The experiences of adults with complex mental health seeking support for their mental health.

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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.

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Lay Summary

Literature Review

Some groups of people find it more difficult to access services for their mental health. Autism Spectrum Condition (ASC) and Attention Deficit Hyperactivity Disorder (ADHD) are lifelong conditions that impact on how individuals interact with others. Complex Emotional Need (CEN) is a diagnosis that is given to people who have difficulty maintaining relationships and who have often experienced trauma. There is some evidence to suggest that these three conditions share some characteristics. When thinking about how to improve health services for everyone, it can be helpful to look at studies that have explored the experiences of different groups of people to see what lessons can be learned. A literature review was carried out to look for studies of people with ASC or ADHD or CEN and their experiences of seeking a diagnosis or services when they were experiencing psychological distress. Three databases were searched and 17 studies were found. The results showed that there were similarities of experience across the groups with participants experiencing being misdiagnosed or unable to access the right support. They all wanted continuity of care to help them express how they feel with a trusted professional.

Empirical Study

Complex mental health (CMH) is an umbrella term for people who may struggle with their relationships with other people, regulating their emotions, frequent changes in mood, post-traumatic stress disorder (PTSD) or experience high levels of psychological distress. They may also experience long periods of depression or anxiety. Sometimes they have a diagnosis of ASC or ADHD alongside CEN. This group of people often find it hard to access services through their General Practitioner (GP). This can be because there are no services for

them or poor signposting to services. Alternatively, they may experience difficulties in asking for help. This thesis explores the experiences of people with CMH accessing help from their GP and other sources of support. The findings were that people find services difficult to navigate and often find that there are no services for them or there are long waiting times. The things that can help are better collaboration in their care, a choice of treatments and flexible access to services that meet their needs.

Acknowledgements

I would like to thank the 19 participants who shared their difficult experiences with the interviewer with such courage and honesty. The decision to take part in research and to discuss extremely painful experiences in the hope that it will help others in a similar situation is to be applauded as without them we would not have the opportunity to make positive changes for the better. I would also like to thank Ada Achinaya who managed to skilfully navigate very sensitive and at times distressing interviews with genuine compassion and positive regard for the participants. Also, thank you to the experts by experience who guided the wider research project and gave feedback on my results.

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Finally, I would like to thank my husband, Ayd, and our three wonderful children. You have been amazing sources of support and inspiration I couldn’t have done this without you. Thank you for your long-suffering patience, it hasn’t been easy, we will celebrate together.

Table of Contents

Section One: Literature Review

The experience of engaging in healthcare for adults with a diagnosis of Complex Emotional Need, Autism Spectrum Condition or Attention Hyperactivity Disorder: A thematic synthesis.

Abstract

Objectives

This review aims to explore two questions:

1) What are the experiences of individuals with autism, ADHD or complex emotional need when accessing care for mental health distress or diagnosis?

2) Are the barriers or facilitators to being able to engage in care similar or different across the conditions?

Method

A search was conducted in three databases (Web of Science, Scopus and PsycInfo) for peer-reviewed studies that explored the experiences of adults with autism, ADHD or CEN when accessing services for psychological distress or diagnosis. Search terms were created using the SPICE search strategy tool.

Results

Thematic synthesis of 17 papers identified three themes and eight sub-themes. The themes included an "untidy parcel" representing how participants were made to feel by services and how services felt to them; "the words don't come" and "needing better connections".

Conclusions

The results showed that there were similarities across the conditions with similar experiences of the diagnostic process and difficulty accessing psychological therapy due to inflexible referral process. Participants expressed a need for continuity of care and better collaboration with services.

Practitioner Points

- More nuanced understanding of how ASC, CEN and ADHD impact on a person’s ability to engage in healthcare would improve the experience.

- Awareness of local services that may be helpful for individuals post diagnosis.

- Ensuring that reasonable adjustments are made for sensory differences and social interaction difficulties.

- Allowing for flexible services that meet the needs of the individuals with collaboration over treatment options.

Keywords:

Autism, ADHD, Complex Emotional Needs, thematic synthesis, diagnosis, mental health

Introduction

Previous research has shown that there is inequitable access to mental health care via primary services. Barriers to accessing care include lack of awareness that there is a problem to seek help for, a lack of knowledge of appropriate services and the stigma of mental ill health (Dowrick et al., 2016; Kovandžić et al., 2011; Salaheddin & Mason, 2016). Although attempts to improve knowledge of mental health has increased awareness, with 27% of UK 16–34-year-olds saying they often think about their mental health, disparity remains with only 10% of over-65s falling into the same category (Ipsos, 2019). Targeted and informed strategies for increasing awareness of services and tackling stigma are needed for including more "hard to reach" groups (Lamb et al., 2012).

One group which has been poorly served by mental health services are those with more complex mental health, for example, Borderline Personality Disorder (BPD). In the *ICD-11 for Mortality and Morbidity Statistics* (2023) it is characterised as a disturbance in personality resulting in disruptions to personal and social life with marked impairments to inter- and intra- personal relationships and difficulties in understanding the other's perspective, low self-esteem and difficulties with emotional experience and expression. BPD is a controversial label that brings stigma and shame to many of those who are given it. Both clinicians and service users express unease at the use of a label that often results in a withdrawal of care and a communication that nothing can be done for the individual (Klein et al., 2022). The label ignores the social determinants of poor mental health and distress; for example: poverty, poor housing, racism, sexism and high rates of childhood trauma (Bellis et al., 2014; MIND, 2018; Recovery in the Bin, 2024; Yuan et al., 2023) and the alternative label of CEN has been used for this review.

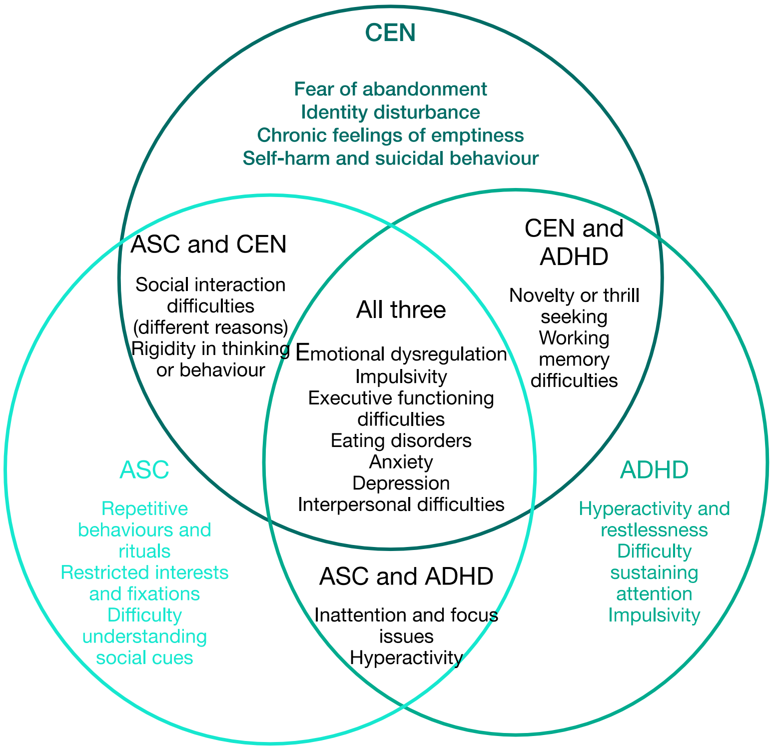
Two neurodevelopmental conditions that have received increasing attention with regard to accessing services for diagnosis and care are ASC and ADHD. ASC is characterised by impairments in social and communication skills, repetitive and stereotyped behaviour and sensory difficulties (DSM-5, 2013). ADHD is a condition evidenced before the age of 12 of inattention, hyperactivity and impulsivity that impacts on educational, occupational, and social functioning (*ICD-11 for Mortality and Morbidity Statistics*, 2023). There have been recent reviews of the experiences of individuals with either CEN, ASC or ADHD when accessing mental health support or diagnosis. Previous reviews of mental health services for people with CEN revealed that negative attitudes of staff, lack of knowledge and skills as well as unclear pathways were all potential barriers to successful treatment (Klein et al., 2022; Pigot et al., 2019). The themes of holistic care, the impact of diagnosis and long-term perspectives on treatment were important for people with CEN (Rains et al., 2021). Another review found the priorities of the clinicians and service users were misaligned, with risk management being most important for clinicians and relational aspects for service users, (Haslam et al., 2024). A lack of professionals' knowledge, the demands of processing information and the need for adaptation were themes that emerged for adults with ADHD (Radev et al., 2024). And for adults with ASC they reported that the experience of accessing services for mental health issues was lonely, inflexible and needed better collaboration between clinicians and service users (Brede et al., 2022).

Learning from the experiences of diverse excluded groups can provide valuable insights across presentations or conditions. For example, Lamb et al. (2012) developed recommendations for enabling the treatment of common complaints in a wide range of vulnerable groups, including the homeless, adolescents with eating disorders and asylum seekers and refugees. Recommendations included careful consideration of when group work is appropriate/inappropriate, working on concepts of identity for those that felt stigmatised and using cultural considerations for enabling engagement in treatment.

It has been suggested that reducing the reliance of services on diagnostic labels, taking a transdiagnostic approach, will enable better access to care. Most healthcare services organise treatment in relation to established taxonomies, using clinical thresholds to determine who receives care. However, diagnostic criteria frequently exclude people in need of support from accessing care and there are both high levels of comorbidity of conditions sharing similar symptoms and also high levels of heterogeneity of expression within a named diagnosis (Dalgleish et al., 2020). An example of diagnostic overlap are co-occurring diagnoses of CEN, attention deficit hyperactivity disorder (ADHD) and autism (ASC) and childhood trauma (Dudas et al., 2017; Gajwani et al., 2022; McKay et al., 2021; Richards et al., 2023 and Zarse et al., 2019). In a small cross-sectional study investigating the risk factors for severe mental illness, Gajwani et al. found 79% comorbidity of neurodevelopmental disorders and CEN in a sample size of 48 young adults. Only 28% of the participants entering the study had a diagnosis of a neurodevelopmental disorder which raised questions of diagnostic overshadowing. Similarity of presenting characteristics, for example, emotional dysregulation and communication difficulties were proposed as reasons for this co-occurrence. A review of the literature on the co-occurrence of ASC and CEN found a prevalence of 4% CEN in ASC and 3% ASC in CEN in 12 studies included for meta-analysis (May et al., 2021) and between 18%-34% of adults with ADHD are estimated to have co-occurring CEN (Weiner et al., 2019), whilst prevalence of ADHD in ASC was 40.2% (Rong et al., 2021). Evidence of overlapping presenting difficulties, which may have different underlying causes and be expressed differently, can be seen in Figure 1, adapted from Neff (2024).

Figure 1

The Overlap of Difficulties in ADHD, CEN and ASC



The ability to access healthcare can be conceptualised in different ways. Anderson includes individuals' ability to perceive a health need and access to a regular source of care (Andersen & Aday, 1978). A more comprehensive approach considers five dimensions of access: availability, accessibility, accommodation, affordability and acceptability and how well services meet the need of the individual (Penchansky & Thomas, 1981). A widely used tool for evaluating access to healthcare is Levesque's conceptual framework (Levesque et al., 2013). The framework defines access to healthcare as being when a person perceives they have a need for healthcare and have the opportunity to successfully engage with a service or intervention. What is novel about Levesque's framework is that it conceptualises the journey of the individual through a healthcare pathway punctuated by interfaces between the healthcare provider and the individual. At each interface there is the possibility that barriers to healthcare may arise preventing the individual reaching their goal or slowing them down in the journey. It is preferred by many researchers for its useability and its multi-dimensional approach that considers the healthcare setting perspective as well as that of the service user (Cu et al., 2021). In their recent review of studies using the Levesque framework, Cu et al (2021) found that some areas of the framework were more frequently assessed than others. For example, there were fewer studies that assessed service users' ability to engage once they had accessed healthcare. The Levesque et al. (2013) concept of a service user's ability to engage includes notions of being involved in decisions over treatment options, and capacity and motivation to participate in treatment. In turn, these abilities are reliant on the service user having good communication skills, health literacy, self-efficacy and self-management. All these elements are only helpful if the treatment or service provided is appropriate for the service user.

Whilst there are apparent similarities between the conditions, no study has so far compared experiences. In empirical qualitative research there has been a recent move to compare groups in studies. This enables researchers to uncover similarities and differences between conditions and highlight where further support may be required (Lindsay, 2018). Exploring barriers and enablers to accessing healthcare is particularly important for "hard-to-reach" groups if equitable service in the NHS is to be achieved.

This review aims to produce a qualitative evidence synthesis (QES) of the literature on the barriers to healthcare, with a specific focus on ability to engage, for individuals with a diagnosis of CEN, ASC or ADHD. The focus of the review will be on qualitative studies with individuals with lived experience exploring access to general primary care and secondary mental health care.

Aims of the review

What are the experiences of individuals with ASD, ADHD or CEN when accessing care for mental health distress or diagnosis?

Are the barriers or facilitators to being able to engage in care similar or different across the conditions?

Method

This Qualitative Evidence Synthesis (QES) was registered with Prospero, the international register for prospective reviews, prior to commencing full data searches and analyses (PROSPERO Reg No. CRD42024546138). The Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement can be found in Appendix A.

Search Strategy

The SPICE (Setting, Perspective, Intervention/Interest, Comparison, Evaluation) tool was used to help define the parameters and focus of the study (Booth, 2004) see Table 1.

The search strategy including search terms (see Table 2) and databases were chosen in consultation with supervisors and the subject librarian. Three databases were searched in May 2024, Web of Science, PsycINFO, and Scopus.

