a desire for increased compassion and understanding from employers, colleagues, and the wider population, as without this, participants felt powerless against the systems that are supposed to enable support. Finally, autistic people recognised their mental health needs perpetuated by negative workplace processes and experiences and attempted to proactively manage their well-being through self-reflection and understanding, physical exercise, therapy, and meaningful activity. This study highlights the need for clinicians working with autistic adults to be aware of these employment challenges and to provide a non-judgemental space to make sense of their experiences through a lens of self-compassion. Further, anti-stigma interventions are needed in the workplace, and an organisational commitment to inclusivity and diversity is required to enable autistic people to feel empowered from the beginning of their employment journey.

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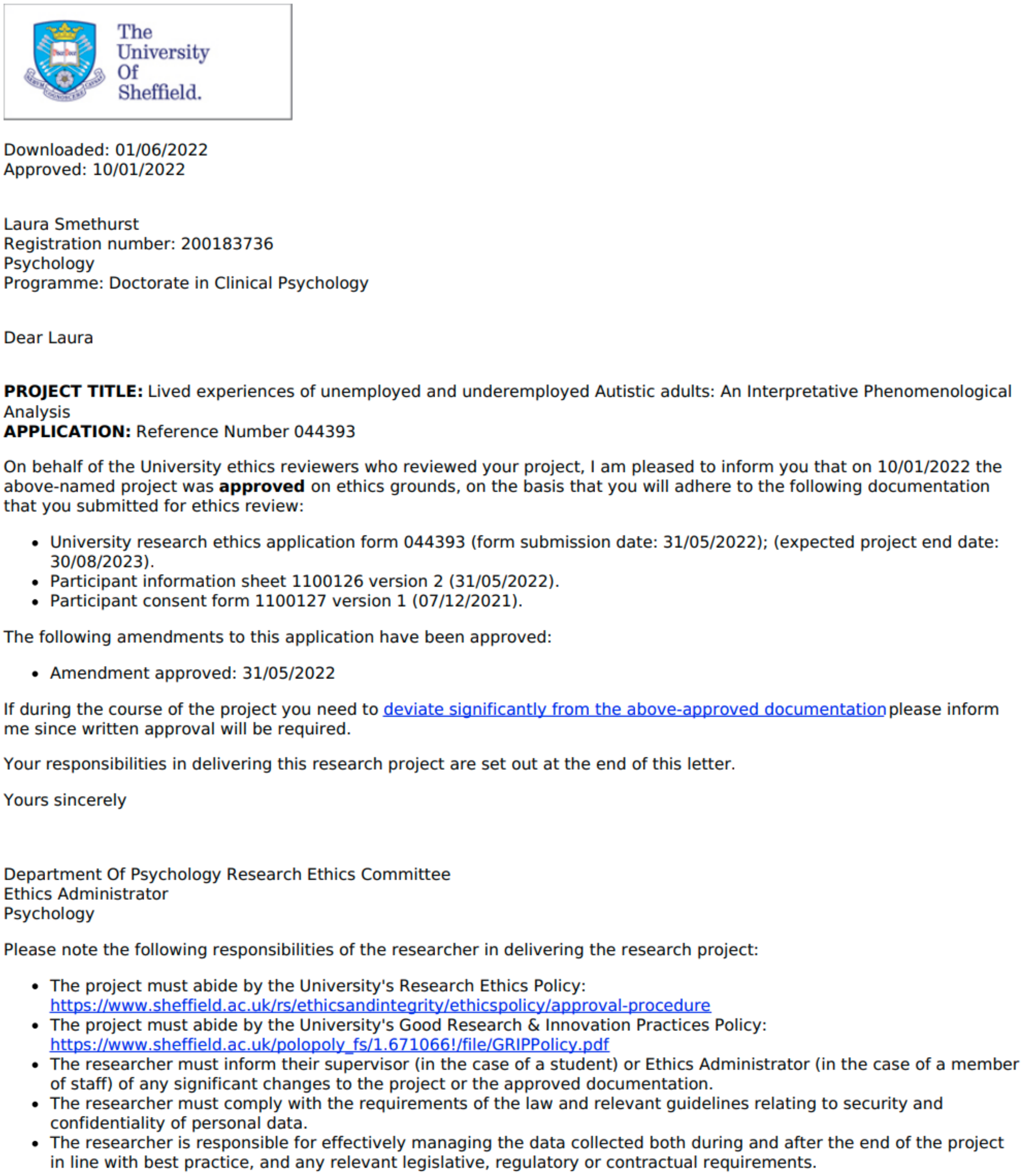
Appendices

Appendix A

University of Sheffield Ethics Approval Letter



Approved: 10/01/2022

Laura Smethurst
Registration number: 200183736
Psychology
Programme: Doctorate in Clinical Psychology

Dear Laura

PROJECT TITLE: Lived experiences of unemployed and underemployed Autistic adults: An Interpretative Phenomenological Analysis
APPLICATION: Reference Number 044393

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 10/01/2022 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 044393 (form submission date: 31/05/2022); (expected project end date: 30/08/2023).
- Participant information sheet 1100126 version 2 (31/05/2022).
- Participant consent form 1100127 version 1 (07/12/2021).

The following amendments to this application have been approved:

- Amendment approved: 31/05/2022

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Department Of Psychology Research Ethics Committee
Ethics Administrator
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix B

Interview Schedule

Demographic Information

What name or terminology do you prefer to use to refer to your diagnosis?

What gender do you identify with?

How old are you?

How would you describe your ethnicity? *(Prompts: for example, British)*

How old were you when you were diagnosed with Autism?

Have you received any other diagnosis from other healthcare professionals?

Do you have any formal qualifications? (*Prompts: can you tell me what they are? If "no" what age did you leave school?)*

What is your current employment status? *(Prompts: If underemployed, how many hours per week, how many hours would you like to work per week?)*

How many jobs have you had in the past?

How many periods of unemployment have you experienced in the past?

Main Interview Schedule

1. When you were coming to the end of your school years, what did you want to do for work?

Prompts: What influenced your decision or desire to want to go into your chosen area of work? Did you receive any support in school that may have helped with the process of gaining/maintaining employment?

2. Can you tell me about your experience of when you first started applying for jobs?

Prompts: How old were you when you first started to look for a job? What sorts of jobs were you looking at/going for? Have you ever been offered a job – if so, what was that like for *you?*

3. Can you tell me about your current experience of trying to gain the type of job that you want?

Prompts: What is the process of applying for your desired job like? Is there anything you've found helpful? Or any particular challenges you faced/continue to face? What do you see as the barriers to gaining your desired level of employment? Can you tell me about other people, training, or kinds of support you may have accessed during the employment process?

4. What has it been like for you during periods of being out of work (unemployed) and/or not doing the jobs you'd ideally like to do (underemployed)?

Prompts: What does 'underemployed' mean to you? How important is/was getting a job that fully utilises your skill level? How would you have liked/like things to be different?

5. How does being unemployed / underemployed affect your day-to-day life?

Prompts: What areas of your life do you feel are most affected by being unemployed/underemployed? (e.g., finances, living independently, emotional wellbeing, relationships)

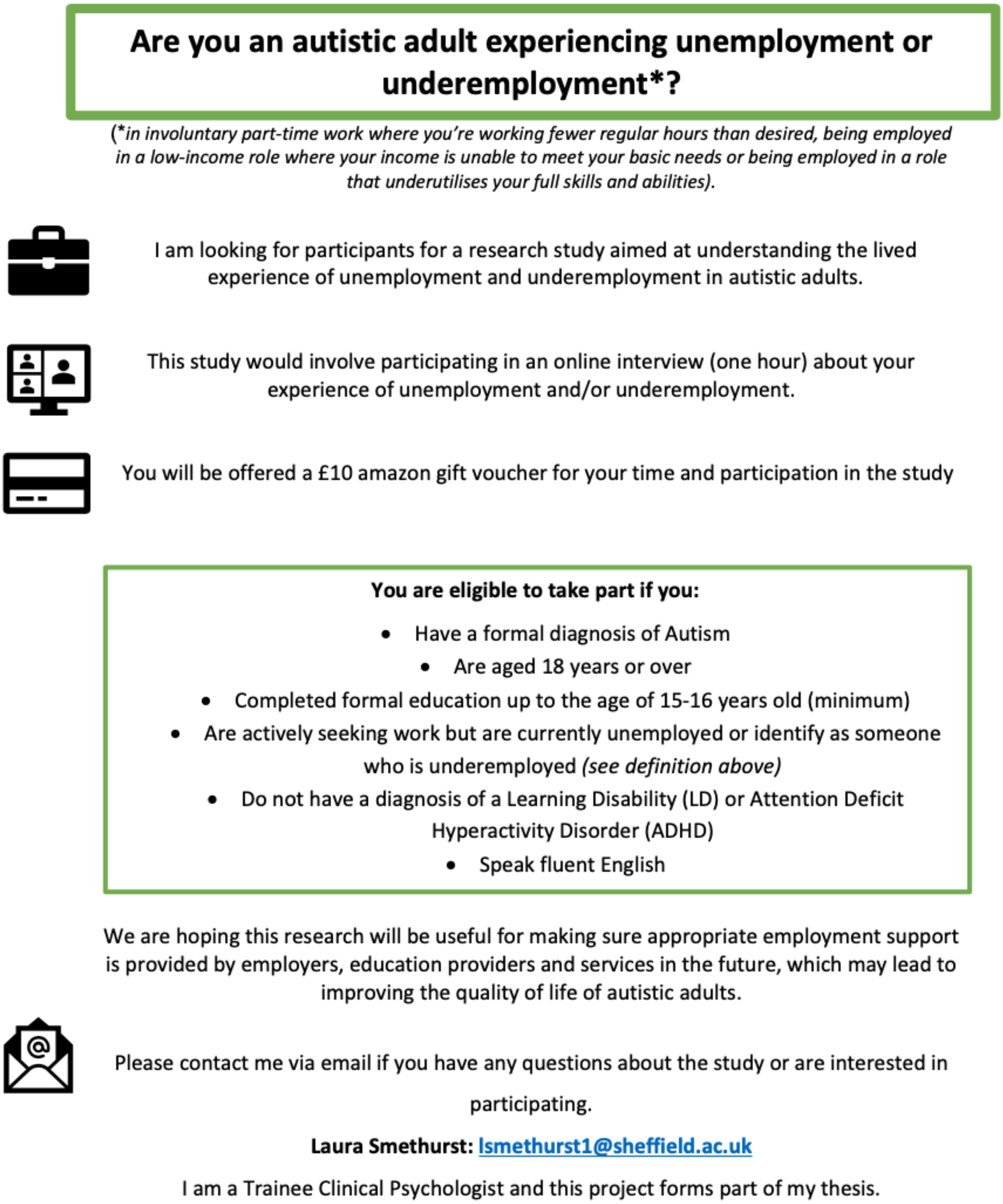
6. What sorts of thoughts and feelings have you had about being unemployed and/or not having the job that you want that uses all of your skills?

Prompts: *How would you describe your self-esteem because of being out of work, and/or not being in your desired role (underemployed)? What kind of impact has being underemployed has on your self-confidence?*

7. Is there anything else that you have not had the chance to tell me about today that you feel would be important for me to know about your employment experiences?

Appendix C

Research Advert



Are you an autistic adult experiencing unemployment or underemployment*?

(*in involuntary part-time work where you're working fewer regular hours than desired, being employed in a low-income role where your income is unable to meet your basic needs or being employed in a role that underutilises your full skills and abilities).*

I am looking for participants for a research study aimed at understanding the lived experience of unemployment and underemployment in autistic adults.

This study would involve participating in an online interview (one hour) about your experience of unemployment and/or underemployment.