Table 1

SPICE Tool (Booth, 2004)

Criteria	Description
Setting	Primary and secondary healthcare settings in UK
Perspective	Adults* with CEN or ASC or ADHD
Intervention/Interest (phenomenon of)	Experiences of accessing care for mental health distress, including diagnosis-seeking
Comparison (if relevant)	Not applicable
Evaluation	Attitudes, feelings, experiences as captured in themes

Table 2

Search terms

Construct	Search term
Conditions	"Borderline personality disorder*" OR "Complex PTSD" OR "complex emotional need*" OR "Emotionally unstable personality disorder" OR Autistic OR Asperger* OR ADHD
Health setting	General practic* OR healthcare OR diagnos* OR "mental health"
Help seeking	Access* OR barrier* OR approach* OR accept* OR facilitat* OR reject* OR seek* OR support
Evaluation	Experience OR attitude* OR perspective* OR thematic analys* OR qualitative OR "grounded theory"

*Papers studying transition from child to adult services may be included if comments or findings from those aged 16 and above are identifiable in the paper and can be extracted for synthesis.

Study Selection

Grey literature was excluded from the search and only papers written or translated into English were included. There was no date restriction to ensure a comprehensive search for empirical papers and that no previous synthesis had been completed. Results from the database searches were exported to Rayyan (a research collaboration platform) and duplicates were removed. Titles and abstracts were screened using the inclusion and exclusion terms in Table 3. A full text review was completed on the remaining studies to remove any ineligible studies and then forwards and backwards searching of references. A second reviewer did a full text screen of 20% of the remaining papers for the purposes of rigour and reliability.

Table 3

Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
Samples include individuals with CEN OR ASC OR ADHD	Studies which are quantitative only
Studies exploring the experience of individuals relating to accessing care for mental health distress OR diagnosis	Studies which explored experiences of care seeking in forensic services
Studies which are qualitative OR are mixed methods with a qualitative element	Studies not in English or translated into English
Studies written or translated into the English language	Studies not based in the UK
Studies based in the UK	Studies that do not include individuals with CEN, ASC or ADHD

Data Extraction

Data relevant to the aims of the literature review were extracted from the papers from the results or findings sections of the identified papers. This included author, date, country, participant demographics, method of data collection and methodology, and the main themes for each study (see Table 4). If mean ages were missing, this was calculated when the reported data allowed.

Table 4

Extracted Data from Studies

Author (year)	Country and setting	Sample (N)	Recruitment	Data collection & methodology	Key findings, themes
			Autism studies		
Au-Yeung et al., (2019)	UK, no specific setting	N=420 (208 autistic people) Aged 18-67 years (mean age=38.6) 72 males, 136 females	Recruited online via charities, Cambridge Autism Research Database	Free text box response to question about their agreement with mental health diagnosis. Thematic analysis	Autism symptoms and their expression were sometimes misdiagnosed as mental health difficulties. Participants felt mental health issues were as a result of the difficulties living with autism. Clinical barriers to care were lack of autism understanding in professionals and communication difficulties.
Mason et al., (2021)	UK, no specific setting	N=26 (11 autistic people) Aged 29-65 (no mean reported as 5 participants declined to give their age) 6 males, 5 females	Recruited via social media advertising	Three focus groups were held with two, six and four participants respectively (one participant came with a supporter). Framework analysis	Seeing the same clinician is important for accessing healthcare, reasonable adjustments should be made and cognitive differences in how information is processed should be considered.
Camm-Crosbie et al., (2019)	UK, no specific setting	N=200 Aged 18-67 years (mean age=38.9) 77 males, 122 females, 1 unreported	Recruited online via charities, Cambridge Autism Research Database	Free text box response to question about their agreement with mental health diagnosis. Thematic analysis	Difficulties in accessing support were identified. There was a lack of understanding of autism by professionals. A lack of services suitable for autistic people and no mental health pathway.
Crane et al., (2018)	UK, no specific setting	N=130 (21 took part in semi-structured interviews) Aged 16-25 years (mean age=20.9) 9 males (including	Recruited via databases (Ambitious about Autism and Centre for Research in Autism and Education), online	Semi-structured interviews took place face to face (16), on the phone (one), Skype (one) or via instant messenger (three)	The process of understanding and accepting autism. Multiple barriers to feeling satisfied with the diagnostic process. Inadequate post-diagnostic support.

		transgender male), 10 female (including transgender female), 2 non-binary	advertising and contacts of research team.	Thematic analysis	
Crane et al., (2019)	UK, no specific setting	N=130 (21 took part in interviews) Aged 16-26 years (mean age=20.9) 9 males (including transgender male), 10 female (including transgender female), 2 non-binary	Recruited via databases Ambitious about Autism and Centre for Research in Autism and Education),	Online survey. Semi-structured interviews conducted face-to-face, on the phone, via Skype or instant messenger Thematic analysis	Young autistic people found it hard to evaluate their mental health, face stigma and obstacles to accessing mental health support.
Coleman-Fountain et al., (2020)	UK, no specific setting	N=19 Aged 23-24 years (mean not reported) 17 males, 2 females	Recruited from cohort study via invitation to participate	Face-to-face semi-structured interviews either at home or on their university campus. Thematic analysis	Young autistic adults preferred self-management strategies. This was due to fear about aetiology of mental health, feeling more vulnerable because of their autism, sense that there was no or only inadequate formal support.
			ADHD studies		
Matheson et al., (2013)	UK, NHS adult ADHD clinic and voluntary sector	N=30 Aged 18-57 years (mean age=34.9) 13 males, 17 females	17 recruited via an ADHD charity. 13 via two outpatient clinics	Face-to-face semi-structured interviews. Grounded theory	Accessing services was an uphill struggle. Challenges of getting a diagnosis as an adult. Sense of failure and psychosocial burden. Negative attitudes of staff.
French et al., (2020)	UK, primary and secondary care	N=20 Adults with ADHD=5 Aged 29-63 years (mean age=48.2) 2 males, 3 females	ADHD adult support groups known to researcher	Semi-structured interviews. Thematic analysis following Grounded Theory principles	Impact of receiving or not receiving a diagnosis of ADHD, complex pathways, lack of services, limited GP knowledge and communication issues

Gudka et al., (2024)	UK Primary care	N=20 With ADHD N=6 Aged 17-25 years (mean age=21.8) 2 males, 4 females	Via their GP in primary care practices	Semi-structured interviews conducted over Microsoft Teams or telephone Reflexive thematic analysis	A system under stress, incompatibility between ADHD and healthcare system, strategies for change.
Morgan, (2023)	UK, University	N=52 Aged 19-56 years (mean not reported) 52 females	Through the university via email flyer and snowballing	Semi-structured interviews conducted over Microsoft Teams Thematic analysis	Difficulties in being referred. Diagnosis empowering with sadness over difficult life. Minimal mental health support. Inadequate monitoring of medication. Gender and race stereotypes.
Price et al., (2019)	UK, NHS Specialist and generic adult ADHD services	N=92 Of relevance N=43 Aged 17-29 (mean not reported) 28 males, 15 females	Purposive sampling by invitation via participating NHS Trusts	Semi-structured interviews conducted face-to-face, by telephone or over Skype Thematic analysis	Negative experiences of poor communication. Information about transition and ADHD in adulthood.
CEN studies					
Horn et al., (2007)	UK, Community Mental Health Service	N=5 Aged 23-44 years (mean age=34.8) 1 male, 4 females	Recruited via Mental health professional involved in their care	Semi-structured interviews conducted face-to-face in local NHS therapy rooms IPA	Knowledge as power, Uncertainty about meaning of diagnosis, rejection, not fitting in, hope and the possibility of change.
Bilderbeck et al., (2014)	UK, Community Mental Health Team, Specialist mood disorder clinic, Complex needs service	N=28 Aged 20-58 years (mean age=36) 10 males, 18 females	Purposive sampling using GP referral letters for assessment of mood instability	Semi-structured interviews conducted face-to-face. Location of interviews not known Qualitative framework (Ritchie & Spencer, 1994)	Important to receive an explanation for symptoms, value of good interpersonal relationships, being listened to and acknowledged. Needs not always met.
Morris et al., (2014)	UK, Voluntary sector organisations	N=9 Aged 31-47 years (mean not reported) 2 males, 7 females	Poster display in voluntary sector organisations	Face-to-face semi-structured interviews. Location not known	The diagnostic process influences how people feel about diagnosis. Non caring care. It’s all about the relationship.

				Inductive thematic analysis	
Fallon, (2003)	UK, unstated variety of settings in a mental health Trust	N=7 Aged 25-45 years (mean not reported) 3 males, 4 females	Via Psychiatrist in the mental health Trust	Unstructured interviews conducted face-to-face at participant’s setting of choice Grounded theory	Value contact with psychiatric services despite negative experiences. Relationships with others help contain emotions.
Patel & Konstantinidou, (2020)	UK, Specialist outpatient clinic	N=7 Aged 20-52 years (mean not reported) 4 males, 3 females	Recruited via professional involved in their care	Semi-structured interviews face-to-face in focus groups Thematic analysis	Medication has a powerful impact, but unclear how it is affecting them. Good relationship with doctor important. At times feel dismissed. Confront power of the doctor with anger.
Trevillion et al., (2022)	UK, Primary care, community teams or Voluntary sector mental health organisations	N=30 Aged 18-74 years (mean not reported) 6 males, 24 females	Recruited through advertisements on social media and via the voluntary sector	Semi structured interviews face-to-face in university setting, MS Teams or Zoom Thematic analysis	Some good practice in services, but some very stigmatising. Lack of support and service fragmentation. Collaborative, trauma-informed care that is flexible and holistic was valued.

Assessment of Quality

An adapted Critical Appraisal Skills Programme (CASP, 2018; Long et al., 2020; Appendix B) was used to assess the quality of the included studies. The Long et al. adaptation of the CASP tool adds an additional question relevant for qualitative studies about fidelity and transparency of the researchers' ontological and epistemological perspectives. A scoring system was implemented for determining the overall quality of a study. A question answered with 'no' = 0, 'can't tell' = 0 and 'yes' = 1. Totals for each paper were calculated and a score of <3 received a 'poor' quality rating; of 4-6 a 'moderate quality rating, and 7-11 a 'high' quality rating. These parameters were set using previous approaches to quality ratings in qualitative syntheses and methodological recommendations (French et al., 2018; Kmet et al., 2004) A second reviewer[1] completed an independent assessment of the quality of the papers selected at random (20%, *n*=3) . There were discrepancies in the checklist questions with five differences over 33 questions resulting in an 85% agreement of quality rating. Differences in opinion were resolved in discussion.

Data Synthesis

Data were analysed using thematic synthesis for qualitative literature, (Thomas & Harden, 2008). Relevant data was extracted from the findings or results sections of the identified papers. Only qualitative data was extracted for those papers that were mixed methods and only data relating to the target population. For example, studies that interviewed multiple stakeholders: parents, clinicians and those with ASC, ADHD or CEN, only the qualitative data relating to the target adult service user population was extracted.

Thomas & Harden's (2008) approach has three stages – the coding of text line by line, the development of descriptive themes and finally, analytical themes (see Appendices C-E). The last stage involves the researcher interpreting the themes to generate new insights. As this synthesis is looking at different groups, during data extraction a sense of the whole set was gained but held lightly. Following that, coding was completed within each group and descriptive themes developed. The descriptive themes were checked against the original papers to ensure they captured the findings and then analytical overarching themes were developed across the three groups which enabled similarities and differences to be revealed. This comparative thematic synthesis takes its core approach from Thomas and Harden (2008) with the addition of comparative approaches from qualitative empirical studies (Bailey et al., 2016; Chambers et al., 2011; Lindsay et al., 2016; Ludvigsson, Milberg, Marcusson, & Wressle, 2015; Peterson, 2010; Reedy, Haines, Steckler, & Campbell, 2005; Sandelowski, Harris, & Black, 1992).

Researcher Reflexivity

Awareness of the attitudes and beliefs that shape our understanding and perspectives of the world is important for qualitative researchers. Interacting with the papers in the process of analysis it is important to interrogate assumptions and interpretations (Olmos-Vega et al., 2023; Stiles, 1993). The lead researcher identifies as a white middle-aged female who has lived experience of accessing diagnostic and other services for family members relating to learning disability, autism and ADHD. They also had a mid-life genetic diagnosis which raised questions about their own neurodiversity. Their professional career has included work with individuals on the autism spectrum, ADHD and those with complex emotional needs. To capture reflections throughout the development of the analysis, the researcher kept a journal (see Appendix F) and discussed preliminary findings with her supervisors.