You will be offered a £10 amazon gift voucher for your time and participation in the study

You are eligible to take part if you:

- Have a formal diagnosis of Autism
- Are aged 18 years or over
- Completed formal education up to the age of 15-16 years old (minimum)
- Are actively seeking work but are currently unemployed or identify as someone who is underemployed *(see definition above)*
- Do not have a diagnosis of a Learning Disability (LD) or Attention Deficit Hyperactivity Disorder (ADHD)
- Speak fluent English

We are hoping this research will be useful for making sure appropriate employment support is provided by employers, education providers and services in the future, which may lead to improving the quality of life of autistic adults.

Please contact me via email if you have any questions about the study or are interested in participating.

Laura Smethurst: lsmethurst1@sheffield.ac.uk

I am a Trainee Clinical Psychologist and this project forms part of my thesis.

Appendix D

Participant Information Sheet

The
University
Of
Sheffield.

Laura Smethurst
Trainee Clinical Psychologist
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield S1 2LT
UK

Email: lsmethurst1@sheffield.ac.uk

PARTICPANT INFORMATION SHEET

You are being invited to take part in a research project. Before you decide, it is important to understand why the research is being done and what it will involve. Please read the following information carefully and ask me any questions you have.

Why have I been invited?

You have been invited to take part in this research project because you are an autistic adult actively seeking employment but are unemployed or self-identify as someone who is underemployed.

Underemployed can be defined as: in involuntary part-time work – working fewer regular hours than desired, being employed in a low-income role where your income is unable to meet your basic needs or being employed in a role that underutilises your full skills and abilities.

Do I have to take part?

No. Participation in this study is voluntary. That means you are free to choose if you would like to take part or not. If you do decide to take part, please keep this information sheet. You will be asked to sign a consent form, which is a document that confirms you agree to participate. You are also free to discontinue your participation at any time without giving a reason and can withdraw your data up to two weeks after your interview.

What will happen if I take part?

You will be contacted via email by the lead researcher within three weeks. The interview will take an hour, during which time you will be asked some demographic questions and some questions about your experience of unemployment and/or underemployment.

The interview will take place online. You are welcome to have a supportive individual with you if this would help, but they won’t be able to participate in the actual interview itself.

The interview will be recorded and then transcribed by a University approved transcriber or the lead researcher. Following this process, it will be analysed using Interpretative Phenomenological Analysis.

You will be offered a £10 amazon gift voucher for your time and participation in the study. You will be asked to sign a form confirming that you have received this gift via email. This form will be kept securely as a digital copy for at least 7 years after the end of the project, accessible by University finance and administrative staff for reference in the event of a financial audit.

What are the benefits of taking part?

If you decide to take part, you will get the opportunity to share your experience of unemployment and/or underemployment. A written report of the findings will be compiled with the hope of providing information to ensure employment support is tailored to individuals and offered when needed.

What if there is a problem?

If you feel that there is a problem at any time, you can let the researcher know. This topic may be difficult to talk about or could cause some people distress. If you experience any distress whilst sharing your experience, the researcher will be able to discuss this with you and discuss what further support might be of help (e.g., contacting your GP).

Will all the information be kept confidential?

All the information we collect about you will be kept strictly confidential, which means we do not share it. It will not be possible to identify you from any reports or publications that come from the study.

There is one exception to this confidentiality policy – the risk of harm to self or others. During your interview, if the researcher has concerns about a risk of harm to yourself (e.g., suicidal risk), or someone you talk about (e.g., risk of physical harm to a person other than yourself), then confidentiality may need to be broken. In such a situation, the researcher would discuss the need to break confidentiality with you.

The aim of breaking confidentiality would always be to support yourself and those you mention and ensure everyone's safety. For example, it may involve letting relevant services know about the situation to help provide those involved with support. Again, any break in confidentiality will be discussed with you first.

What will happen to the results of the study?

The results will be submitted as part of the researcher's doctoral thesis in May 2023. You can let the researcher know at the start of the study if you would like a copy of this and this can be sent to you. The final project will also be submitted for a journal publication. As mentioned above all information within reports and publications will be kept strictly confidential. You will be anonymous, and you will be allocated a pseudonym, which means your real name will not be used or be seen by anyone other than the lead researcher.

You may withdraw your data without giving a reason why two weeks after your interview, which is when I will begin analysing the data. To withdraw your data, you can contact the lead researcher (details below). After data analysis starts you will be given a pseudonym (a fictitious name) and you will no longer be able to withdraw your data from the study.

The University of Sheffield is organising and funding this research. This project has been ethically approved via the University of Sheffield Clinical Psychology department, using the University of Sheffield's Ethics Review Procedure.

What if I wish to complain about the way the study has been carried out?

In the first instance you can contact the lead researcher, Laura Smethurst on lsmethurst1@sheffield.ac.uk. Alternatively, you can contact the other researcher involved in the project, Megan Freeth, Lecturer and Researcher on m.freeth@sheffield.ac.uk.

If you feel that your complaint has not been handled to your satisfaction following this, you can contact Prof Elizabeth Milne, Head of Department at e.milne@sheffield.ac.uk or Dr.Robert Schmidt & Dr Jilly Gibson-Miller, Joint chairs of the Department Ethics Subcommittee on psy-ethics@sheffield.ac.uk.

Contact Information

This research is being conducted by **Laura Smethurst,** a Trainee Clinical Psychologist. This research will be used to write a thesis that is part of their doctoral training. If you have any questions about the research, you can leave a telephone message with the Research Support Officer on: 0114 222 6650 and he will ask **Laura Smethurst** to contact you.

Additional Information about your data

New data protection legislation came into effect across the EU, including the UK on 25 May 2018; this means that we need to provide you with some further information relating to how your personal information will be used and managed within this research project.

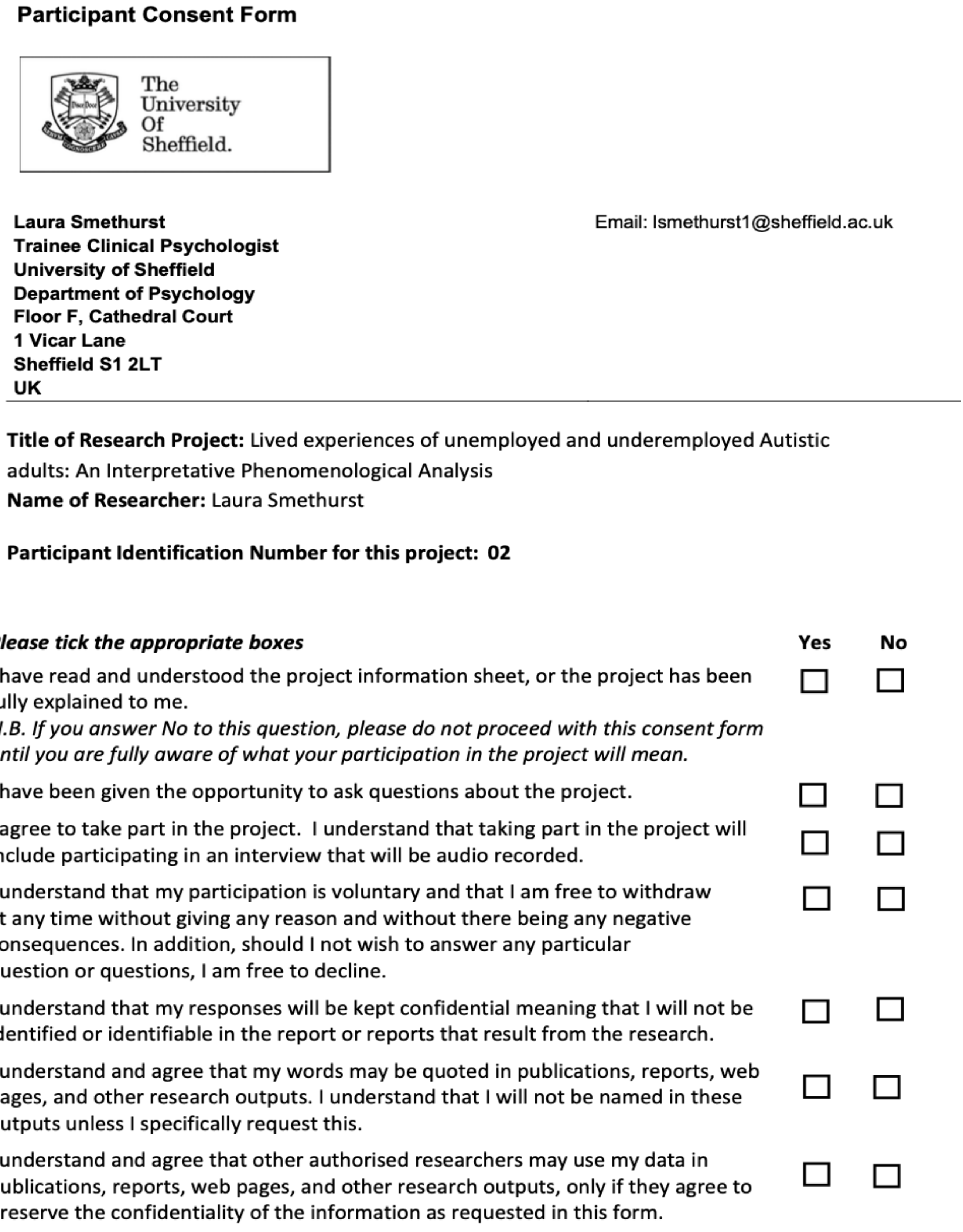
The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'.

As we will be collecting some data that is defined in the legislation as more sensitive (e.g. information about your health), we also need to let you know that we are applying an additional condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Appendix E

Participant Consent Form



Participant Consent Form

Laura Smethurst
Trainee Clinical Psychologist
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield S1 2LT
UK

Email: lsmethurst1@sheffield.ac.uk

Title of Research Project: Lived experiences of unemployed and underemployed Autistic adults: An Interpretative Phenomenological Analysis

Name of Researcher: Laura Smethurst

Participant Identification Number for this project: 02

	Please tick the appropriate boxes	**Yes**	**No**
1.	I have read and understood the project information sheet, or the project has been fully explained to me. *N.B. If you answer No to this question, please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.*	☐	☐
2.	I have been given the opportunity to ask questions about the project.	☐	☐
3	I agree to take part in the project. I understand that taking part in the project will include participating in an interview that will be audio recorded.	☐	☐
4	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.	☐	☐
6	I understand that my responses will be kept confidential meaning that I will not be identified or identifiable in the report or reports that result from the research.	☐	☐
7	I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	☐	☐
8	I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐

9 I agree for the data collected from me to be stored anonymously and potentially used in future research. ☐ ☐

10 I agree to take part in the above research project. ☐ ☐

12 I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield. ☐ ☐

__________________________ __________________ ______________________
Name of Participant Date Signature

__________________________ __________________ ______________________
Lead Researcher Date Signature
To be signed and dated in presence of the participant

Appendix F

Example Reflective Diary Entry

Reflections following interview:

The interview got off to a challenging start, when explaining the study used the phrase ‘people with autism’ despite knowing the preferred term is ‘autistic person’ – human error. Participant spent a long time explaining the importance of language which instantly made me want the ground to swallow me up, as I knew this given the literature I had read. Despite this mistake, participant did not seem offended, and wanted to engage with the interview. Made note to self for future interviews be more mindful of language used, but also be compassionate to self and as a human, we make mistakes – own up to mistake and move on together.

Discovered autistic in 40’s – reflected on how difficult it must have been to go through life not knowing or fully understanding the self, over 10 years older than myself which feels an incredibly long time and I wondered how frustrating that must be for them; the lost years. Felt a parallel sense of sadness that they had experienced years of traumatic experiences and continued difficulties with self-esteem and confidence – would this have been different if they have sought a diagnosis earlier, or someone had picked this up for him?

Version of underemployment made sense to me, as they were working part-time and wanted to be working more hours, thus getting paid more. Also felt to be a mismatch of skills given the number of qualifications he had but was not utilising them. Previous interviews had felt a little more abstract / not as concrete which helped me within the interview to be more present and thinking less about the conceptualisation of their employment status.