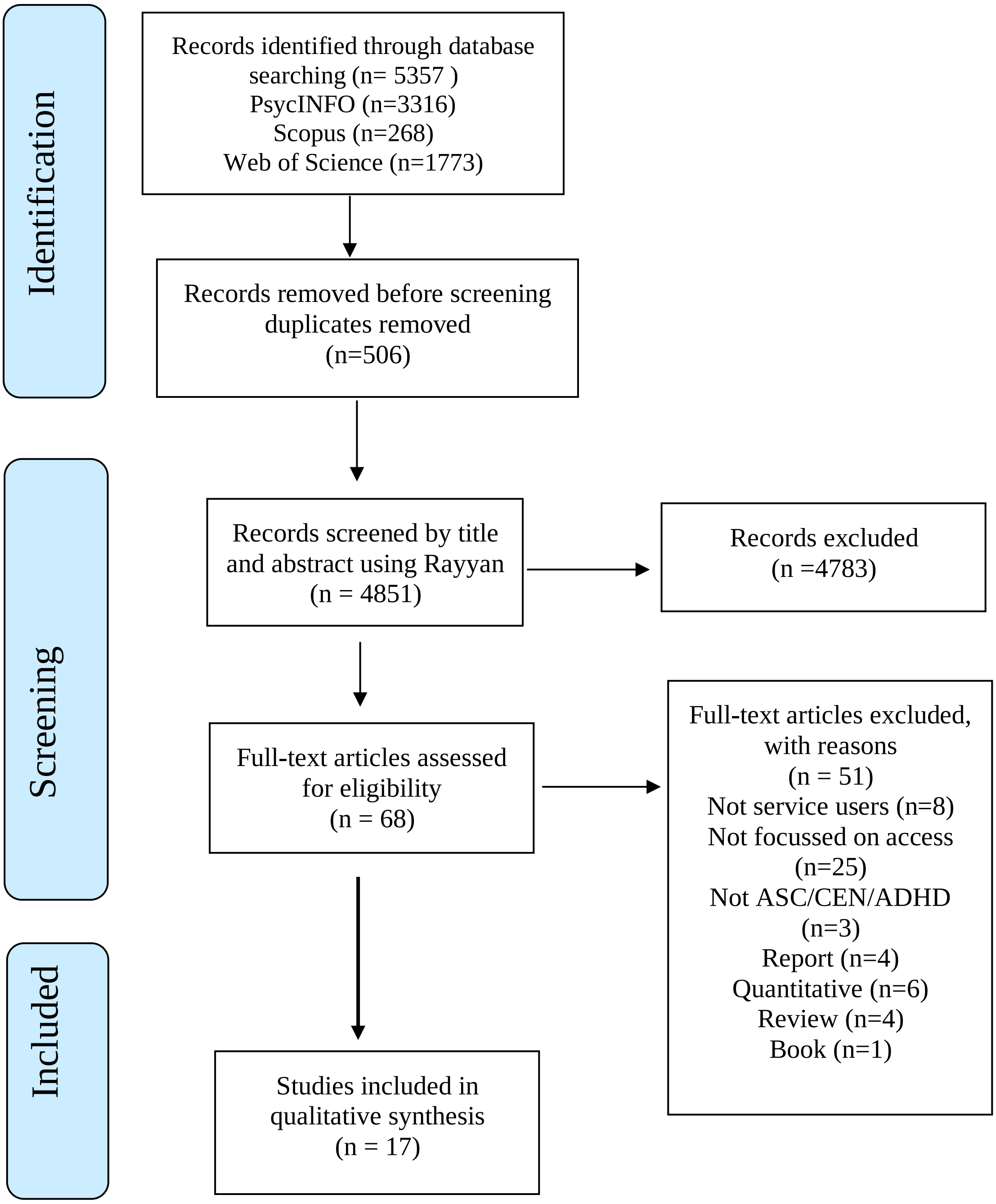
Results

Summary of Included Studies

The searches across the three databases yielded 4851 papers after duplications were removed. Screening titles and abstracts was aided with the use of Rayyan software which allowed for keyword searching and this led to a further 4783 papers being removed. A full-text review of the remaining 68 papers was conducted by the lead researcher using the inclusion and exclusion criteria yielding a final total of 16 papers to be included in the review. The screening process is captured in the PRISMA diagram (Figure 2, Page et al., 2021).

Figure 2

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



The identified studies were all conducted in the United Kingdom. The autism study dates ranged from 2018-2021; the ADHD studies from 2013-2024 and the CEN studies from 2003-2020. Data were gathered variously by semi-structured interview, focus groups or open text questions in online questionnaires. See Appendix G for quality ratings.

Thematic Synthesis

There were overarching themes, “an untidy parcel”, “the words don’t come” and “time to connect”. The three themes had several sub-themes. For “an untidy parcel” there were three, “no pathway, no signposts”, “diagnosis a gift?” and “wrongly labelled”. The second theme was “the words don’t come”. It had two sub-themes of “no space to think” and “feelings but not the words”. The final theme “needing better connections” had three sub-themes of “help follows crisis”, “an othering experience” and “relationships take time”. The papers contributed to all themes showing that there were many similarities in how the participants with ASC, CEN or ADHD experienced accessing care for their mental health and diagnostic needs and how they were able to engage with that care. However, there were also some experiences which differentiated the participants and their conditions from each other. These differences are discussed within the themes.

An untidy parcel

The theme “An untidy parcel” describes both how the participants were left feeling uncontained by services and how services appeared to them. Participants spoke of seeking answers and understanding for their distress, but this was often a hard-fought battle with experiences of having to research their symptoms on social media. It described how participants felt a lack of provision specifically adapted for their needs or being excluded from services because their condition rendered them ‘too complex’. It also reflects the lack of clear pathways for services which left participants feeling abandoned. There were three sub-themes.

No pathway, no signposts

This sub-theme captured participants' loss of faith in services being provided for them or being suitable for them. It also spoke of the confusion participants and GPs felt over diagnostic and service pathways which were either unclear, unknown or non-existent.

Participants expressed that the diagnostic pathway was poorly explained and they were often left waiting with no information regarding their referral for months. Those who received a diagnosis of CEN had a very different diagnostic experience with no sense of a pathway just a *"dustbin label" CEN-P Horn et al., (2007) p. 260* appearing in their records with no explanation. For those adults seeking an ADHD diagnosis they were reliant on a service being commissioned in their locality and this wasn't always provided. Once diagnosed they found services very disjointed and struggled to have their medication managed by their GP. Those with ASC also experienced disjointed care and like those with ADHD struggled to locate adult services.

> *"You hit 18 and all your services just go 'poof' and just disappear" [ASC-P] Crane et al., (2018) p. 486*

Diagnosis a gift?

This sub-theme related to receiving a diagnosis as a longed for understanding of the self that came with the hope of accessing appropriate support. For some participants there was relief expressed that they now had a name for their condition, it explained why they felt 'different' to others and meant they could seek targeted help.

> *"for so many years I haven't … had a label, I've sort of … floated" CEN-P Horn et al., (2007) p. 260*

The confusion that GPs and other clinicians seemed to feel about diagnoses was evidenced by participants bringing their research into what diagnosis they may have to the consulting room.

> *"I knew I'd got Asperger's … I was just gaining the rubber stamp" [ASC-P] Crane et. al. (2018) p3764.*

There was a sense from participants across the conditions that support post-diagnosis was lacking and mostly non-existent. All groups wanted a collaborative diagnostic process that acknowledged their own insights but benefited from professional knowledge and understanding to help them live well with their diagnosis.

Wrongly labelled

This sub-theme encompassed two different concepts around the giving of diagnoses: misdiagnosis and diagnostic overshadowing. Many of the participants received mental health diagnoses either alongside or prior to receiving diagnoses of CEN, ASC or ADHD with some receiving diagnoses of CEN prior to a diagnosis of ASC or ADHD. For some of these participants the consequences of this were long periods on unnecessary medication.

> *"I was given anti-psychotics for my behaviour … they think because [I don't] look at them and [I] am nervous of talking then [I] am 'guarded' or have 'flat affect'" [ASC-P] Au-Yeung et al. p 1513.*

For those given a late diagnosis of ADHD they had previously been told that ADHD was not a condition seen in adults. In addition, a lack of knowledge of how gender influences presentation prevented participants with ADHD or ASC getting a diagnosis earlier in life. This left an impression for many participants that there was a lack of specialist knowledge or training in differential diagnosis, or that outdated and stereotyped understanding of conditions prevailed.

> *“you are too old to have ADHD” and “people would have noticed at school” [ADHD-P] (Morgan, 2023) p.6*

> *“I was diagnosed with [CEN] because ... they didn’t have a clue really ... there was nothing else they could get me focussed on” [CEN] Horn et al., (2007) p.262*

Diagnostic overshadowing meant some participants’ difficulties were all ascribed to their condition or that they no longer fitted into any services ‘neatly’. This reflected the experience of people seeking secondary mental health support who found that overstretched services managed their waiting lists with tight exclusionary criteria.

> *“If you have ASC then mental health say it’s not their problem” [ASC-P] Camm-Crosbie et al. p.1435*

The ASC and ADHD groups differed from the CEN studies in that participants expressed that some of their difficulties arose from their ASC or ADHD being poorly supported or managed. There was a sense that if they were given strategies or their needs were accommodated for, a lot of their difficulties would be resolved.

The words don’t come

This second theme conveyed the sense that participants felt misunderstood by health care workers and the struggle they had to express how they felt when in a consulting room. It encompassed ideas that accessing services may be difficult due to unsuitable environments. This left participants feeling overwhelmed and unable to engage meaningfully in the consultation. It also spoke to the difficulties that participants across the conditions had in expressing themselves to their GP or clinician. It had two sub-themes “space to think” and “feelings but not the words”.

No space to think

This sub-theme related to the unsuitable environment that participants found themselves in and how this impacted on their ability to communicate effectively with their GP or clinician. For many of the participants across the groups busy waiting areas, prolonged waits to see the clinician raised their anxiety which made them less able to express themselves once in the consulting room. There were differences in the reasons for these difficulties arising. For those with ASC there were sensory and social communication issues that increased anxiety.

> *“When your name is called, everyone points to where you have to go … Why do they do that? Why are they bothering with my appointment? It’s my appointment, it’s unwanted social interaction.” [ASC-P] Mason et. al. (2021) p.780*

Those with CEN struggled with waiting areas in GP practices or Accident and Emergency because of *“strong paranoid ideas” [CEN] Fallon, (2003) p. 396* and a fear of strangers who could not be trusted. Whilst for those with ADHD issues with organisation and remembering appointments were often more of a barrier to care. The ADHD unfriendly service protocols only heightened their anxiety and led to internalising shame of their disorganisation. Entering a consulting space in a heightened state was not conducive for a positive outcome and participants across the conditions often expressed acquiescence to the professional's suggestions be that to end the appointment, changes to medication or therapy.

Feelings but not the words

This sub-theme described the sense that participants across the conditions experienced, at times, unbearable emotions, which hampered communication with the clinician.

> *"He'd just seen me crying and shaking and saying I have difficulty concentrating so I don't blame him for thinking I was in pieces really" [ADHD-P] Matheson et al., (2013) p.6*

Those with ASC referenced spending years masking their emotions to survive in childhood which left them less able to identify and regulate them. For the participants with CEN 'big' emotions were sometimes a way of being heard and seen by services that often appeared to dismiss them. There was a sense expressed by participants across the groups that heightened emotions played a significant part in their difficulties in consulting rooms and that given the right environments and scaffolding these difficulties could be ameliorated and a helpful consultation be achieved.

Needing better connections

This last theme related to the widely expressed need for continuity of care with familiar clinicians to allow for the building up of relationships for trust and communication.

There were three sub-themes: “crisis brings help?”, “us and them” and “relationships take time”.

Help follows crisis

This sub-theme spoke to the fact that all groups frequently reached a point of crisis before they sought help from services. There was frustration across the groups that crisis point was almost a necessity before help was given. Lack of service capacity led to increased thresholds of distress before participants were accepted into services.

> *“Because I’m not waving a knife and saying I’m going to kill myself, they’re like, … you’re not quite sick enough . . . I’m trying my hardest to tell them and explain . . .” [CEN-P] Bilderbeck et al., (2014) p.237.*

An othering experience

This sub-theme was about the sense that participants from each of the conditions had that they were not believed or trusted by clinicians. Many of the participants explained that they had taken family members into the consulting room to corroborate their request for help. For those with ADHD there were common themes around the dispensing of medicine and the difficulties that participants encountered with this. Some waited months to have their prescriptions fulfilled and others were reluctant to raise concerns about side effects in case their medication was removed.

For those with CEN many expressed that they didn’t feel trusted by clinicians.

> *“Most of the time a family member has to come with me cos I’m sure they think I am telling porkies or something” [CEN-P] Patel & Konstantinidou, (2020) p.4*

Relationships take time

This final sub-theme spoke to the idea that building trust and understanding takes time. That having familiar staff ultimately leads to a better understanding of the issues the participants sought help for. All participants felt that collaboration over their care would result in better treatment but to do this they needed to have a good relationship with their GP or clinician. Participants reported that in building this connection their communication style would be better understood and their needs better met. To facilitate this, participants all expressed a desire for longer appointments with their GP and regular appointments with the same individual.

Discussion

This qualitative evidence synthesis aimed to review the literature on the experiences of accessing healthcare services for mental health and diagnosis for individuals with CEN, ASC or ADHD. There was a particular interest in exploring the similarities and differences between the three groups in terms of barriers to engaging with services for diagnosis and mental health distress. The findings show that there are many similarities across these three groups, but there are also nuanced differences. Three themes were presented: “an untidy parcel”, “the words don’t come” and “time to connect”.

The first theme, “an untidy parcel”, reflected how participants felt uncontained and at times confused by a lack of service provision or lack of signposting for services. This left them with feeling abandoned by services and compounded a sense that they did not deserve help (Camm-Crosbie et al., 2019; Matheson et al., 2013; Patel & Konstantinidou, 2020). The consequences of not providing timely support for psychological distress for individuals with ASC, CEN or ADHD is over-medication, hospitalisation and poorer social outcomes (Harpin et al., 2016; NHS England, 2023; Sheridan Rains et al., 2021). This synthesis echoed these findings whilst adding to the evidence base that individuals with these conditions share harmful consequences of poor provision of services. The current findings supported previous research that has found co-occurring diagnoses of CEN and ASC or CEN and ADHD (Cheney et al., 2023; Ditrich et al., 2021; Weiner et al., 2019) and strengthens calls for more nuanced differential diagnostic processes that prevent the unnecessary treatments, including medications, being given to individuals wrongly diagnosed (Asherson et al., 2014; Rinaldi et al., 2021).

Within this theme was the sub-theme “diagnosis a gift?” which reflected the notion of identity and sense of self. Social Identity Theory highlights the importance of group membership and the value that is intrinsically placed on maintaining one’s inclusion in a particular group (Tajfel & Turner, 1979). It seeks to explain how we identify as part of a group and how we categorize and compare ourselves to other in-group members. Self-categorisation is the process by which individuals consciously or unconsciously align themselves to a group to make sense of and understand their role in society (Turner et al., 1987). Many of the participants seeking a diagnosis saw their label as giving shape to their identity and as a form of validation of their life-experience (Camm-Crosbie et al., 2019; Crane et al., 2018; Horn et al., 2007; Matheson et al., 2013; Patel & Konstantinidou, 2020). However, the lack of post diagnostic support left many feeling abandoned and wanting support to navigate this new identity (Crane et al., 2018; Morgan, 2023; Morris et al., 2014).

The second theme, “the words don’t come” spoke to the environment of services and how they impacted on participants’ ability to successfully access care. Although all three groups experienced issues with accessibility, there were differences in the cause of those difficulties. For those with ASC, the findings supported previous work that has identified sensory over-stimulation as overwhelming for patients (Mason et al., 2019; Nicolaidis et al., 2015). For those with ADHD emotional overwhelm and difficulties with waiting were a barrier (Matheson et al., 2013; Gudka et al., 2024). Whilst individuals with CEN had difficulties with engagement relating to paranoid thoughts and distrust of strangers that made accessing care a challenge (Fallon, 2003; Patel & Konstantinidou, 2020). For participants across the conditions the overwhelming nature of their emotions impacted their cognitive abilities and contributed to the difficulties in communicating with their clinician. The Window of Tolerance model provides a helpful tool for thinking about the external and internal influences that will impact on an individual’s ability to engage successfully in a healthcare setting (Fisher & Ogden, 2007; Siegel, 1999). When an individual is in a hyper-aroused state they are hypervigilant, fearful, flooded with emotion and reactive. The opposite to this state is hypo-aroused when an individual is in a numb, dissociated, flat affect state. Neither state is conducive to engaging meaningfully and the Window of Tolerance is the zone in which an individual can process information, engage cognitively and tolerate emotions. An individual’s Window of Tolerance can be influenced more fundamentally by experience of trauma or by neurodevelopmental conditions. However, it can also be influenced by fluctuating states like quality of sleep, physical health or emotional states. Ensuring that accommodation is made for those with ASC is widely understood to be good practice and this review adds to calls for this to be extended to others who may struggle with busy waiting areas as the Equality Act (2010) requires. Providing an appropriate environment for engaging in health care brings equitable access to those who have been excluded by the symptoms of their conditions.

The final theme “needing better connections” spoke to the need for relational approaches to help these groups maintain positive engagement with services. The Minority Stress Model provides a framework to understand how mental health issues arise in certain minority groups (Meyer, 2003). The framework includes external (distal) stressors like prejudice towards a group or environmental stressors and internal (proximal) stressors for example, internalised stigma, the need to conceal one's minority status and expectations of rejection because of that status. Originally developed for sexually minoritised groups, it has been used in studies into experiences of individuals with ASC. The framework was found to indicate that societal stressors influenced the mental health of individuals with ASC and that they reported their autism was negatively perceived by society resulting in a tension of how they perceived themselves and how they perceived society viewed them. Internalised stigma resulted from this tension which was managed in various adaptive and maladaptive ways (Botha & Frost, 2018; Botha et al., 2020). Recommendations for mitigating the impact of negative societal attitudes include ensuring services recognise the distal stressors that can lead to mental health issues (Botha & Frost, 2018). Internalised stigma has been evidenced in both ADHD and CEN groups and the framework of the Minority Stress Model could be extended to provide insight into these groups' experiences too (Masuch et al., 2018; Ociskova et al., 2023).

Participants across the conditions expressed a need for continuity of care with a familiar clinician, whether this was with a GP, Psychiatrist or Support Worker (Camm-Crosbie et al., 2019; Fallon, 2003; Matheson et al., 2013; Patel & Konstantinidou, 2020; Trevillion et al., 2022). These findings highlighted that not only was this important for trust but also for facilitating communication. Being able to read other people's faces and guess their intentions is something that those with CEN, ADHD or ASC struggle with as evidenced by previous quantitative reviews (Mitchell et al., 2014; Olaya-Galindo et al. 2023; Webster et al., 2021). Therefore, the benefit of a familiar member of staff will not only help someone to develop trust and enable them to open up, but it will also allow the clinician to gain a more nuanced understanding of how that person communicates and what the signs are that indicate they are beginning to struggle (Horn et al., 2007). However, trust is built relationally and many of the participants expressed not feeling trusted by professionals with those from the

CEN and ADHD groups bringing others with them to consultations to corroborate what they were saying (Patel & Konstantinidou, 2020; Price et al., 2019). Nurturing a trusting environment is crucial for successful healthcare (Bilderbeck et al., 2014; Trevillion et al., 2022).

The development of trust is particularly important for services to try and achieve as across the groups participants expressed that they only sought help when they were in crisis. There were differences between the groups as to why crisis was reached before help was sought, but across the conditions attempts to seek help were made, but they were deemed not ‘bad enough’ to need support. For those with an ASC diagnosis, some spoke of needing to learn how to communicate their feelings having spent their childhoods supressing their overwhelming nature. Participants with an ADHD diagnosis expressed similar difficulties of expressing their emotions which they often found hard to contain. Similarly, those with a CEN diagnosis expressed it was hard to communicate their feelings accurately. All the groups had the disadvantage of either not being able to identify that something was wrong before it was too late or knowing that there was a problem but being unable to explain what it was.

Limitations and future directions

As distinct populations there is a growing body of evidence into how individuals with these conditions experience accessing healthcare. What was novel about this review was the comparison across the groups to look for similarities and differences between them. As there is some co-occurring diagnoses within these three presentations, it could be that some of the participants had multiple conditions.

Only peer-reviewed literature was searched and this could be a limitation of the findings. Grey literature can contain relevant data that would add a richness to the results.

Another strength of this review was that it focused on the UK, other reviews have included other counties which have very different health care systems, like the USA.

The quality ratings of the CASP adapted tool (Long et al. 2020) provided high score ratings for the papers although this is a subjective tool. A strength was that a second reviewer also rated 20% of the papers. Two of the papers were from the same data set and may have drawn results from the same participants (Crane et al. 2018 and Crane et al., 2019) therefore giving extra weight to the thoughts of those participants. However, they were answering discreet questions so there would not be double weighting of the themes.

The review has provided insight into similar difficulties that people with these three conditions face when trying to access healthcare settings. Future research could synthesise the experience of clinicians working with these three different groups or the parents and carers to see if there are similar themes of difficulty expressed.

Clinical Implications

This review highlights the need for continuity, particularly considering the needs of the client groups. Building a relationship was important for each group and while it can be argued this is the case for many people accessing care, for these individuals who mask or find it difficult to express themselves or understand their own emotions, this is more important.

Training staff on models like the Window of Tolerance would help to increase their awareness of when someone is in a zone in which psychological therapy or engagement in an intervention is optimal.

It would also help each of the three groups to have adaptations made for easier access like longer than standard length appointments, suitable locations and timings of appointments. In addition, much more flexibility is needed in care pathways.

Increasing psychological awareness in multi-disciplinary teams will help ensure that psychological thinking is embedded successfully in the service. This can take the form of developing team formulations.

Training for staff on trauma-informed care would be helpful, including for administrative staff who are often the gatekeepers to clinicians. Recognition should be given to the impact of vicarious trauma for primary care staff including administrative and support staff (e.g. cleaners).

Psychologically informed co-production and service development will give individuals with ASC, ADHD and CEN the opportunity to provide meaningful feedback into how services should be run and what would facilitate engagement in their care.

Setting up more proactive support systems by building on relationships and strengthening connections between staff and service users so that service users are more encouraged to seek help every time they need it.

Introducing reflective practice to teams allows staff to reflect in a psychologically safe environment and can increase understanding of stigmatised conditions like CEN, ASC and ADHD.

Conclusion

This novel review of the experiences of individuals with ASC, ADHD and CEN highlighted the similarities in their episodes of care and diagnosis-seeking and also some of the differences. All three groups wanted to have an understanding of their condition with a desire that this would be reached collaboratively with a clinician. Similarly, across the groups there were disparities in how individuals reacted to their diagnosis with some welcoming a label and others finding it a harder adjustment. Internalised stigma in part mediated an individual's positive or negative self-regard and this in turn was found to impact on their mental health. Barriers to accessing care had similar themes like unsuitable environments or the desire for a continuity of care, however the underlying causes of these differed across the conditions. All individuals expressed a paucity of available and effective services tailored to their needs. A better understanding in services of these conditions to reduce organisational stigma was indicated by the review.

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Appendices

Appendix A

Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ Checklist (Tong, *et al.*, 2012)

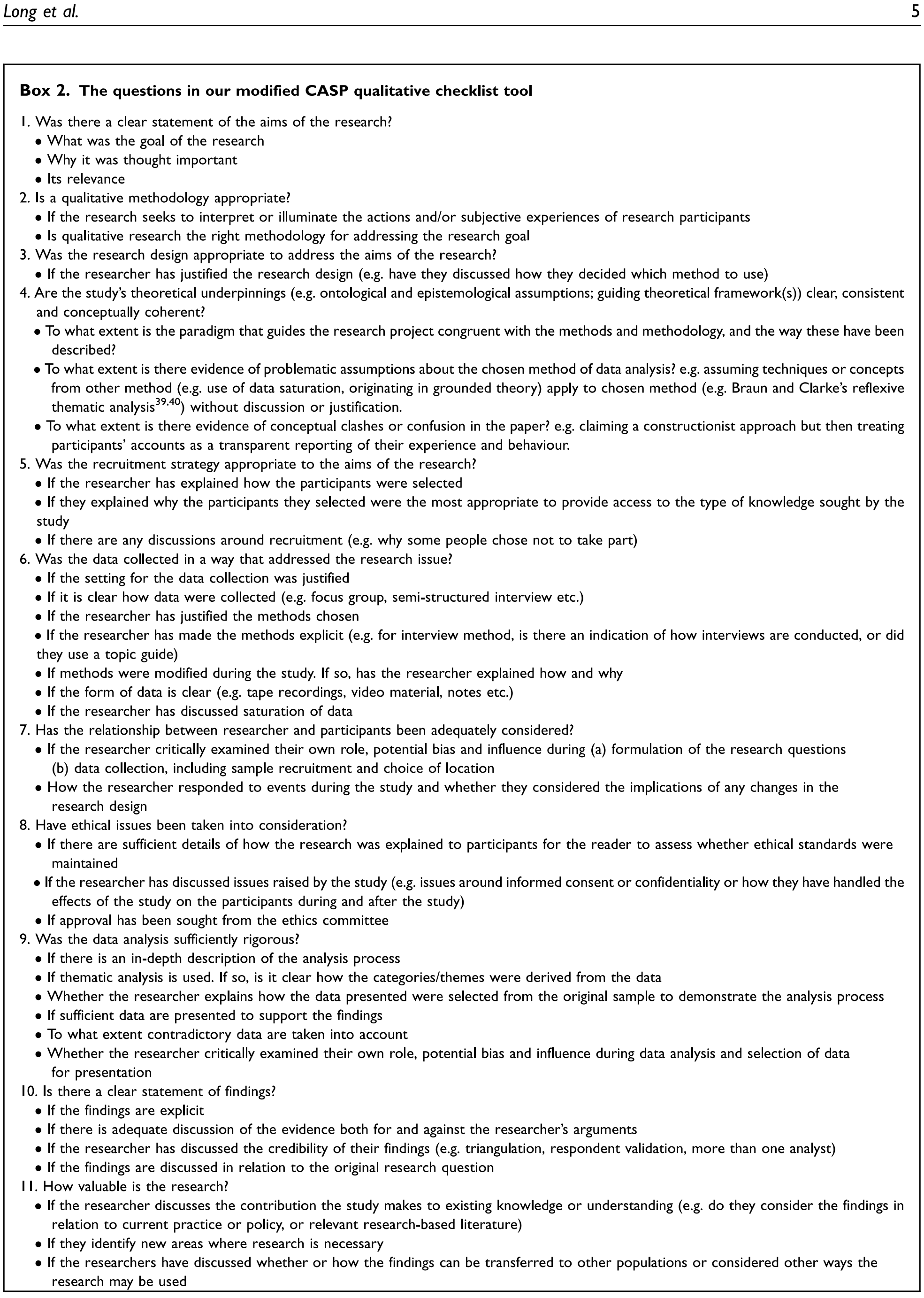
Item No.	**Guide and Description**	**Page no.**
1. Aim	State the research question the synthesis addresses	P9
2. Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)	P17
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)	P11
4. Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type)	P11
5. Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO), 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	P9
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)	P10
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)	P19
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)	P13

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 to the research question and/or contribution to theory development)	P20
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)	P17
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)	P17
12. Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required	P17
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	P19
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)	P19
15. Software	State the computer software used, if any	P19
16. Number of reviewers	Identify who was involved in coding and analysis	P18
17. Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts)	P17
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)	P18
19. Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive	P17
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	P22-27
21. Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new	28-35

	interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct)	

Appendix B

Adapted CASP quality appraisal checklist (Long et al., 2020)