Felt some sense of inadequacy and an imposter at times throughout the interview, participant had a degree similar to my undergraduate and when they asked about specific theorists name, I froze. At times felt intimidated by their awareness of himself and the world around them. They had spent a lot of time discovering themself and understanding where they fit in the world. They seemed particularly confident about their needs, whilst simultaneously sharing themes of exhaustion, trauma and fragility. I wonder if sometimes that is how I present, as though I have my life and career together, but internally feel a sense of fragility via imposter syndrome.

Reflections during analysis:

‘Discovered autistic’ gives a lot of power to that process – seems significant in their life and ‘reframing the past’ feels like it has been an enlightening yet exhausting process. Where were they missed? Is this due to age and not being as informed re: autism as a child? Unsure if things have moved on or whether some people are generally just must better at masking through life subconsciously. Can’t help but feel a little angry about the direction of his life, and would this have been different if diagnosed earlier? But also, from experience of ASD assessment services, there is limited post-diagnostic support – so perhaps things wouldn’t have been different? Sense that things are getting better now, but given participant’s age, the support would not have been available back then.

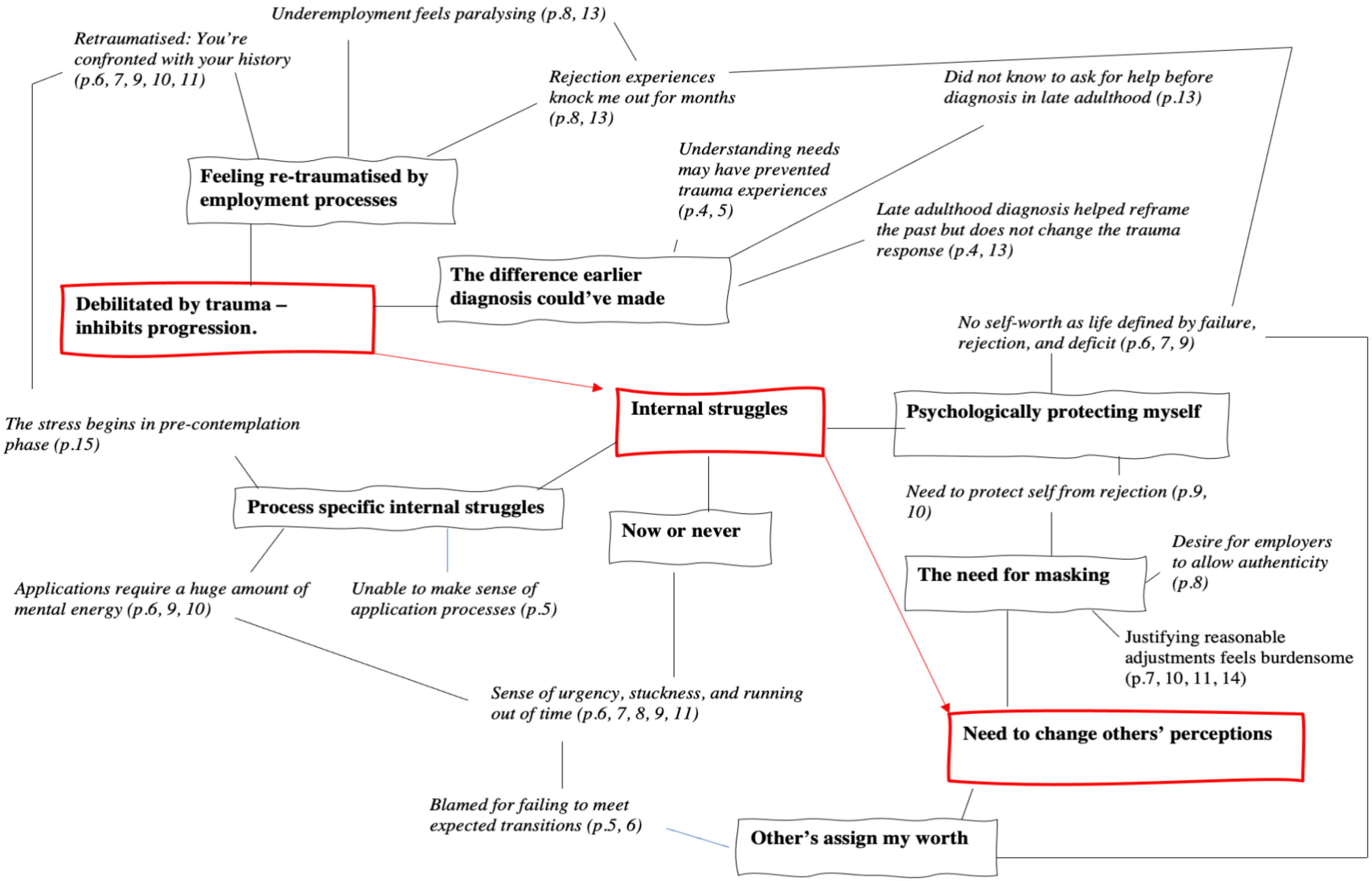
Clear statement of trauma and re-traumatisation throughout – as a mental health clinician it is difficult not give too much weight to this, although doesn’t feel disproportionate to the experience discussed. Re-reading the transcript highlighted my anger and sadness about their experience and how difficult it is for them to even consider applying to other roles. Although going into this I imagined things would have been hard – I was struck by how sad I felt for them.

Despite clear age differences – could relate to the urgency of wanting to feel settled and having a place in the world. Something about feeling as though they are running out of time for their life to begin – feel similar when thinking about wanting the DClin to end, so my life can begin?

Does gender come into any of this? Something about seeming ‘fine’ on the outside, but internally struggling – is this due to societies expectations of men? Rising worry whilst re-reading the transcript given the high prevalence of male suicide, and personal experience of this – worries subsided by the end of the transcript, conversation re: accessed support from services previously and is aware where he would find mental health support if needed (e.g., via GP).

Appendix G

Example Participant Conceptual Map



Appendix H

Examples of Each Stage of Analysis

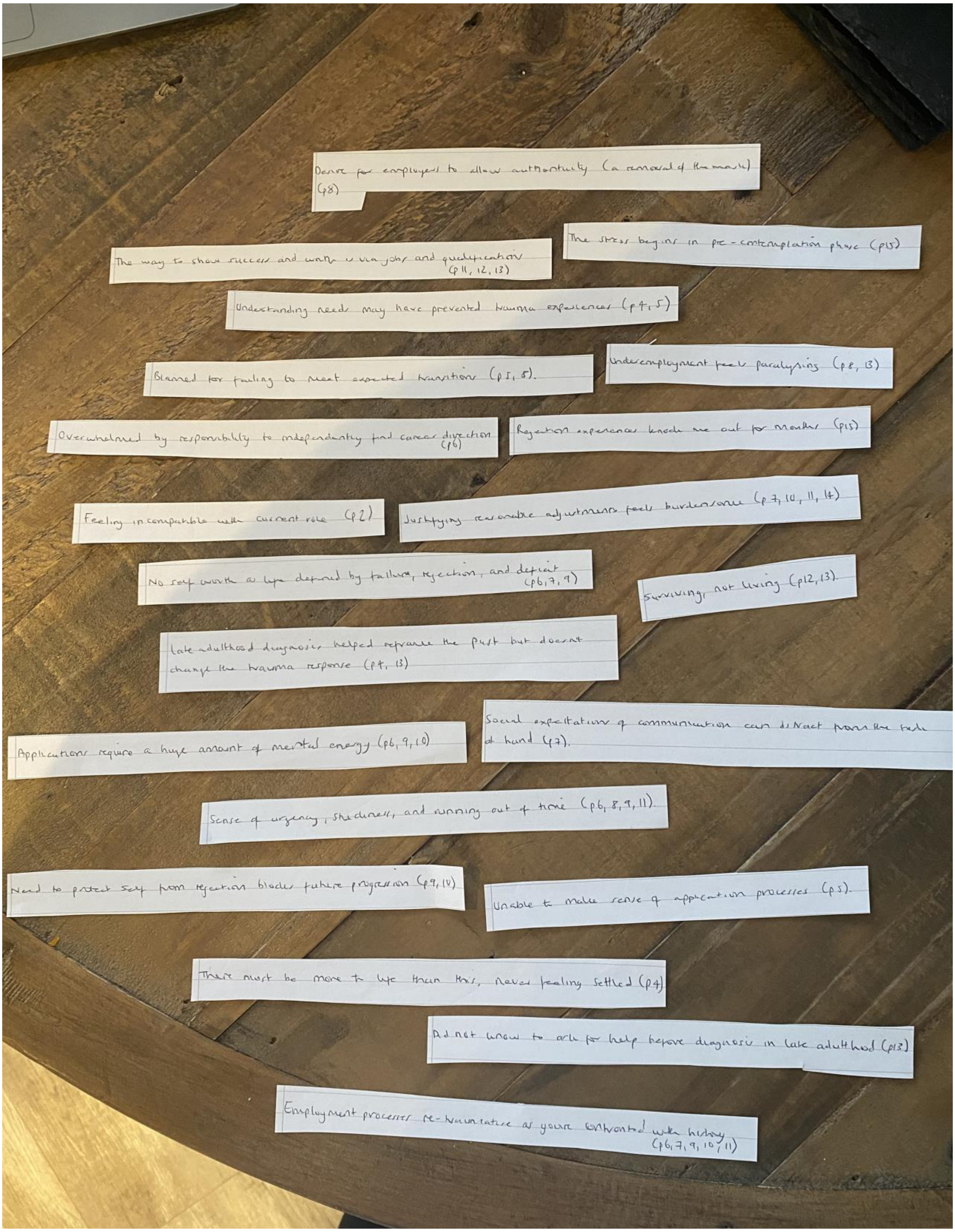
Example transcript with notes and experiential statements

Sense of urgency, stuckness and running out of time **There must be more to life than this, never feeling settled.** **Diagnosis helps reframe the past but doesn't change the trauma.** **Re-traumatisation as you're confronted with your history**	**P**	This has been consistent, I suppose all the way through is that sense of, I'm not sure what I want to do when I grew up and I still, you know, obviously approaching 50 still feel that way and I joke about this, but there's a real trauma there, and a real anxiety about that, and erm interviews, and the whole application process is just one enormous stress ball erm because first of all, it's figuring out what is it that I could apply for what is that I could do that work and then where do I find out about that, and of course, you know, back when I was starting doing this, you know, the internet didn't exist at all, erm you know, for I guess half of my experience, so it was just like look in the paper and of course I'd open the paper, and I was like, you know, there would be pages of, of jobs and what, what, which one, what is there to do, and, and then feeling self very self conscious about one about being at home and wanting to, I suppose appease, or please my parents and like, look like, you know, I've got something and they were, I suppose could, not cajoling me but erm directed me as best they could have - Oh, get a job with a bank or get a job with in the civil service, that sort of steady kind of thing and I was forever thinking that something else, there must be something else, other options, what, what is there, what else is there and I probably wasn't articulating myself enough, I don't know. There was as obviously, as I've said, there was no understanding of either you needed some more specific support, erm, but, but even that has persisted even as I've grown up and even as I said, I've I've just literally applied for another job erm in the past week and the whole application process, going through an application form is just really difficult. And of course, once it's, most of my life has been has been defined by failure, or not getting, not knowing what to apply for and then when I did not getting a job and being in the interview and thinking, this is just the most traumatic and terrible experience, you know, I hope I get out the other side, I hope I'm okay and then I suppose the next time I'm thinking god I'll have	Uncertain/unsettled re: career direction Sense of urgency, nervousness Applications induce trauma memories Aimlessly searching for jobs – where do you start? Feeling overwhelmed People appeasing High expectations from employment, jobs never met expectations Self-criticism Negative experience of applications Lots of rejection experiences Fear of having to go through the process again