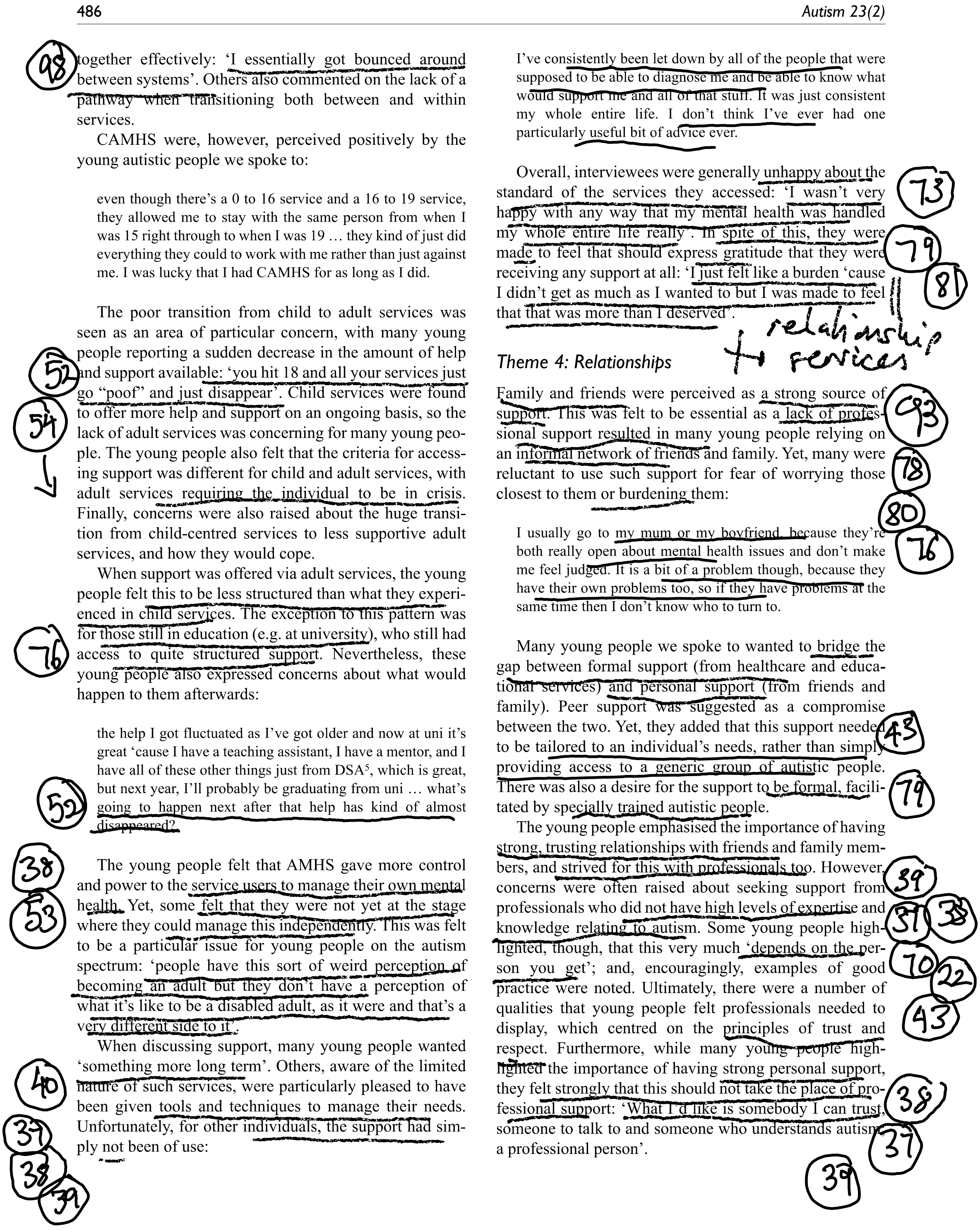
Long et al. 5

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



(98) together effectively: 'I essentially got bounced around between systems'. Others also commented on the lack of a pathway when transitioning both between and within services.

CAMHS were, however, perceived positively by the young autistic people we spoke to:

> even though there's a 0 to 16 service and a 16 to 19 service, they allowed me to stay with the same person from when I was 15 right through to when I was 19 … they kind of just did everything they could to work with me rather than just against me. I was lucky that I had CAMHS for as long as I did.

The poor transition from child to adult services was seen as an area of particular concern, with many young people reporting a sudden decrease in the amount of help (52) and support available: 'you hit 18 and all your services just go "poof" and just disappear'. Child services were found (54) to offer more help and support on an ongoing basis, so the lack of adult services was concerning for many young people. The young people also felt that the criteria for accessing support was different for child and adult services, with adult services requiring the individual to be in crisis. Finally, concerns were also raised about the huge transition from child-centred services to less supportive adult services, and how they would cope.

When support was offered via adult services, the young people felt this to be less structured than what they experienced in child services. The exception to this pattern was for those still in education (e.g. at university), who still had (76) access to quite structured support. Nevertheless, these young people also expressed concerns about what would happen to them afterwards:

> the help I got fluctuated as I've got older and now at uni it's great 'cause I have a teaching assistant, I have a mentor, and I have all of these other things just from DSA[5], which is great, but next year, I'll probably be graduating from uni … what's (52) going to happen next after that help has kind of almost disappeared?

㊳ The young people felt that AMHS gave more control and power to the service users to manage their own mental (53) health. Yet, some felt that they were not yet at the stage where they could manage this independently. This was felt to be a particular issue for young people on the autism spectrum: 'people have this sort of weird perception of becoming an adult but they don't have a perception of what it's like to be a disabled adult, as it were and that's a very different side to it'.

When discussing support, many young people wanted ㊵ 'something more long term'. Others, aware of the limited nature of such services, were particularly pleased to have been given tools and techniques to manage their needs. ㊲ Unfortunately, for other individuals, the support had simply not been of use:

㊳ ㊴

> I've consistently been let down by all of the people that were supposed to be able to diagnose me and be able to know what would support me and all of that stuff. It was just consistent my whole entire life. I don't think I've ever had one particularly useful bit of advice ever.

Overall, interviewees were generally unhappy about the standard of the services they accessed: 'I wasn't very (73) happy with any way that my mental health was handled my whole entire life really'. In spite of this, they were made to feel that should express gratitude that they were (79) receiving any support at all: 'I just felt like a burden 'cause I didn't get as much as I wanted to but I was made to feel (81) that that was more than I deserved'.

relationship + services

Theme 4: Relationships

Family and friends were perceived as a strong source of support. This was felt to be essential as a lack of profes- (93) sional support resulted in many young people relying on an informal network of friends and family. Yet, many were reluctant to use such support for fear of worrying those (78) closest to them or burdening them:

(80)

> I usually go to my mum or my boyfriend, because they're (76) both really open about mental health issues and don't make me feel judged. It is a bit of a problem though, because they have their own problems too, so if they have problems at the same time then I don't know who to turn to.

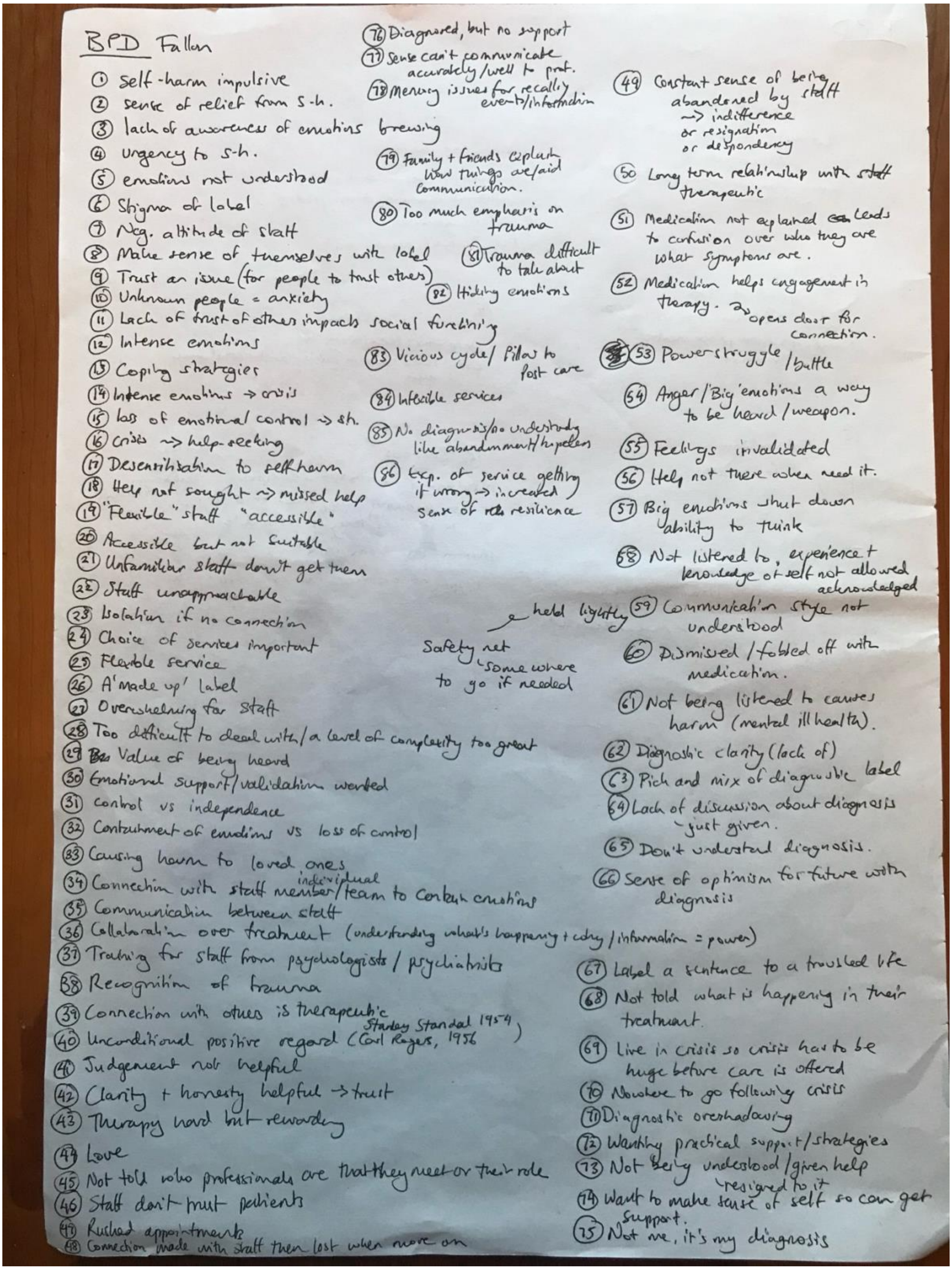
Many young people we spoke to wanted to bridge the gap between formal support (from healthcare and educational services) and personal support (from friends and family). Peer support was suggested as a compromise between the two. Yet, they added that this support needed ㊸ to be tailored to an individual's needs, rather than simply providing access to a generic group of autistic people. There was also a desire for the support to be formal, facili- (79) tated by specially trained autistic people.

The young people emphasised the importance of having strong, trusting relationships with friends and family members, and strived for this with professionals too. However, ㊴ concerns were often raised about seeking support from professionals who did not have high levels of expertise and ㊲ ㊳ knowledge relating to autism. Some young people highlighted, though, that this very much 'depends on the per- (70) ㉒ son you get'; and, encouragingly, examples of good practice were noted. Ultimately, there were a number of ㊸ qualities that young people felt professionals needed to display, which centred on the principles of trust and respect. Furthermore, while many young people highlighted the importance of having strong personal support, they felt strongly that this should not take the place of pro- ㊳ fessional support: 'What I'd like is somebody I can trust, someone to talk to and someone who understands autism, ㊲ a professional person'.

㊴

Appendix D

Code labels for line-by-line coding



BPD Fallon

① self-harm impulsive
② sense of relief from S-h.
③ lack of awareness of emotions brewing
④ urgency to S-h.
⑤ emotions not understood
⑥ Stigma of label
⑦ Neg. attitude of staff
⑧ Make sense of themselves with label
⑨ Trust an issue (for people to trust others)
⑩ Unknown people = anxiety
⑪ Lack of trust of others impacts social functioning
⑫ Intense emotions
⑬ Coping strategies
⑭ Intense emotions → crisis
⑮ loss of emotional control ~> s.h.
⑯ crisis ~> help-seeking
⑰ Desensitisation to self harm
⑱ Help not sought ~> missed help
⑲ "Flexible" staff "accessible"
⑳ Accessible but not suitable
㉑ Unfamiliar staff don't get them
㉒ Staff unapproachable
㉓ Isolation if no connection
㉔ Choice of services important
㉕ Flexible service
㉖ A 'made up' label
㉗ Overwhelming for staff
㉘ Too difficult to deal with / a level of complexity too great
㉙ ~~Ba~~ Value of being heard
㉚ Emotional support/validation wanted
㉛ control vs independence
㉜ Containment of emotions vs loss of control
㉝ Causing harm to loved ones
㉞ Connection with staff individual member/team to contain emotions
㉟ Communication between staff
㊱ Collaboration over treatment (understanding what's happening + why / information = power)
㊲ Training for staff from psychologists / psychiatrists
㊳ Recognition of trauma
㊴ Connection with others is therapeutic
㊵ Unconditional positive regard (Carl Rogers, 1956 Stanley Standal 1954,)
㊶ Judgement not helpful
㊷ Clarity + honesty helpful → trust
㊸ Therapy hard but rewarding
㊹ Love
㊺ Not told who professionals are that they meet or their role
㊻ Staff don't trust patients
㊼ Rushed appointments
㊽ Connection made with staff then lost when move on

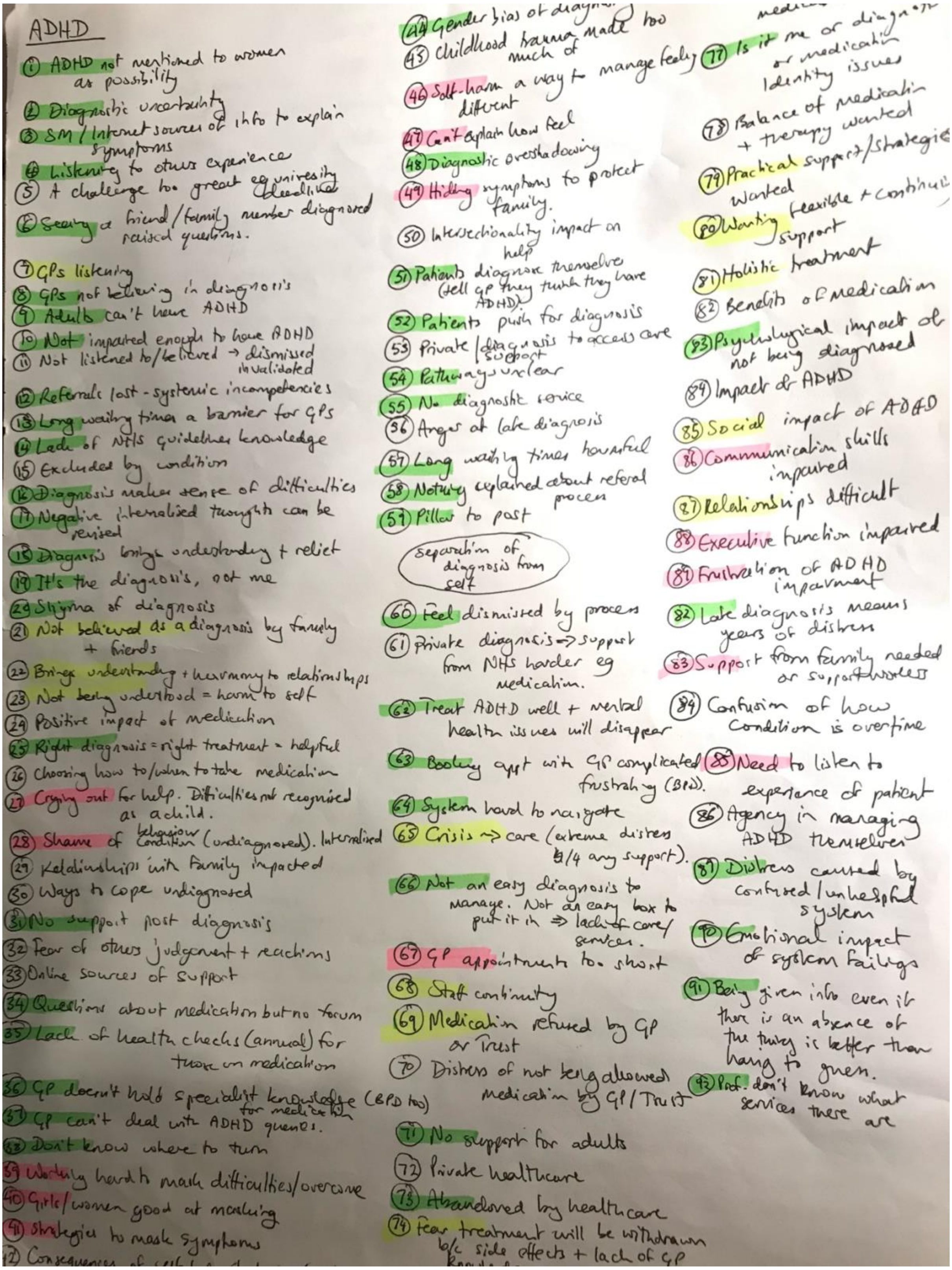
㊾ Constant sense of being abandoned by staff
~> indifference
or resignation
or despondency
(50) Long term relationship with staff therapeutic
(51) Medication not explained ~~can~~ leads to confusion over who they are what symptoms are.
(52) Medication helps engagement in therapy. ~> opens door for connection.
(53) Power struggle / battle
(54) Anger / 'Big' emotions a way to be heard / weapon.
(55) Feelings invalidated
(56) Help not there when need it.
(57) Big emotions shut down ability to think
(58) Not listened to, experience + knowledge of self not allowed acknowledged
(59) Communication style not understood
(60) Dismissed / fobbed off with medication.
(61) Not being listened to causes harm (mental ill health).
(62) Diagnostic clarity (lack of)
(63) Pick and mix of diagnostic label
(64) Lack of discussion about diagnosis – just given.
(65) Don't understand diagnosis.
(66) Sense of optimism for future with diagnosis
(67) Label a sentence to a troubled life
(68) Not told what is happening in their treatment.
(69) Live in crisis so crisis has to be huge before care is offered
(70) Nowhere to go following crisis
(71) Diagnostic overshadowing
(72) Wanting practical support/strategies
(73) Not being understood / given help – resigned to it
(74) Want to make sense of self so can get support.
(75) Not me, it's my diagnosis

(76) Diagnosed, but no support
(77) Sense can't communicate accurately/well to prof.
(78) Memory issues for recalling events/information
(79) Family + friends explain how things are/aid communication.
(80) Too much emphasis on trauma
(81) Trauma difficult to talk about
(82) Hiding emotions
(83) Vicious cycle / Pillar to Post care
(84) Inflexible services
(85) No diagnosis/no understanding like abandonment/hopeless
(86) Exp. of service getting it wrong → increased sense of resilience

held lightly
Safety net – somewhere to go if needed

Appendix E

Developing descriptive and Analytical Themes



ADHD

① ADHD not mentioned to women as possibility
② Diagnostic uncertainty
③ SM / Internet sources of info to explain symptoms
④ Listening to others experience
⑤ A challenge too great eg university deadline
⑥ Seeing a friend / family member diagnosed raised questions.

⑦ GPs listening
⑧ GPs not believing in diagnosis
⑨ Adults can't have ADHD
⑩ Not impaired enough to have ADHD
⑪ Not listened to / believed → dismissed invalidated
⑫ Referrals lost - systemic incompetencies
⑬ Long waiting times a barrier for GPs
⑭ Lack of NHS guideline knowledge
⑮ Excluded by condition
⑯ Diagnosis makes sense of difficulties
⑰ Negative internalised thoughts can be revised
⑱ Diagnosis brings understanding + relief
⑲ It's the diagnosis, not me
⑳ Stigma of diagnosis
㉑ Not believed as a diagnosis by family + friends
㉒ Brings understanding + harmony to relationships
㉓ Not being understood = harm to self
㉔ Positive impact of medication
㉕ Right diagnosis = right treatment = helpful
㉖ Choosing how to / when to take medication
㉗ Crying out for help. Difficulties not recognised as a child.
㉘ Shame of behaviour condition (undiagnosed). Internalised
㉙ Relationships with family impacted
㉚ Ways to cope undiagnosed
㉛ No support post diagnosis
㉜ Fear of others judgement + reactions
㉝ Online sources of support
㉞ Questions about medication but no forum
㉟ Lack of health checks (annual) for those on medication
㊱ GP doesn't hold specialist knowledge for medication (BPD too)
㊲ GP can't deal with ADHD queries.
㊳ Don't know where to turn
㊴ Working hard to mask difficulties / overcome
㊵ Girls / women good at masking
㊶ Strategies to mask symptoms
㊷ Consequences of

㊹ Gender bias of diagn
㊺ Childhood trauma made too much of
㊻ Self-harm a way to manage feeling different
㊼ Can't explain how feel
㊽ Diagnostic overshadowing
㊾ Hiding symptoms to protect family.
㊿ Intersectionality impact on help
(51) Patients diagnose themselves (tell GP they think they have ADHD).
(52) Patients push for diagnosis
(53) Private / diagnosis / support to access care
(54) Pathways unclear
(55) No diagnostic service
(56) Anger at late diagnosis
(57) Long waiting times harmful
(58) Nothing explained about referral process
(59) Pillar to post

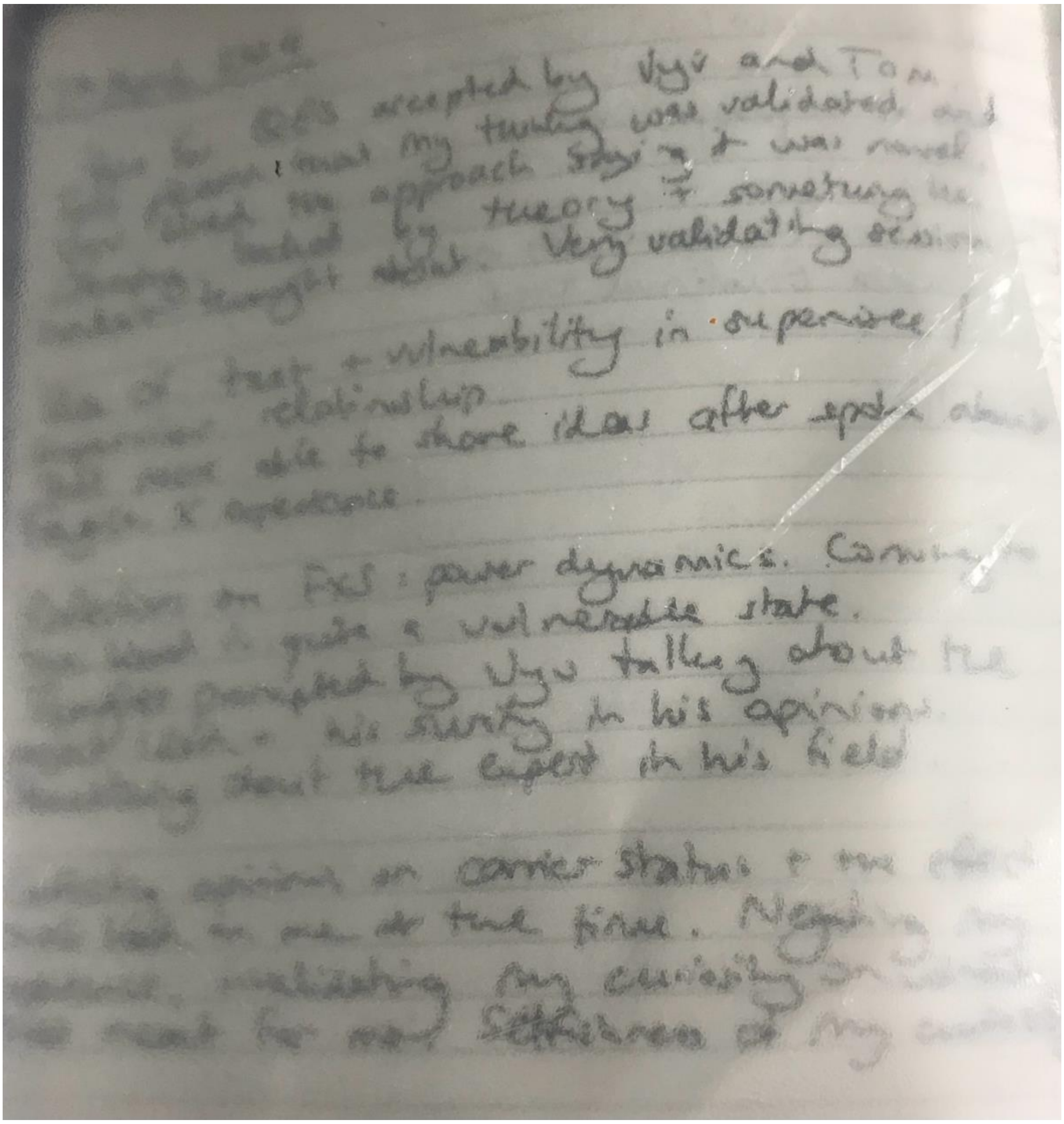
separation of diagnosis from self

(60) Feel dismissed by process
(61) Private diagnosis → support from NHS harder eg medication.
(62) Treat ADHD well + mental health issues will disappear
(63) Booking appt with GP complicated frustrating (BPD).
(64) System hard to navigate
(65) Crisis → care (extreme distress b/4 any support).
(66) Not an easy diagnosis to manage. Not an easy box to put it in ⇒ lack of care / services.
(67) GP appointments too short
(68) Staff continuity
(69) Medication refused by GP or Trust
(70) Distress of not being allowed medication by GP / Trust
(71) No support for adults
(72) Private healthcare
(73) Abandoned by healthcare
(74) Fear treatment will be withdrawn b/c side effects + lack of GP

medica
(77) Is it me or diagn or medication
Identity issues
(78) Balance of medication + therapy wanted
(79) Practical support / strategies wanted
(80) Wanting flexible + continuing support
(81) Holistic treatment
(82) Benefits of medication
(83) Psychological impact of not being diagnosed
(84) Impact of ADHD
(85) Social impact of ADHD
(86) Communication skills impaired
(87) Relationships difficult
(88) Executive function impaired
(89) Frustration of ADHD impairment
(82) Late diagnosis means years of distress
(83) Support from family needed or support workers
(84) Confusion of how condition is overtime
(85) Need to listen to experience of patient
(86) Agency in managing ADHD themselves
(87) Distress caused by confused / unhelpful system
(90) Emotional impact of system failings
(91) Being given info even if there is an absence of the thing is better than having to guess.
(92) Prof. don't know what services there are

Appendix F

Reflective Journal Extract



[illegible] accepted by Vyi and Tom.
[illegible] my thinking was validated and
[illegible] approach saying it was novel
[illegible] by theory & something like
[illegible] thought [illegible]. Very validating session

[illegible] of trust & vulnerability in supervisee /
[illegible] relationship
[illegible] able to share ideas after spoke about
[illegible] experience

[illegible] on P&S: power dynamics. Coming to
[illegible] quite a vulnerable state.
[illegible] prompted by Vyu talking about the
[illegible] his surety in his opinions.
[illegible] about the expert in his field

[illegible] opinions on carrier status & the [illegible]
[illegible] to me at the time. Negating my
[illegible] invalidating my curiosity [illegible]
[illegible] for me, selfishness of my [illegible]

Appendix G

Table of Quality Ratings CASP (Long et. al, 2020)

Author (year)	**Clear statement of the aims?**	**Qualitative methodology appropriate?**	**Research design appropriate?**	**Theoretical underpinnings clear?**	**Recruitment strategy appropriate?**	**Data collection?**	**Relationship between researcher and participants?**	**Ethical issues?**	**Rigorous data analysis?**	**Clear statement of findings?**	**How valuable?**	**Quality rating**
Au-Yeung et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Mason et al., 2021	Yes	Yes	Yes	No	Yes	Yes	No	Can’t tell	Can’t tell	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High

Camm-Crosbie et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Crane et al., 2018	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Crane et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Coleman-Fountain et al., 2020	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Can’t tell	Yes	Findings were discussed in relation to previous research	High

											and existing policy. Recommendations were made for better service provision and future research	
Matheson et al., 2013	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
French et al., 2020	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Gudka et al., 2024	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for	High

											better service provision and future research.	
Morgan, 2023	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Price et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Horn et al., 2007	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High

Bilderbeck et al., 2014	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Morris et al., 2014	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Fallon, 2003	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Findings were discussed in relation to previous research and existing policy. Recommendations were made for better service provision and future research.	High
Patel & Konstantinidou, 2020	Yes	Yes	Yes	Can’t tell	Yes	Yes	No	Yes	Yes	Yes	Findings were discussed in relation to previous research	High

											and existing policy. Recommendations were made for better service provision and future research.	
Trevillion et al., 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes		High

Section Two: Empirical Project

The experience of adults with complex mental health in Primary Care. A reflexive thematic analysis of how they understand their conditions and their help-seeking behaviours.