Applications require a huge amount of mental energy		to do this all over again and you don't want to so I suppose I, to be honest I stopped even, I'll not even look because I just don't I just don't even want to go there, and and and then when I completed an application, it's the worry of oh my goodness if if they call me for an interview I've got to go for an interview.	No energy to manage future negative experiences Contrasting emotions experienced when offered interview
	I	Yeah. And you mentioned that the application form itself can be quite difficult, do you mind telling me a bit more about that?	
The stress begins in pre-contemplation **Fear of judgement** **Rejection experiences knock me out**	**P**	Yeah, that's difficult because, it's, you're confronting, this, I suppose this more so with having years of of of not feeling successful as such or not feeling like fully fulfilled or whatever because you're confronted with, you're confronted with your past failures whenever you fill in, how many jobs have you had? Oh, I've had 10 or 12 job whatever, and then you think, gosh, what is this gonna look like to the employer. I'm always thinking ahead to how is this going to be perceived, what are they gonna think, Is this gonna make me look good or bad, what is this going to, how is this going to influence whether I'll you know be getting the job or not. Erm, and I'm looking at, I'm you know I'm filling in the details and thinking goodness, yes remember that job, oh that was awful, or I really haven't I don't know I've amounted to too much or you know so even that, and I suppose nobody ever really, maybe with your fantastic study people will get an insight into that the whole application process for for I suppose particularly erm autistic people and erm minority people, people who are used to, people who are used to being knocked back. The application form itself can be a a erm triggering a triggering experience or a, like a slap in the face. There's not, they're not just neutral things, because you're confronted with your past history.	Internalising the failures Expecting judgement from others Lack of self-worth Fear of judgement from others Anxiety surrounding potential employer judgement Self-criticism – not met self or others' expectations Metaphors for how rejection is a punishing experience
	I	So, thinking about being underemployed… what was it like for you being underemployed, like, what does it mean to you?	
Underemployment is paralysing	**P**	It's, it's debilitating because, erm because I'm forever wondering about my my place in the scheme of things, my being thinking about erm what age am, and what is there to come, and what have I done. And so, I suppose every day just having that constant chatter, mental chatter about what it is to succeed, and what it is to be and to be and to be satisfied and it ties in as well with the whole, erm and this is where the social psychology will come in to the the social messages	Feeling paralysed, worn down, stuck Where do I belong? Questioning identity Running out of time Societal expectations put onto us

The way to show success/worth is via jobs/qualifications **Blamed for failing to meet expectations**		that we get, you know, every day about being a success or succeeding, and all really you must do, and it's ties in with individualism and erm neoliberalism, capitalism whatever by being self-sufficient, and well, sort of, if you don't have enough money in your pension that was your fault, what were you doing. Erm, when I'm really frustrated I think well I'm trying my best, and I would really erm, I've, I've acquired lots and lots of experience and and qualifications, and I'm not quite sure where to put them and, and even even now knowing about being autistic, there isn't a real strong support structure there to to guide erm adults and late late diagnosed, now I'll say diagnosed and I don't really have a problem with that, late diagnosed adults. Erm and it's, so it's just really debilitating to be getting those messages to be feeling that self-consciousness erm erm while being met with well it's your fault, it's your problem and you're really just, you know, you should know what you want to do and you should have started a long time before.	Failure is our responsibility, you're on your own Not feeling good enough Feeling alone / isolated Feeling like a failure – not meeting expectations Feeling like it's too late

Personal Experiential Statements into personal experiential themes (PETs) for one participant



Desire for employers to allow authenticity (a removal of the mask) (p8)

The way to show success and worth is via jobs and qualifications (p11, 12, 13)

The stress begins in pre-contemplation phase (p15)

Understanding needs may have prevented trauma experiences (p4, 5)

Blamed for failing to meet expected transitions (p5, 8).

Underemployment feels paralysing (p8, 13)

Overwhelmed by responsibility to independently find career direction (p6)

Rejection experiences knock me out for months (p15)

Feeling incompatible with current role (p2)

Justifying reasonable adjustments feels burdensome (p7, 10, 11, 14)

No self worth as life defined by failure, rejection, and deficit (p6, 7, 9)

Surviving, not living (p12, 13).

Late adulthood diagnosis helped reframe the past but doesn't change the trauma response (p4, 13)

Social expectations of communication can distract from the task at hand (p7).

Applications require a huge amount of mental energy (p6, 9, 10)

Sense of urgency, stuckness, and running out of time (p6, 8, 9, 11).

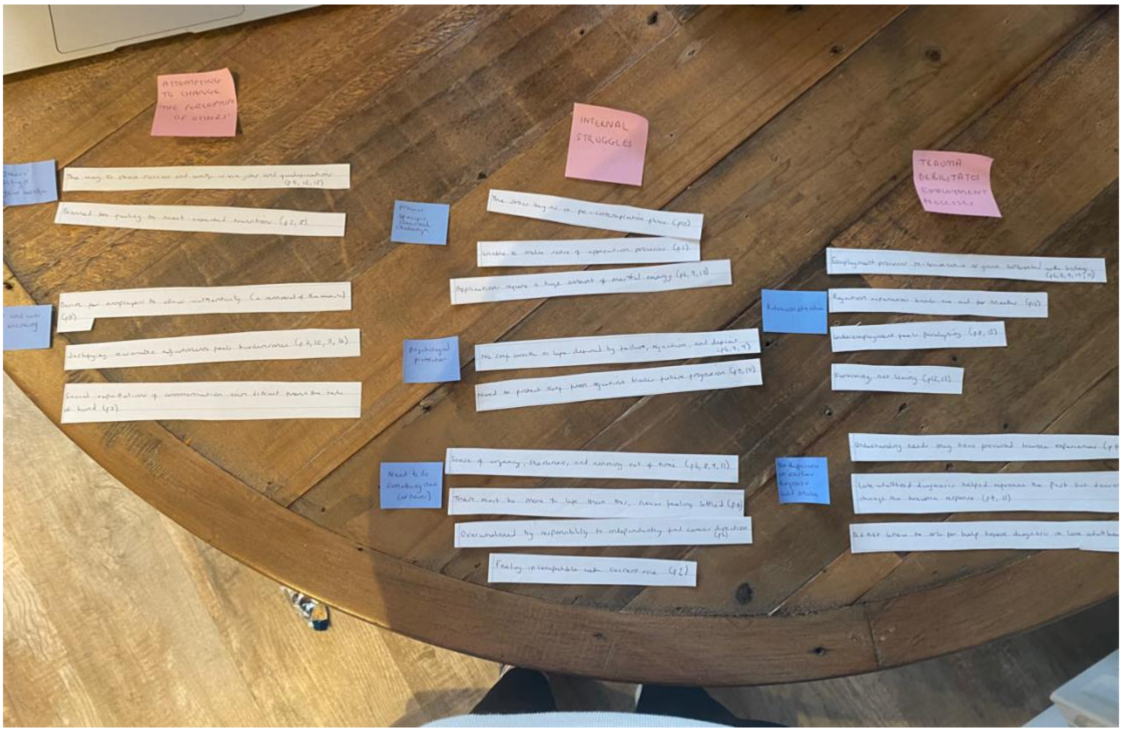
Need to protect self from rejection blocks future progression (p9, 10)

Unable to make sense of application processes (p5).

There must be more to life than this, never feeling settled (p4)

Did not know to ask for help before diagnosis in late adulthood (p13)

Employment processes re-traumatise as you're confronted with history (p6, 7, 9, 10, 11)

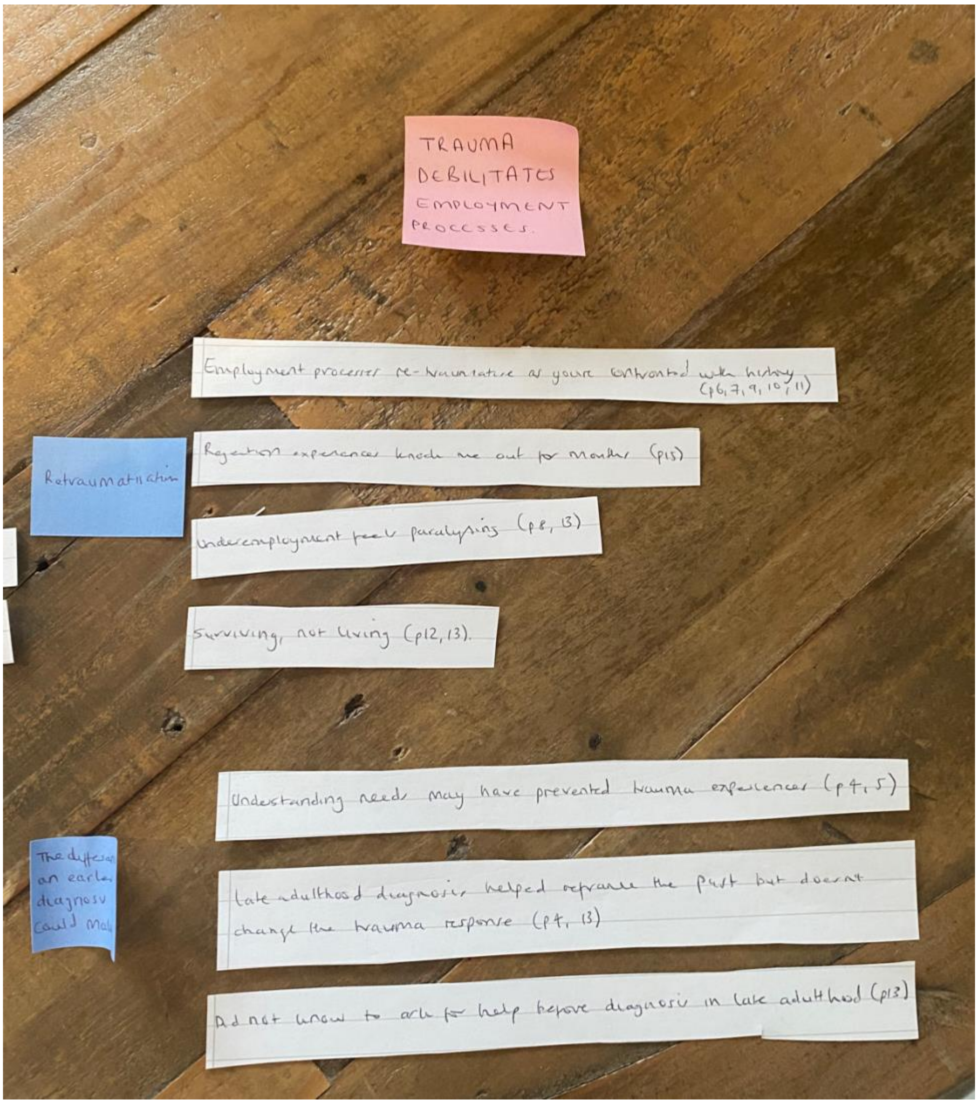


ATTEMPTING TO CHANGE THE PERCEPTION OF OTHERS'

INTERNAL STRUGGLES

TRAUMA DEBILITATES EMPLOYMENT PROCESSES

Need to do something new (or never)



TRAUMA DEBILITATES EMPLOYMENT PROCESSES.

Employment processes re-traumatise as you're confronted with history (p6, 7, 9, 10, 11)

Retraumatisation

Rejection experiences knock me out for months (p15)

Underemployment feels paralysing (p8, 13)

Surviving, not living (p12, 13).