Abstract

Objectives

This study aimed to better understand the experiences of adults with complex mental health as they access primary care services. It sought to further understand how they made sense of their of predicament and psychological distress.

Method

This study used a qualitative design with reflexive thematic analysis. Nineteen participants with complex mental health were interviewed using a semi-structured schedule. They were recruited via their GP practice following a planned recruitment strategy devised by the research team which included search terms for the following diagnoses CEN, PTSD, ASC and ADHD.

Results

Three themes and eight sub-themes were identified. Participants expressed a desire to understand why they felt the way they did. They brought insight to their predicament and wanted to develop a trusting collaboration with their clinicians. Continuity of care was seen to be important for developing a connection to their care provider and flexible services that accommodated reasonable adjustments for different access needs was important.

Conclusions

Overall, the study provided further evidence that those with complex mental health are currently underserved in the NHS. Novel insight into their health literacy questioned the assumptions that those with complex mental health lack insight, rather it gave evidence that services need to collaborate effectively with service users to enable better communication.

Practitioner Points

- Stigma around complex mental health is still present and felt by service users, being aware of this and addressing it will be helpful.
- Those with complex mental health often have a history of trauma, introducing trauma-informed care will help services be more welcoming and will benefit staff's well-being too.
- Ensuring that reasonable adaptations are made for service users will facilitate their access to healthcare, this can be things like continuity of clinician or flexible booking systems that take into account the functional impact of their lived experience.
- Fostering continuity of care and allowing time for true collaboration over treatment options.

Keywords

Complex mental health, primary care, access, thematic analysis

Introduction

Complex mental health is an umbrella term for people who live with multiple sources of distress. The term was suggested in the consensus statement from MIND (2018) which tackled the problematic label of “personality disorder” arguing that such a narrow label ignores the multiple origins of peoples’ distress. The statement outlines these sources of distress as childhood trauma, poverty, difficult attachment styles and relationships and challenges with emotional regulation to name a few (MIND, 2018). The term ‘complex mental health’ was also used in the Community Mental Health Framework for Adults and Older Adults, alongside conditions such as persistent depression, alcohol-use disorder, severe depression and coexisting neurodevelopmental disorders (National Collaborating Centre for Mental Health [NCCfMH], 2021). This framework was developed alongside the NHS Long Term Plan (NHS England, 2019) to set out how people with mental health problems could access flexible and effective treatment in their local community with the vision of a ‘core community mental health service’ bringing together mental health services in primary and secondary care. Primary care is where many individuals with complex mental health, as described above, are expected to find support and therapeutic intervention. Many common mental health difficulties like anxiety and depression can be addressed successfully by Talking Therapies, originally known as Improving Access to Psychological Therapies (IAPT). Expanded services to treat a broader range of issues and treatment offerings in addition to Cognitive Behavioural Therapy (CBT) indicate the potential for more widely accessible psychological therapy (Clark, 2018). However, they do not offer interventions to address the needs of those with more complex mental health difficulties. In addition, concerns have been raised about the more medical model that Talking Therapies offers which lessens the important relational aspect of psychotherapy by focusing on outcome measures and leaves little room for the complexity that people bring with their psychological difficulties (Bruun, 2023). Furthermore, specialist mental health services frequently reject referrals for individuals with complex mental health from General Practitioners (GPs) as they do not meet their acceptance criteria, leaving some of the most vulnerable people without adequate support (Naylor, 2020).

The social determinants of mental ill health and the imbalance of power that fuels peoples' distress has been widely researched and resonates with those who self-identify as having mental health difficulties (Smail, 1993; Allen et. al., 2015). Determinants include racism and discrimination, conflict and violence, lack of social interaction and support, finance, housing and life events (Huggard et al., 2023). Health economics informs NHS planning and part of the considerations is health literacy of the population. This is the concept of an individual's ability to understand their health and health needs, it is dependent on their educational background, insight into their condition and understanding of good mental and physical health (Drummond et al., 2005). A paper on the lack of help-seeking by adolescents suspected to meet criteria for a CEN diagnosis states that it is their lack of mental health literacy that prevents them from understanding that they are unwell (Wall et al., 2021). There is an assumption that some people have better health literacy than others and they will be at an advantage in seeking healthcare. This assumption is found in models for barriers to healthcare such as Levesque et al. (2013).

The fragmented nature of the social, physical health and mental health system is thought to further contribute to the poorer outcomes for those with complex mental health needs. Navigating between primary and secondary care is not always easy as people with complex mental health needs may be negotiating a life fraught with poverty, substance misuse and housing insecurity. Attending appointments with these social pressures places a heavy burden on the individual seeking help and they can frequently find themselves discharged from a service before they have accessed it because of missed sessions (Arundell et al., 2020). Eligibility criteria for secondary mental health treatments add to the difficulty in accessing care as some people do not meet the distress thresholds required by services (Andersen et al., 2021). The early identification of complex mental health by GPs has been suggested as one way to begin supporting people with complex mental health difficulties (Williams & Apter, 2017). In addition, previous research has indicated that integrating care systems with meaningful training for primary care workers and clinicians embedded in the community can enhance access and uptake of psychological interventions in primary settings by reducing stigma around mental ill health (Dowrick et al., 2016).

The psychological impacts of stigma are well documented in help-seeking behaviours for mental distress. Stigma is a culturally constructed concept and there is an interaction with help-seeking behaviour on a personal, service level and societal level (Corrigan et al., 2014). When internalised, stigma can prevent initiation of help-seeking and this can be further exacerbated by the cultural networks around the individual which construct the narrative around a condition and make it acceptable or not to go and seek care. Labels that are given and the associated meanings attached to those labels are therefore powerful arbitrators of decisions to seek care or continue without it (Corrigan et al. 2014). For CEN and other conditions which fall under the complex mental health umbrella, stigma is firmly attached (Recovery In The Bin, 2024). A mixed methods scoping review on the impact of structural stigma on healthcare for people with CEN found that clinicians' negative beliefs about people with CEN, discrimination in accessing care and the dominance of the biomedical model all negatively impacted on service users' self-esteem, quality of life and therapeutic outcomes (Hatzenbuehler, 2016). The stigma that is attached to some of the diagnostic labels under the umbrella of complex mental health can in part prevent help-seeking behaviours and influence the level of engagement that people have if they do access care.

One of the drivers of the Community Mental Health Framework is the aim to enable better engagement with services including psychological therapies. Engagement has been conceptualised as more than attendance at therapy sessions. It is a multi-faceted process involving the individual recognising a need for help, good therapeutic alliance, collaboration and shared goals and a recognition that treatment already accessed has been helpful (O’Brien et al., 2009). In their review of service user engagement, O’Brien et al. (2009) found the relationship to engagement in terms of socioeconomic factors was varied with no conclusions on gender, an understandable complexity in terms of ethnicity, and similar findings for lack of employment or forensic history. The review highlights the importance of intersectionality (Crenshaw, 1998) when researching and when developing or evaluating services, ensuring that service users’ voices are heard.

Engagement can also be thought of in terms of the therapeutic alliance. Developing a strong patient-centred collaboration with service users over treatment decisions helps to reduce the risk of informal coercion in services (Valenti & Giacco, 2022). A recent review of the therapeutic alliance in community mental health services analysed data of 15 studies with either adults with a mental health disorder or clinicians working in primary mental health teams. The meta-regression produced only a positive result for length of illness and therapeutic alliance. More positive ratings of therapeutic alliance were generated from collaborative, recovery-focussed services which recognised service users’ needs (Marchi et al., 2024).

The Community Mental Health Framework for Adults and Older Adults (NCCfMH, 2021) sets out the new expectations for local primary care to meet the needs of individuals with CMH within their communities. Their definition of CMH includes people living with the consequences of trauma, neurodevelopmental conditions, persistent depression and CEN. There are often co-occurring diagnoses which adds to the complexity of finding appropriate intervention. Gaining a better understanding of how individuals with CMH experience accessing mental health services will highlight where changes could be made. A recent review of the experiences of adults with CEN accessing community mental health services included studies from around the globe. Findings were that long term support was wanted in addition to an holistic approach to care with specialist knowledge (Sheridan Rains et al., 2021). Studies included originated from the USA and Europe meaning direct comparison with UK health care systems was not possible. However, familiar themes of stigmatisation and lack of services echoed from previous work with this group in the UK (Bilderbeck et al., 2014; Gudka et al., 2024; Price et al., 2019). Over-reliance on medication and the lack of psychological therapy was a finding from a qualitative study on medication for adults with CEN (Patel & Konstantinidou, 2020). A qualitative study into the experiences of autistic and non-autistic adults of receiving mental health diagnoses revealed themes of autistic individuals feeling misunderstood and that their autistic traits were wrongly attributed to mental health difficulties or that any mental health issues they felt they had were the result of their experiences with ASC (Au-Yeung et al., 2019). This finding was echoed in other papers (Ditrich et al., 2021; Dudas et al., 2017 & Gillett et al., 2023). An exploration of adult survivors of childhood trauma showed a complex relationship with mental health and mental health services with findings suggesting that seeking help successfully as an adult, having experienced trauma in childhood, is fraught with shame but can be ameliorated by a good therapeutic relationship (McCormack & Thomson, 2017).

To date there isn’t a study that explores how adults with complex mental health issues and co-occurring diagnoses experience accessing support from primary care. Gaining a better understanding of these experiences would help inform pathways and treatment for complex mental health conditions. Adult mental health is a key priority in the NHS Long Term Plan, and listening to the experiences of an underserved population will help bring insights to the direction and development of services designed to alleviate distress.

Research Aims

This study aims to generate a deeper understanding of the experiences of adults with complex mental health in relation to accessing care. It aims to answer the following questions:

How do adults with complex mental health describe and understand their condition?

How do they experience accessing primary care and other sources of support?

Method

Epistemological Position

The aim of this research was to understand how people with complex mental health understand their condition and how they experience accessing support via primary care. A critical realism and contextualist position were taken.

Design

This study forms part of an HRA approved mixed methods project which aimed to produce a guidance framework for GPs in their work with individuals with CMHD.

Studies using interview data can employ different methods of interpreting them depending on the aims of the research project and the position of the researcher. The cyclical process of Grounded Theory is used to generate new theories derived from the data focusing on the factors and social processes involved in the subject of interest. Narrative analyses focus either on the content or the structure of the stories that individuals construct to make sense of their experiences. Some branches of narrative analysis explore how dominant discourses give shape to individual's interpretations of significant life events. IPA has the ability to explore differences between individuals' accounts as well as presenting commonalities of the lived experience of a homogenous group (Smith et al., 2022).

Reflexive thematic analysis allows for a reflexive and rigorous approach to understanding qualitative data and is widely used in health and psychology research (Braun & Clarke, 2014; Braun & Clarke, 2021). Reflexive thematic analysis allows for an analysis across a data set, providing insights and interpretations and going beyond the merely descriptive. The development of themes is an iterative process that allows the researcher to bring layered interpretations to the experiences, thoughts and beliefs of the participants. It brings a depth of understanding and allows for an inductive constructionist approach to answering research questions (Kiger & Varpio, 2020). The findings will help to inform clinical work with individuals with complex mental health by illuminating common themes in their understanding of their conditions and their ability to seek help from primary care. It is anticipated that there will be both helpful and unhelpful experiences of primary care. In addition, the insights gained from participants' reflections on other sources of support may help inform how individuals who struggle to navigate a healthcare system can be supported.

Ethics

This study is part of a wider project which aims to provide a framework for GPs to better identify patients under their care who have CMHD. It has ethical approval from the Health Research Authority (Appendix A)

Some extracts of the participants' interviews will be used in the report, however, all efforts will be made to minimise the risk of identification. All identifying information was removed including names of individuals, locations and services.

Participants

Participants were recruited from General Practitioners (GPs) in the North of England. There was a purposeful aim to focus on practices in areas of relatively high deprivation (practices in the most deprived 40% of English Index of Multiple Deprivation). The GP practices that agreed to participate in the study were given information packs with instructions for searching their SystmOne or EMIS databases. General Practice staff undertook the electronic searches using the search strategy developed and piloted by the research team. The search strategy included codes for “personality disorder”, “complex PTSD”, and “dysthymia”. Once potential participants were identified, the practice GP was asked to manually review the list to ensure the patients identified were suitable for an interview based on the inclusion and exclusion criteria.

Inclusion criteria

- Adults, aged >18.
- Identified by their GP as having complex mental health difficulties including a diagnosis of CEN, ASC or ADHD.
- Able to access online video conferencing software or telephone.
- Mental health considered stable enough to participate in the study as determined by their GP.

Exclusion criteria

- Aged <18 years old.
- Lack capacity to consent to take part in study.
- Mental health not considered to be stable enough to take part in the study as determined by their GP.

Sample size

In total 19 patient participants were interviewed and all the gathered data were used in the analysis. This breadth of data allowed the researcher to reach well supported themes drawn across the sample (Braun & Clarke, 2006; Fugard & Potts, 2015; Kiger & Varpio, 2020.

Participant Demographics

Participants (N=19) were aged 30-67. There were 14 women and five men. Although recruitment had been targeted at General Practices in diverse ethnic areas, all participants were White British apart from one South Asian participant. Relationship status varied from single, married, divorced and there was a range of employment status. See Table 1 for further details.