Understanding needs may have prevented trauma experiences (p4, 5)

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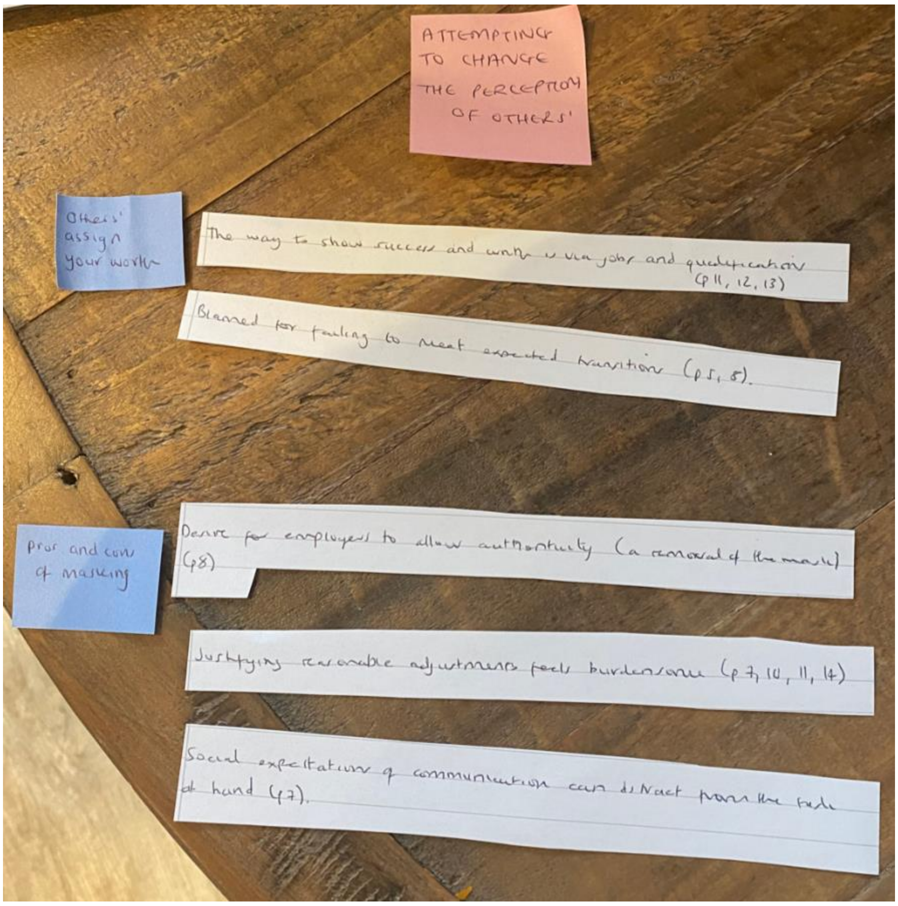


ATTEMPTING TO CHANGE THE PERCEPTION OF OTHERS'

Others' assign your worth

The way to show success and worth is via jobs and qualifications (p11, 12, 13)

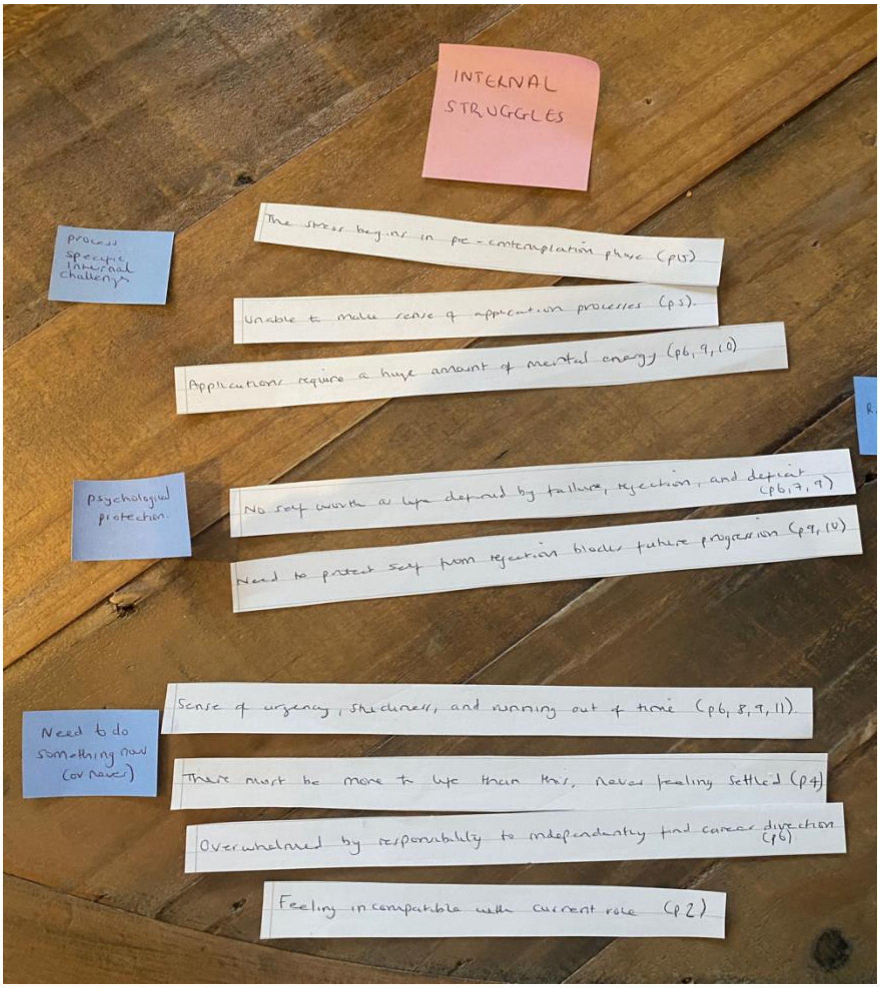
Blamed for failing to meet expected transitions (p5, 8).

Pros and cons of masking

Desire for employers to allow authenticity (a removal of the mask) (p8)

Justifying reasonable adjustments feels burdensome (p 7, 10, 11, 14)

Social expectations of communication can distract from the task at hand (p7).



INTERNAL STRUGGLES

process specific internal challenges

The stress begins in pre-contemplation phase (p15)

Unable to make sense of application processes (p5).

Applications require a huge amount of mental energy (p6, 9, 10)

psychological protection.

No self worth as life defined by failure, rejection, and defeat (p6, 7, 9)

Need to protect self from rejection blocks future progression (p9, 10)

Need to do something now (or never)

Sense of urgency, stuckness, and running out of time (p6, 8, 9, 11).

There must be more to life than this, never feeling settled (p4)

Overwhelmed by responsibility to independently find career direction (p6)

Feeling incompatible with current role (p2)

Table of all PETs for all participants

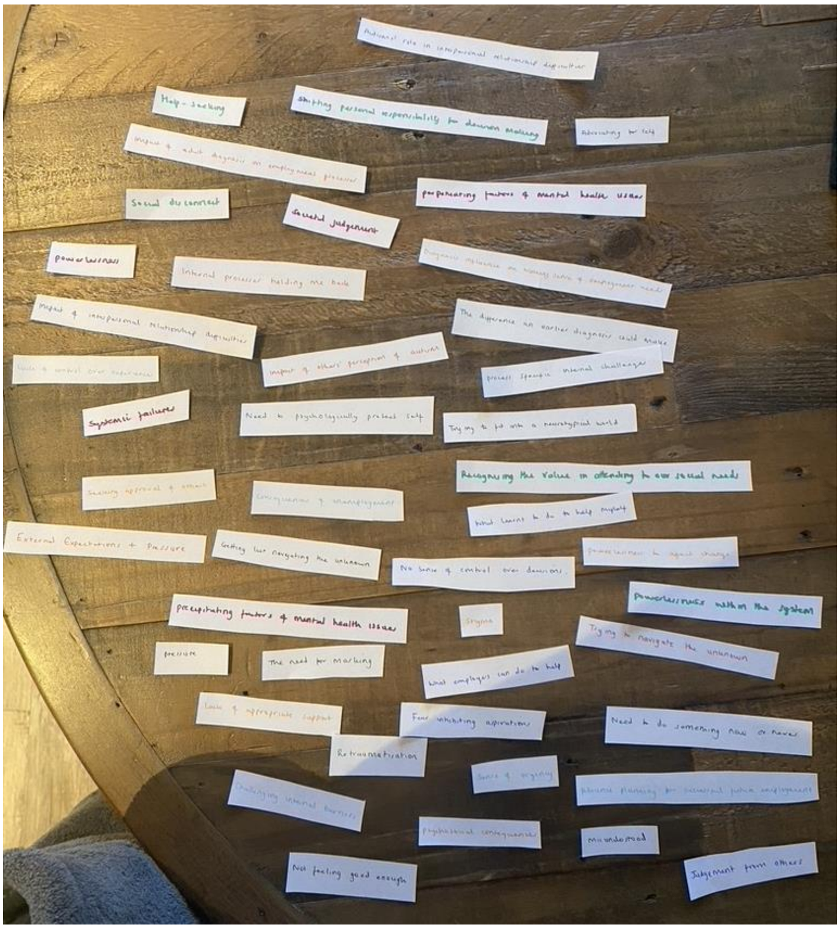
Participant One	**Participant Two**
External Expectations and Pressure *Attempting to align with societal expectations of adulthood (p.3)* *Feeling pressure to be in any employment (p.4)* *Feel less worthy than those in full-time roles (p.8)* *Worrying about finances can be all consuming (p.8)* **Trying to Navigate the Unknown** *Feeling lost when expected to transition to employment (p.3, 4)* *No idea what career path to follow, need to get it right (p. 3, 4, 6)* *Support in school feels like a tick box (p.4)* *Underemployment status not bad enough to warrant support (p.7)* *Application forms allow for a sense of control, interviews don't (p.4)* **Internal processes holding me back** *Lack of confidence holding me back (p.5, 8, 9)* *Haven't pushed myself hard enough (p.6)* *Intolerance of change keeps me in my comfort zone (p.9)* *Not reaching my potential when I'm capable of more (p.6)* *Want more for myself (p.5)* **Impact of adult diagnosis on employment processes** *Did not think about adaptations until diagnosis in adulthood (pp.5)* *Not knowing about diagnosis may have made the process harder (p.5)* **Impact of others' perception of autism** *Disclosure can have negative consequences for progression (p.7)* *Importance of others taking time to learn about autism (p. 10)* *Wary of others' perceptions of adaptations (p.5)* *Acting is forced to be the norm: masking (p.4)*	**Re-traumatisation** *Employment processes re-traumatise ad you're confronted with your history (p.6, 7, 9, 10, 11)* *Rejection experiences knock me out for months (p.8, 13)* *Underemployment feels paralysing (p.8, 13)* *Surviving, not living (p12, 13)* **The difference an earlier diagnosis could make** *Understanding needs may have prevented trauma experiences (p.4, 5)* *Late adulthood diagnosis helped reframe the past but does not change the trauma response (p.4, 13)* *Did not know to ask for help before diagnosis in late adulthood (p.13)* **Process specific internal challenges** *The stress begins in pre-contemplation phase (p.15)* *Unable to make sense of application processes (p.5)* *Applications require a huge amount of mental energy (p.6, 9, 10)* **Need to Psychologically Protect self** *No self worth as life defined by failure, rejection, and deficit (p.6, 7, 9)* *Need to protect self from rejection blocks future progression (p.9, 10)* **Need to do something now or never** *Sense of urgency, stuckness, and running out of time (p.6, 7, 8, 9, 11)* *There must be more to life than this, never feeling settled (p. 4)* *Overwhelmed by responsibility to independently find career direction (p. 6)* *Feeling incompatible with current role (p.2)* **Others' assign your worth** *The way to show success is via jobs and qualifications (p.11, 12, 13)* *Blamed for failing to meet expected transitions (p.5, 6)* **The need for masking** *Desire for employees to allow authenticity (p.8)* *Justifying reasonable adjustments feels burdensome (p.7, 10, 11, 14)* *Social expectations of communication can distract from the task at hand (p.7)*
Participant Three	**Participant Four**
Judgement from others *Time consuming process trying to anticipate employers' expectations (P3)* *Bullying (P6)*	**Powerlessness to Affect Change** *Lack of confidence to negotiate fair pay (P2, 9, 11, 12)* *People pleasing nature influences career direction (P6)*

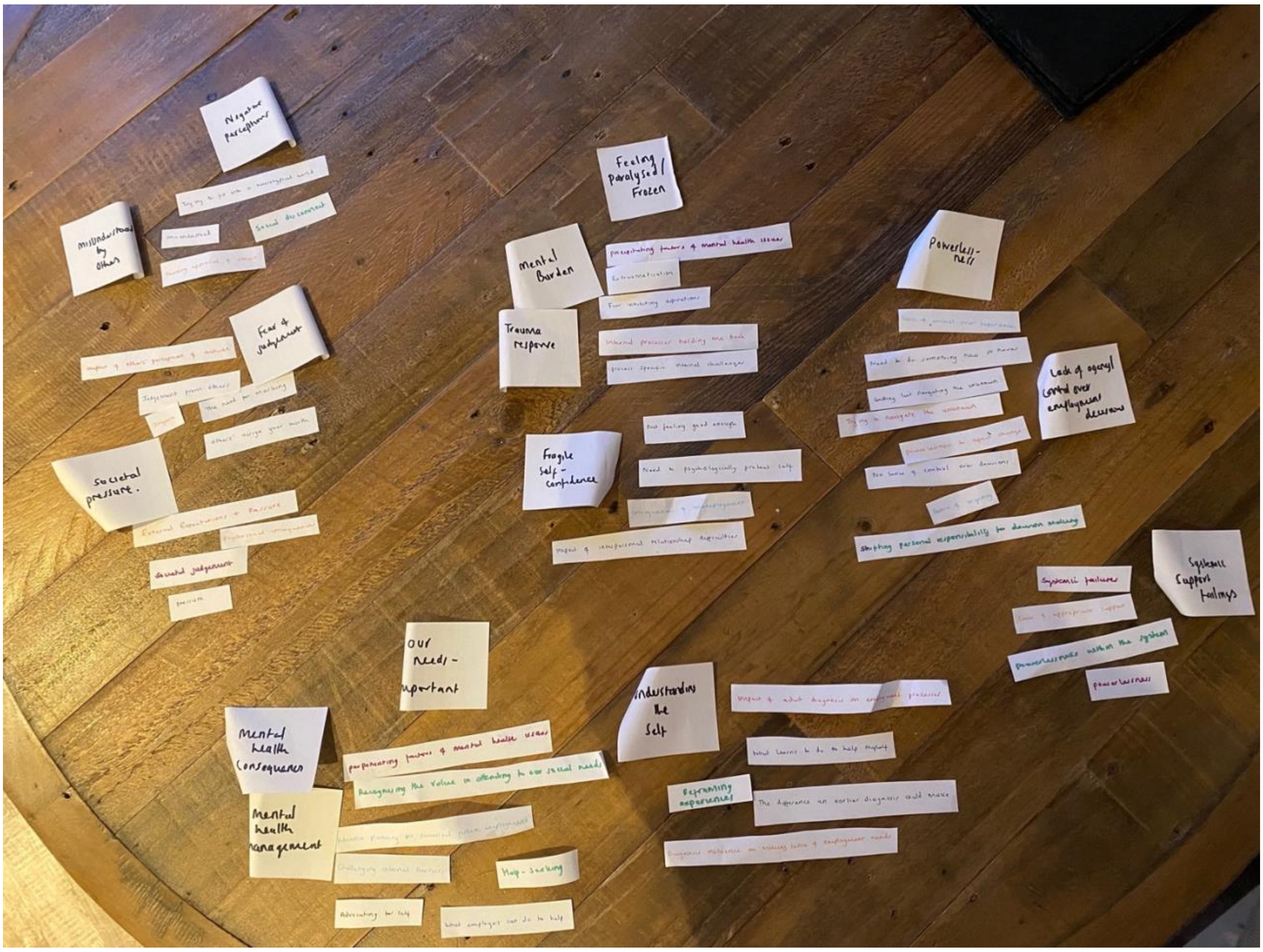
Seen as a useless member of society (P8) *Societal understanding of autism feels very generic (P15)* **Impact of interpersonal relationship difficulties** *Unsuccessfully navigating relationships has ruined job experiences (P5, 6)* *Lack of psychological safety in work induced severe mental health difficulties (P7, 8)* *Lack of trust in people as a barrier to initiating process back into work (P10, 11)* **Autism's role in interpersonal relationship difficulties** *Behaviour vulnerable to being misrepresented due to lack of understanding (P7, 12)* **Fear inhibiting aspirations** *Lack of self-belief (P3, 4, 11)* *Intense fear of employment history repeating itself (P4, 8, 11)* *Flight trauma response perpetuating unemployment (P6, 8, 11)* *Later diagnosis helped to accept the past but doesn't stop the fear (P8)* *Importance of getting the right job, not just any job (P12)* **No sense of control over decisions** *No sense of agency felt in decision making through employment history (P3, 7)* *No external encouragement to better myself (P3)* *Feeling set up to fail (P9)* *Feeling controlled by government finance schemes (P12)* **What I have learnt to do to help myself** *Increased understanding of employment needs aids confidence to request adjustments (P9)* *Desire to work for self instead of navigating difficult interpersonal relationships (P2, 10)* *Unemployment forced me to find ways to manage my mental health better (P11, 13)* *Recognising autism as a strength (P15)* **What employers can do to help** *Personalised training is so important to the success of a role (P14)*	*Work environments promoting overworking, few boundaries (P9)* *Fear that change would mean letting go of control (P13, 15)* *Advocating for yourself is anxiety provoking (P13)* **Seeking Approval of Others** *Taking on the responsibility for several people's roles (P3, 8, 11, 12)* *Unable to tolerate fear of disappointing and letting others' down (P8)* *Striving for recognition from others causes overworking (P11, 12)* *Torn between fairness and striving for recognition (P12)* **Stigma** *Requests for reasonable adjustments cloud employers' judgement (P7)* *Societal message of needing to be grateful you're in a job (P13)* **Lack of Appropriate Support** *Tolerate circumstances because services and systems intended to support provoke anxiety (P14)* **Psychosocial Consequences** *Impact on socialisation and isolation (P15)* *Taken advantage of and undervalued (P3, 7, 9, 11, 12, 13)* *Autistic burnout (P3, 7, 8)* *Lack of job stability driving financial consciousness (P3, 4, 10, 11, 12)* *Unable to feel stable in life circumstances (P13)* **Diagnosis influence on making sense of employment needs** *Building relationships prior to a job role influences success (P7)* *Persistent and unrecognised sensory sensitivities impact job performance (P5, 8)* *Adulthood diagnosis helping to make sense of previous negative work experiences (P5)*
Participant Five	**Participant Six**
Challenging Internal Barriers *Challenging self to improve mental health (P10)* *Attempting to reject cultural and societal stigma toward asking for help (P6)* *Recognising need to effectively manage anxiety (P5, 6)* **Advance Planning for Successful Future Employment** *Time spent considering career path (P3)*	**Not Feeling Good Enough** *Too hard to push past the self-doubt independently (P4)* *Lack of self-confidence and high self-criticism prevents progression (P9, 11, 12)* *Fragile confidence easily shattered (P5, 7, 9)* *My characteristics put me at a disadvantage from the start (P8)* **Pressure**

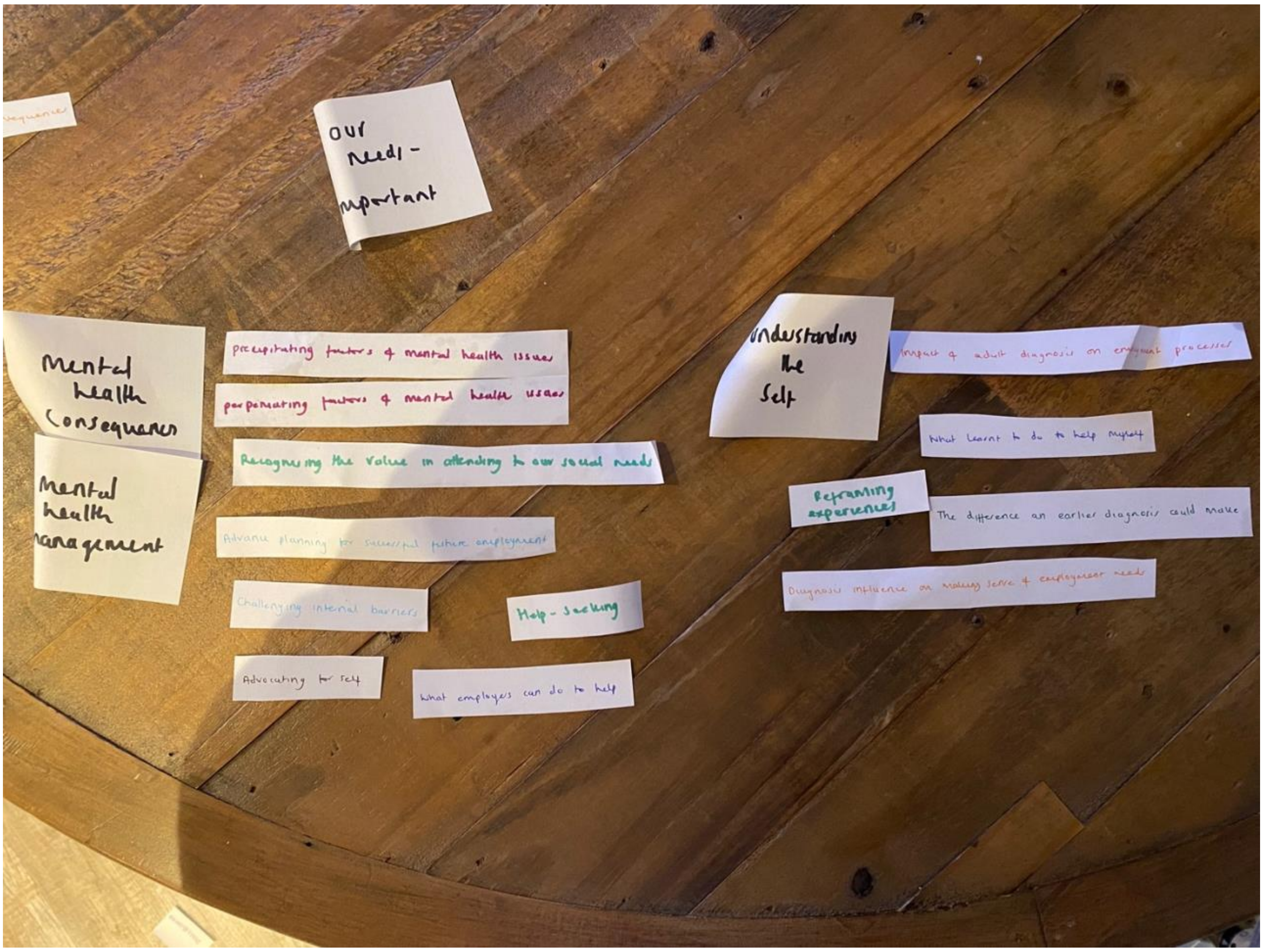
Proactively seeking out agencies for advice and support (P2, 4, 6, 8, 9) *Trying to find what is needed to get back into the field (P8, 9)* *Realistic aims to employment prioritising physical and mental health (P2, 6, 7)* *Educating self on disability rights and employment (P7)* **Lack of control over experiences** *Powerlessness to gaining experience thwarts opportunities (P3, 4)* *Rejected by the systems intended to support (P5, 10)* *Trying doesn't change societies narrative of the unemployed (P9)* *Self-esteem and confidence shattered by colleagues' lack of understanding (P7, 8, 11)* **Sense of urgency** *It's now or never (P9)* *Desperation for work resulted in underemployment (P6)* *No capacity left for failed employment attempts (P8)* **Consequences of unemployment** *Isolated and lonely (P9, 10)* *Deskilled by unemployment (P2, 6, 8, 9)*	*Running out of time (P7)* *Pressure and judgement from others triggered suicidality (P6, 7)* *Government 'support' perpetuates mental health issues (P6, 8)* **Misunderstood** *Late diagnosis disappointment (P6)* *Feeling like a worthless member of society (P6, 12)* **Advocating for Self** *Proactively working to positively impact mental health (P4, 11)* *Diagnosis disclosure helped advocate for change (P10)* *Seeking advocacy (P8, 9, 13)* *Looking for the right job, not just any job (P3, 4, 7, 8, 9)* **Getting Lost trying to Navigate the Unknown** *Lack of stability in role causes anxiety (P10)* *Lack of guidance contributing to aimlessness through adulthood (P3, 4, 7)* *Support can only be useful if you have an idea of what you want to do (P3, 9, 11)* *Feeling deceived by language and intentions of employers (P4, 5, 11, 13)* **Trying to fit into a neurotypical world** *The mask can be removed when you're unemployed (P6)* *The need for masking to be successful (P5, 13)* *Negatively judged by others for being self (P5)*
Participant Seven	**Participant Eight**
Precipitating Factors of Mental Health Issues *Social Isolation (P2, 6, 7)* *Feeling aimless (P2, 4, 6)* *Employment and the processes don't allow for authenticity (P2, 4)* *Fear of getting it wrong (P2)* *Financial hardship (P7)* **Perpetuating Factors of Mental Health Issues** *Unemployment perpetuates mental health difficulties (P4, 6, 7)* *Surviving, not thriving (P4)* *Autistic Burnout (P5, 7)* *Stress and hopelessness hindering willingness to try (P3, 5)* *Time needed to prioritise mental health to recharge energy levels (P5)* **Societal Judgement** *Being autistic means being on the backfoot before starting (P3, 6)* *Failure by societies standards (P7)* **Powerlessness** *Lack of Agency over Life Decisions (P5, 6)*	**Shifting personal responsibility for decision-making** *Happily gave locus of control over decision making to others (P4)* *Having connections and opportunity influenced first job (P4)* *Work is necessary not desired, driven by financial motives (P4, 5, 7, 11)* *Life circumstances perpetuate mental health difficulties which reduces motivation to work (P6)* **Powerlessness within the system** *Rejected from realistic employment opportunities so losing hope (P9)* *Employment has always been unstable in my field of work (P3)* *Change within the field of work have made gaining employment more difficult (P6)* *Job processes are more complicated in present day (P4)* *Learnt to accept and downsize our ambitions (P11)* **Social disconnect** *Fear of historical professional relationship difficulties hindering motivation to work (P7)* *Gaslighting and power imbalance knocked my already limited confidence (P7, 8)* *Fitting in with colleagues was challenging (P6)*

Decisions influenced by others (P3) *It's not what you know, but who you know (P2)* **Systemic failures** *Support offered is not proactive (P2)* *Sensory overload not accounted for in the work environment (P5)* *Society lacks compassion and understanding for autistic people (P4)* *Rejected by the systems of support (P5, 6)*	*Not fulfilling my duties as a husband (P7, 11)* *Society only values those in work (P7)* **Help-seeking** *Therapy important to understand and process experiences before returning to work (P11, 14)* *Seeking an advocate to identify employers who value autistic employees (P9)* **Recognising the value in attending to our social needs** *Interpersonal connection is an important factor in successful employment (P4, 5, 9, 13, 14)* *Desire to use social battery with lack of opportunity (P11)* *Need for clear communication to prevent feeling rejected (P8, 12, 13)* *Autistic people need more compassion and understanding from others (P10, 11, 12)*

Group Experiential Theme (GET) development process (*Note: coloured writing relates to different participant PETs)*




Negative perceptions
Social disconnect
Misunderstood by Others
Misunderstood
Fear & judgement
Judgement from others
The need for masking
Others' assign your worth
Societal pressure.
External Expectations & Pressure
Societal judgement
Feeling paralysed/ Frozen
Mental Burden
precipitating factors & mental health issues
Retraumatisation
Fear inhibiting aspirations
Trauma response
Internal processes holding me back
Process specific internal challenges
Not feeling good enough
Fragile self-confidence
Need to psychologically protect self
Impact of interpersonal relationship difficulties
Powerless-ness
Trying to navigate the unknown
Lack of agency/ control over employment decisions
No sense of control over decisions
Shifting personal responsibility for decision making
Systemic support failings
Systemic failures
Lack of appropriate support
Powerlessness within the system
powerlessness
Our Needs - mportant
Mental health Consequences
perpetuating factors & mental health issues
Recognising the value in attending to our social needs
Mental health management
Advance planning for successful future employment
Challenging internal barriers
Help-seeking
Advocating for self
What employers can do to help
Understanding the Self
Impact of adult diagnosis on employment processes
What learnt to do to help myself
Reframing experiences
The difference an earlier diagnosis could make
Diagnosis influence on making sense & employment needs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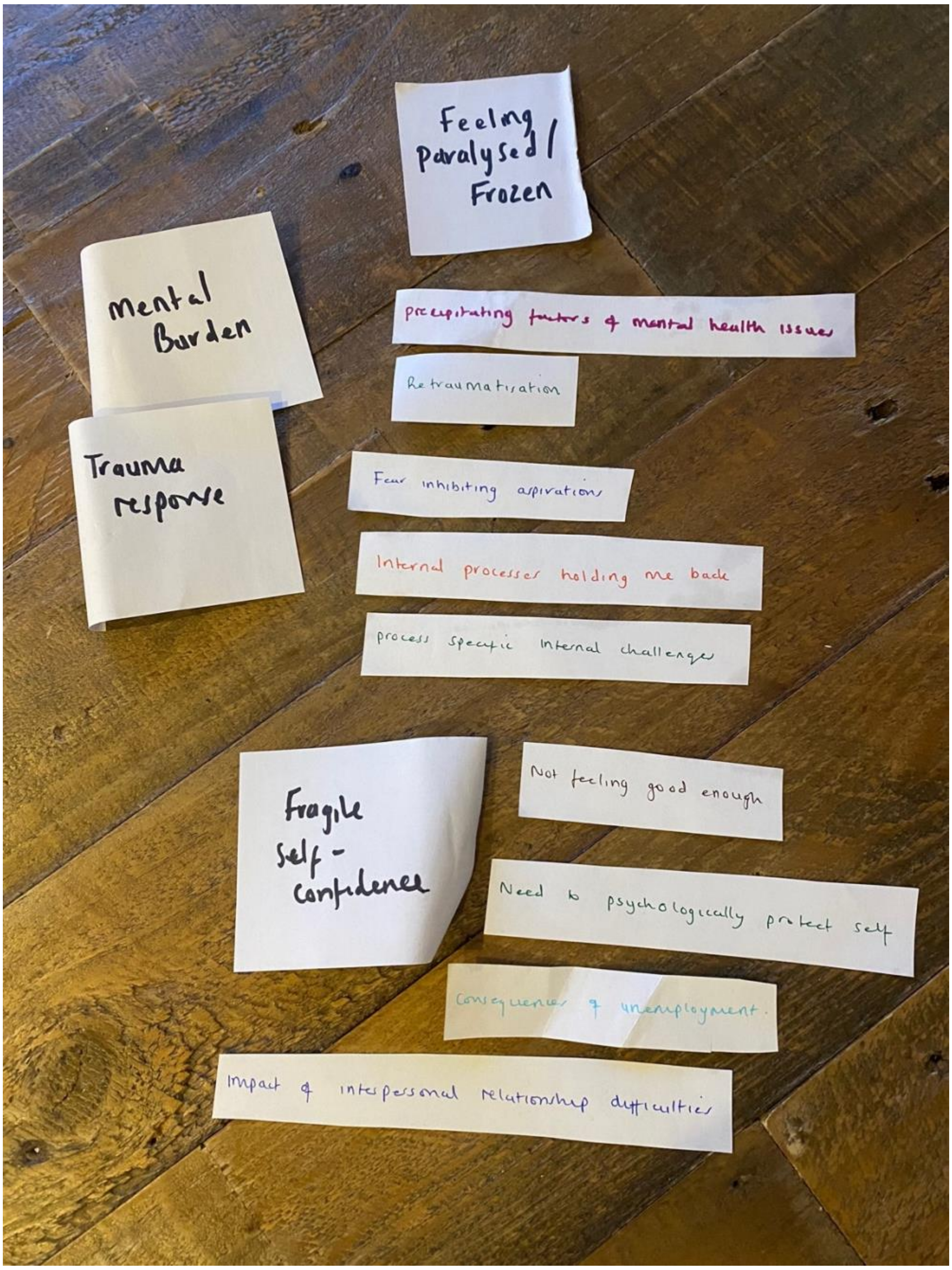
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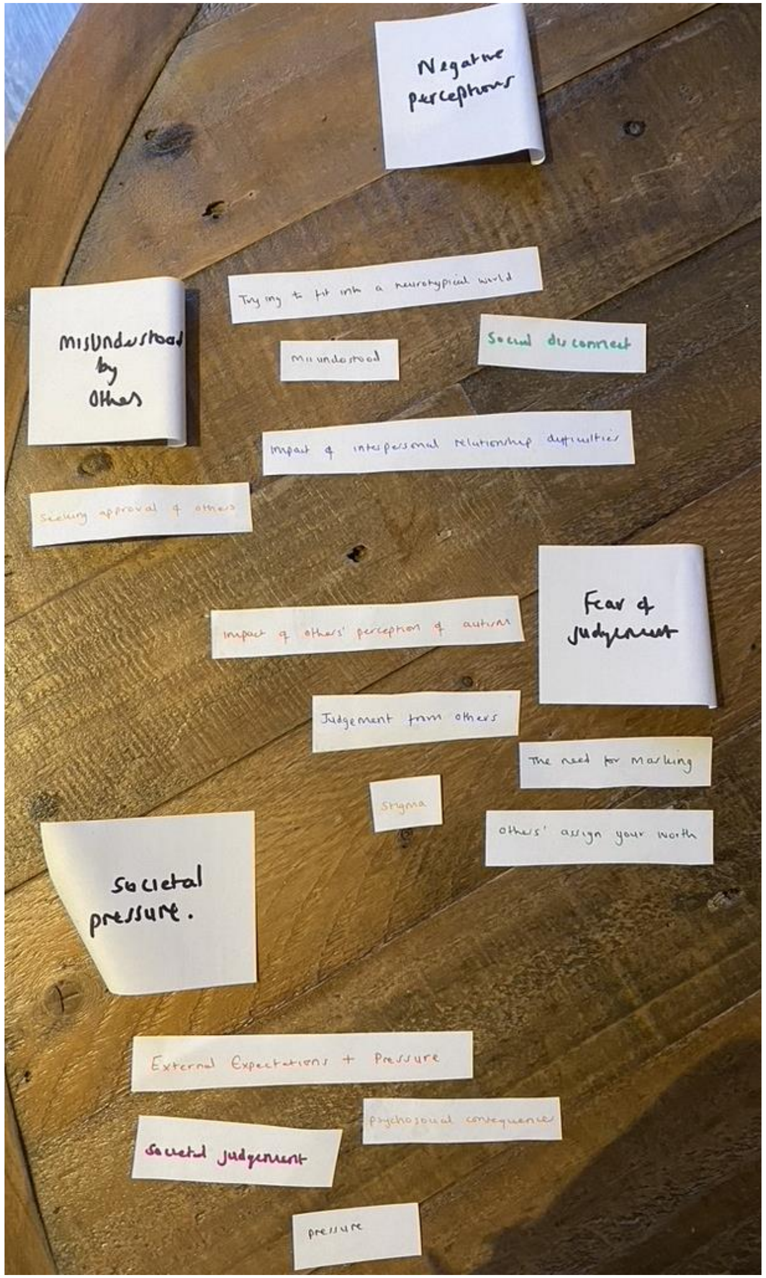
Fragile self-confidence
Not feeling good enough
Need to psychologically protect self
Consequences of unemployment.
Impact of interpersonal relationship difficulties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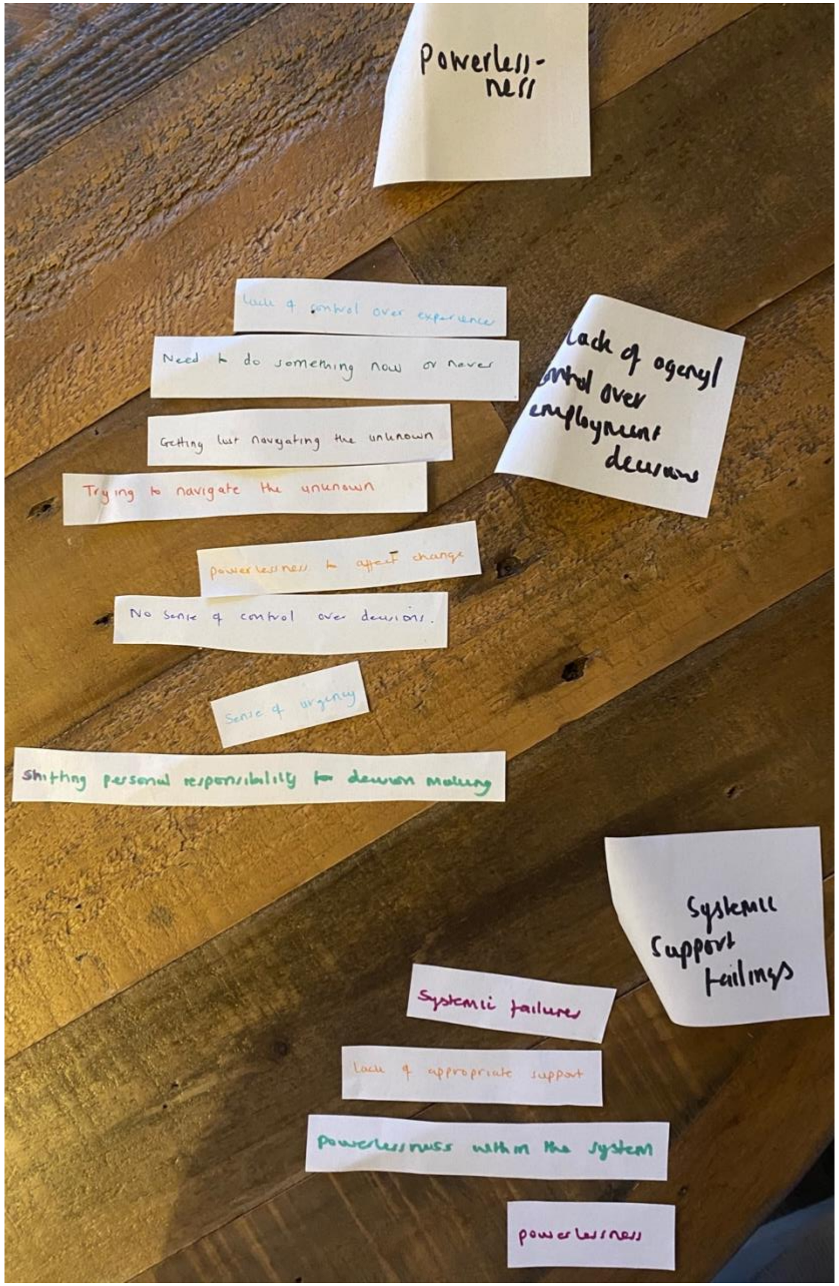
Societal judgement
pressure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Trying to navigate the unknown
powerlessness to affect change
No sense of control over decisions.
Sense of urgency
Shifting personal responsibility for decision making
Systemic Support failings
Systemic failures
Lack of appropriate support
Powerlessness within the system
powerlessness

Appendix I

Audit

Audit Checklist

Data collection

1. Is there evidence that raw data was collected and is appropriate for the research aims?

   [✓ **Yes**]/Partially/No (As evidenced by anonymised transcripts/photo-elicitation/data etc)

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, interview location/time)?

   [✓ **Yes**]/Partially/No

3. Are there reflections/notes/summaries on the data collection process?

   [✓ **Yes**]/Partially/No

Research/analysis process

4. Has the researcher engaged appropriately in supervision as part of the research process?

   [✓ **Yes**]/Partially/No

5. Has the data been sufficiently coded? (e.g., is all the relevant data coded?)

   [✓ **Yes**]/Partially/No

6. Has the data been systematically coded?

   [✓ **Yes**]/Partially/No

7. Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified?

(This may be evidenced by looking at different versions of documents and notes, and changes to coding/themes should be justified).

[✓ Yes]/Partially/No

Cross-checks

8. Crosschecking randomly selected excerpts from the interviews and photo-elicitation items against the corresponding coding and themes recorded.

   Are these consistent?

   [✓ Yes]/Partially/No

9. Vice-versa crosschecking randomly selected themes and subthemes against the corresponding data.

   Are these consistent?

   [✓ Yes]/Partially/No

Study write-up/results

10. Are quotes sufficient to provide evidence of the themes and subthemes?

    [✓ Yes]/Partially/No

11. Does the results/write-up sufficiently address the aims of the study?

    [✓ Yes]/Partially/No

Signature of researcher

Signature of auditor

....

Appendix J

Participant Contribution to Themes and Additional Quotes

Group Experiential Themes and Subthemes	Participants							
	1	2	3	4	5	6	7	8
Feeling Paralysed								
The past weighs heavy	✓	✓	✓	✓			✓	✓
Fragile self-confidence	✓	✓	✓	✓	✓	✓		✓
Powerlessness								
Lack of agency	✓		✓	✓	✓	✓	✓	✓
Systemic support failures	✓	✓		✓	✓	✓	✓	
Negative Perceptions								
Feeling misunderstood	✓	✓	✓	✓	✓	✓	✓	✓
Fear of Judgement	✓	✓		✓		✓	✓	✓
Pressure to meet societal expectations	✓	✓	✓	✓	✓	✓	✓	✓
Recognising our needs								
Managing mental health difficulties		✓	✓	✓	✓	✓	✓	✓
Importance of self-understanding	✓	✓	✓	✓	✓	✓		✓

Group Experiential Theme	Subtheme	Supporting Quotes
Feeling Paralysed	The past weighs heavy	“The sense of being of the of being daunted by what jobs are out there erm erm being rejected in the past, and then thinking I can’t go through that again” (P2) “I know going into it that it’s not going to be accommodating, the whole system is going to be very stressful and difficult for me to even approach let alone get into a job” (P7)
	Fragile self-confidence	“I lack confidence so feel like it’s just myself holding myself back, like I feel like I could do their job if I wasn’t me, if I wasn’t autistic” (P1) “…the belief in myself is always very low” (P3) “It gets more complicated when it comes to being underpaid, because it makes my bargaining position much more difficult, if I was ever brave enough to bargain” (P4) “you’re isolated from people, err second it knocks your confidence you know, like being in err meeting new people” (P5)

		“I don’t have the confidence to go for a higher level job because [employer] have like programmes to help you become a [role] or something like that (pause) no confidence whatsoever to do anything like that” (P6)
Powerlessness	Lack of agency	“I didn’t have a clue what I wanted to do or even like what I was qualified to do and what I wouldn’t be able to do. I literally just applied to random stuff and then ended up getting some of it and then it was just not right at all for me” (P1)
		“When you’re employed as a trainee and they don’t train you and then they wonder why you can’t do the job” (P3)
		“I was unemployed for a period of few years because I didn’t have my papers in the country” … “I wasn’t allowed to work so obviously couldn’t take advantage of that [sandwich year], and I think that’s what also really affected me you know later on to get the job that I really want to do” (P5)
		“I even let them [government schemes] push me into care work which was the worst possible job for me ever in my life” (P6)

Negative Perceptions	Systemic support failures	“I’m helping myself out, that’s it. To be honest with you I was always hoping that I find like a social worker or something to help me out but I wasn’t, I wasn’t lucky you know with that matter” (P5) “I’ve asked for help, the the job centre came to me and said you are overqualified” (P5) “There doesn’t seem to be anywhere, or any agency that helps you, helps me, someone who is autistic go forward with confidence” (P6) “I’ve asked all sorts of people, doctors and all that for any kind of social support, but I’ve never been given any kind of like social worker or anything like that in my lifetime” (P7)
	Feeling Misunderstood	“by the way we will be providing the questions as well as even when you’re going through filling your application form and you may feel more just (pause) comforted, comforted that this is an employer that’s really on my side and wants to give me the best opportunity” (P2) “I believe that I had been totally misrepresented and took out of context, which did a job on my head to be honest” (P3)

		“I guess like knowledgeable and considerate about autistic people, not even just autistic people, but people with all kinds of personality disorders. I just wish people were more mindful of that so they could understand the struggles that they face and honestly understand how simple it would be for them to make slight adjustments to be able to make working life a lot easier for me” (P7) “you know, finding out how to deal with that that I have [autism] could be erm sort of compassionate and understanding basically. I find with this volunteering role that when people mess up a little bit, you know people aren’t just shouting at them, you know it’s just that everybody’s like really understanding” (P8)
	Fear of Judgement	“You’re confronted with your past failures whenever you fill in [completing an application form]… and you think gosh, what is this going to look like to the employer. I’m always thinking ahead to how is this going to be perceived.” (P2) “With the fact of the whole like having a disability thing, it means that I know going into an interview people just aren’t going to choose me it feels like a pointless task if you know what I mean, because there’s going to be 1000 other

		people that have got any kind of degree and aren’t mentally disabled right that they’re just going to choose over me, and it’s demoralising” (P7)
	Pressure to Meet Societal Expectations	“if you don’t go through these transitions then you know, this is where the problems occur in your life” (P2)
		“You don’t feel valued, and you don’t feel functioning as in a functioning member of society, you know you’re judged by other people” (P3)
		“very very very aware that I should be working because of the constantly (pause) everybody’s aware of society and how they think of unemployed people. I was worse because of my condition [autism]” (P6)
		“I guess just having something to do, you know, five days a week and erm kind of the respect that comes with that” (P8)

Recognising Our Needs	Importance of Self-Understanding	"…and when I think back I was obviously in some kind of state of, of trauma, turmoil and distress erm but I had no understanding obviously why, now I know, now I've got a much better understanding of why that would be" (P2) "I want a job, but I don't want to be employed… I would work for myself because of the difficulties I've had with employment" (P3) "It was actually ruined by new uniforms that were so uncomfortable and it just wore me down for over three months to the point where I couldn't face going and I didn't know why. Obviously now I can look back at it knowing" (P4) "I actually told them [support agency] I would like to do some mock interviews with you… like confidence, some sort of confidence when I'm talking, anxiety you know, like social anxiety. So I will be looking into that to do" (P5) "I went through a lot of mental breakdowns and a lot of depression during that period [unemployed], and I wish I'd have been diagnosed earlier because I would have got help. It's too late now, it's done, but it might have helped a little bit" (P6)

	Managing Mental Health Difficulties	“it does a job on your head that when when when you can’t support yourself, that some else is giving you money because you’re ill, but you’re ill because you’ve been made ill by other people’s actions” (P3) “Pushing myself to go out and do do the gym, err I think that improved my psychological well-being, I think it also put me in a more social, social, err challenging environment” (P5) “I mentioned to you before that how burned out I am all the time, but like, being understanding of how difficult that is for autistic people is not just being knackered out and tried and then you just rest for the weekend and you’re back on it, it’s like a lifelong struggle” (P7) “I’m also in psychotherapy so my therapist suggested that I keep like what they call a (inaudible) diary, which is like positive, well I don’t record negative things because that’s not what I’m out for you know. So, it’s anything positive that happens” (P8)