Table 1

Participant Demographics

Participant	Age	Gender	Ethnicity	Diagnoses	Employment	Relationship status
1	65	F	White British	Complex Emotional Needs	Retired	Divorced
2	30	F	White British	Persistent Depression	Pub Manager	In a relationship
3	67	F	White British	Autism Spectrum Condition	Social Services	Single
4	58	F	White British	Complex Emotional Needs	Unemployed	Married
5	37	M	White British	Psychosis	Unemployed	Separated
6	41	F	White British	Bipolar Disorder, Anxiety	Unemployed	Separated
7	30	F	White British	Dissociative Identity Disorder	Hospitality	Single
8	27	F	White British	Obsessive Compulsive Disorder, Complex Emotional Needs	Civil Servant	In a relationship
9	59	F	White British	Bipolar Disorder, Obsessive Compulsive Disorder, Complex Emotional Needs	Unemployed	Divorced
10	55	M	White British	Persistent Depressive Disorder, Complex Emotional Needs, Claustrophobia	Unemployed	Married
11	50	M	South Asian	Persistent Depressive Disorder, Complex Emotional Needs, PTSD	Unemployed	Divorced
12	40	F	White British	Complex Emotional Needs, Depression, Anxiety	Unemployed	Single
13	56	M	White British	Dissociative Personality Disorder, Schizophrenia	Unemployed	Married
14	57	F	White British	Complex Emotional Needs, Depression, Childhood trauma	Unemployed	Married
15	67	M	White British	Post Traumatic Stress Disorder, Depression	Emergency Services	Single
16	30	F	White British	Complex Emotional Needs, Post Traumatic Stress Disorder, Attention Deficit Hyperactivity Disorder, Autism Spectrum Condition	Secretary	Single
17	38	F	White British	Complex Emotional Needs, Depression, Autism Spectrum Condition	Unemployed	Single
18	39	F	White British	Complex Emotional Needs, complex Post Traumatic Stress Disorder, prenatal depression	Support Worker	Single
19	50	F	White British	Complex Emotional Needs, Depression, Anxiety	Unemployed	Married

Materials

Interview Schedule

A semi-structured interview schedule was developed in collaboration with three experts by experience who consulted on the wider project and following the guidance for reflexive thematic analysis (Braun and Clarke, 2006; 2021). See Appendix B.

Data Collection

Semi-structured interviews were conducted online, recorded and transcribed for analysis. Transcripts were stored according to university guidelines.

Data Analysis

Reflexive thematic analysis provides a flexible, thorough and reflexive approach to the data. Widely used in health and psychology research Reflexive thematic analysis has been variously executed. This study used the well documented guidelines of Braun and Clarke (2006; 2021). The lead researcher kept a reflective journal to document her thoughts on the transcripts on first reading and listening and as the analysis developed. Supervision discussions informed credibility checking. See Appendix C.

Familiarisation with the data

The transcripts were read and the original recordings were listened to several times allowing the researcher to immerse herself in the words and expressions of the participants. Notes were made at this stage to capture first interpretations and responses to the narratives. These initial notes and explorations of the data were taken to supervision for further reflection on the researcher’s subjectivity and any surprising or unexpected discoveries were discussed.

Initial coding

The entire data set was coded for interesting elements and data that supported these codes were collated.

Searching for themes

Themes were developed by drawing together related codes. The relevant data was collated for each emerging theme.

Reviewing themes

At this stage the themes were checked by creating a thematic map of the analysis. This involved ensuring that the emerging themes made sense in relation to the coded extracts and the entire data set.

Defining and naming themes

This stage allowed for further reflection and consideration of the themes and gave the opportunity to further refine the themes and provide clear names and definitions for each one. Themes were reviewed to ensure they told a good story of the data. They were shared with one of the experts by experience involved in the design of the study who gave a favourable review of them.

The report

The write up and summary of the analysis provided a last opportunity to review the work and ensure the analysis was well represented in the extracts chosen for illustration. This stage related the themes and findings back to the original research questions and literature.

Patient and Public Involvement

Three individuals with lived experience of mental health and services were involved in shaping the overarching study with advice given on staff recruitment and development of the topic guides. Following completion of the analysis a reflective discussion of the themes was held with one of the individuals involved in the development of the project. They reported that they felt the themes captured the experiences well and gave an authentic voice to the participants.

Results

Reflexive thematic analysis was used by the researcher on the full data set of 19 participants. Three themes and nine sub-themes were developed in the analysis with an overarching theme of “contradiction” running through, see Table 2 and Figure 1 for how these were organised and related to each other. How the participants contributed to the themes can be seen in Table 3.

The overarching theme of “contradiction” can be found through all the themes. Participants expressed great insight into their distress and how to manage it, but this was not always acknowledged by themselves or professionals. There was confidence and assurance shown by participants in relation to what they needed from services, but this was not always expressed in a way that GPs and clinicians could understand. Services are meant to be providing tailored support, but for many participants these did not materialise. There was also contradiction in participants’ views on their relationships with loved ones, a desire to share their troubles, but a reluctance to cause harm.

The ambivalence with which participants expressed an understanding of their condition and the necessity for doing so to enable support was captured in “finding and not finding an understanding of the self”. The sub-themes spoke to the “uncertainty over diagnoses”, and “childhood trauma as seen and not seen” and that participants often felt “abandoned by services” when the anticipated help and support did not materialise.

Accessing care was explored in the theme “the predicament creates barriers to care” with sub-themes of “seeing the GP is hampered by the predicament”, “distress is hard to measure” and “genuine warmth and empathy or miscommunications”. The exploration of other sources of support were captured in the theme “The tightrope of self-care and help-seeking”. This had sub-themes of “recognising and evaluating strategies” and “connecting and distancing” which recognised the effort and thought that participants gave to self-care but the frustrations and dilemmas that this entailed.

Table 2

Main themes

Themes	**Sub-themes**
Overarching theme: Contradiction	
Finding and not finding an understanding of the self	*Uncertainty over diagnoses* *Childhood trauma seen and not seen* *Abandoned by services*
The condition creates barriers to care	*Seeing the GP is hampered by the condition* *Distress is hard to measure* *Genuine warmth and empathy or miscommunications*
The tightrope of self-care and help-seeking	*Recognising and evaluating strategies* *Connecting and distancing*

Figure 1

Map of themes

Table 3

Participant contribution to themes

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	P16	P17	P18	P19
Finding and not finding an understanding of the self	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Uncertainty over diagnoses	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Childhood trauma seen and not seen	√		√	√	√	√	√	√	√	√	√		√	√	√	√		√	√
Abandoned by services	√	√	√	√	√	√		√	√	√	√	√	√	√	√	√	√	√	√
The condition creates barriers to care	√		√	√	√	√		√	√	√	√		√	√	√	√	√	√	
Seeing the GP is hampered by the condition	√	√	√	√	√	√		√	√	√	√		√	√		√	√	√	√
Distress is hard to measure	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Genuine warmth and empathy or miscommunications	√	√	√	√	√	√		√	√	√	√	√	√	√	√	√			√
The tightrope of self-care and help-seeking	√		√	√	√	√	√	√	√	√			√	√	√	√		√	√
Recognising and evaluating strategies	√	√	√	√	√	√	√	√	√	√		√	√	√	√	√		√	√
Connecting and distancing	√	√	√	√	√	√	√	√	√		√	√	√	√	√	√	√	√	√

Finding and not finding an understanding of the self

This theme represents the participants' desires to reach an understanding of their condition that will help to explain how they feel and behave. There was a sense of urgency and frustration in this theme as participants attempted to find a cause for their distress.

> *"I drive myself crackers to be honest. It's like I'm constantly searching for an answer that's going to fix my brain." P6*

And it was important to reach this understanding with the help of a professional in the hope that this would give them certainty about their condition. This would then, it was hoped, lead to appropriate support. Participants were most satisfied when they felt heard and understood in the diagnostic process, a sense of collaboration rather than just being given a diagnosis.

> *"So from there, I'd been able to say to GPs 'BPD' and then it's like 'oh right, OK, we know what that means', you're not just a little bit depressed, OK." P4*

Uncertainty over diagnoses

Uncertainty was expressed about participants' diagnoses which was felt by both clinicians (including GPs) and patients. At times the balance of diagnostic responsibility had fallen too heavily on the participant's side and the clinician had not quite got the nuance of collaboration right.

> *"[she] told me to go off and look at MIND and think about what I thought I had, which I thought was very odd, I'm not a doctor, I'm not a psychiatrist, I don't have any knowledge … So I went back and she said 'well what do you think?'"P18*

Other participants had experienced delays or their diagnosis changing as understanding of conditions deepened or were challenged. Some, who were later diagnosed with autism or ADHD, had previously been told that they couldn't have that condition as they were female, too competent or managing life too well.

Childhood trauma seen and not seen

Many participants had spent a lot of time self-questioning and reflecting when seeking answers and understanding of their conditions. There was an acknowledgement that their early life experiences and significant events had influenced their mental well-being, although this was not always referenced by professionals.

> *"you're the first one to say 'look ... could be childhood trauma', like I'm not being rude because you're the first one to say it, but I figured that out for myself a long time ago" P5*

This gave an understanding of the self-awareness that participants had of their difficulties and revealed that this is not always acknowledged in consultations.

Abandoned by services

This sub-theme is about the difficulty that participants described in accessing appropriate services once they had a diagnosis or it was recognised they may need some/more help. It speaks to the sense of frustration trying to navigate mental health services, the opaque nature of where to go and how to get through the door. They spoke of being referred for secondary services but the support either never materialising or being so short lived that they only have time to lay bare their worst traumas before their limited sessions are over *"It's like dangling a carrot in front of [a] donkey" P6*. The inflexibility, inappropriate or complete lack of provision left participants feeling abandoned.

The lack of services to meet their needs was present throughout the participants' interviews. Rejection from secondary services compounded the feelings of being ‘untreatable’. Participants felt not only the stigma of their CEN diagnosis, as understood from reactions from staff, but they also came to understand that they were not worth a service. This rejection of individuals who often struggle with interpersonal relationships from early trauma seems particularly cruel.

> *“IAPT ... looked at the words ‘personality disorder’ and ‘PTSD’ and went ‘no, no, no, we can’t deal with her, like, we’re not equipped to help her or provide support for her’ ... But there’s nothing else. There’s nowhere else to go.” P16*

The predicament creates barriers to care

This second theme relates to how their mental health manifested which often precluded participants from accessing care. It included the notion that physical health was easier to treat and more of a priority than mental health in service provision. It also captured the still prevalent stigma attached to mental health that participants found difficult to explain to both family/friends and clinicians. Mental ill-health was seen as something to be free from, but this was difficult to achieve and the shame of this was internalised which prevented help-seeking from services.

> *“I used to drink a lot because it used to help mask my feelings. I was ashamed to go to the doctor’s because I thought somebody like me shouldn’t be doing, you know, the drinking.” P1*

This in turn created a sense of hierarchy of mental health with participants angered that ‘others’, *“Joe Bloggs down the road that’s got anxiety issues or whatever” P13*, seemed to get priority treatment. Or that some with the same diagnosis would flout the system and jeopardise their own care.

> *"I know somebody who's got the same diagnosis as me … but she's completely different, she abuses the system … which really annoys me to death because I think … people might think the same about me" P14*

Some participants touched on a narrative of 'us and them' in this theme with an idea that others were getting services that perhaps they didn't deserve whereas they were left to struggle without help. There was some recognition that budget constraints and Government priorities may be driving this perceived inequality.

Seeing the GP is hampered by the predicament

This sub-theme reflects the difficulties that participants had in accessing their GP due to their condition. It shows how not being able to reach the GP as the "*first line of treatment*" *(P16)* increases the risk of emergency or crisis services being needed.

> *"It takes me an awful lot to get to the GP. I am not very good at self-care at all. I'm really rubbish at self-care." P19*

Not only can somatic symptoms be a barrier to accessing care, but a sense of self-worth also hinders help-seeking. Participants spoke of only accessing their GP when they really needed to. However, when they eventually did, their GP may not recognise the gravity of their situation. Participants spoke of not recognising when they needed to seek help with some unable to judge for themselves what was 'reasonable' stress and carrying on with work and family life until their mental health refused to be ignored.

Distress is hard to measure

This sub-theme spoke of the participants' experience of living with daily distress that can at times seem to be well managed but is always present and can be triggered at any time. Participants expressed a sense that they were just expected to live in this state of distress and that only when it was extremely heightened did they receive the offer of help that was often too distant or wholly inadequate. There was also the sense in this theme that participants were very capable at monitoring their emotional vacillations, which if recognised by GPs and secondary mental health clinicians would be one way to provide person-centred, attuned care when it was needed.

> *"I have severe flashbacks, especially now building up to the anniversary, and I know it's going to happen because I can smell grass when I'm asleep and then I wake up and then it starts. And it's not pleasant at all…" P15*

Genuine warmth and empathy or miscommunications

This sub-theme reflects the way that participants spoke of how their distress was responded to. There were positive encounters with GPs and mental health professionals as well as dismissive and demeaning encounters. The administrative staff of services were also mentioned. Regular check ins with a familiar GP were seen as being very therapeutic and helped to establish trust. Continuity of care was key for all the participants, being able to build a trusting relationship with a GP was seen as allowing for true collaborative care.

However, at times the response from mental health workers was wholly inadequate and lacking empathy. When trust was missing, there was a sense of infantilising the participants and treating them like wilful children.

> *"I were in distress … I were shaking and [my mental health worker] rung up, and she says 'do your groundwork', I says 'fuck groundwork'" P9*

The benefit of developing that trusting relationship with the patient was gaining a more holistic understanding of their needs, something which the participants acknowledged as being important for their treatment. There was a sense that being excluded from decision making was not helpful. What was desired was an honesty and open communication that might need scaffolding at times, but which enables informed choices to be made over treatment options.

> *"I'd rather someone just be straight up honest with me because I'm an adult. Treat me like an adult, yeah." P8*

The tightrope of self-care and help-seeking

This last theme reflects the varied ways that the participants found to help themselves in their distress. There was a range of strategies that participants tried, some more measured than others. All participants had found ways to cope with their challenging lives, juggling families, jobs and the distress that their untreated conditions resulted in.

> *"obviously I started self-harming and at that point I didn't really know why I was doing it, other than it helped me, the physical pain was a distraction from everything going on in my head that I couldn't work out." P16*

Some recognised they needed more manageable lives and made changes accordingly. Some expressed surprising ingenuity in their approaches, drawing on various sources of inspiration from friends or internet sources.

> *"you have to come up with systems to help self, like … I've got suicidal thoughts …*

> *instead of being lethal with it, I starve myself, so it gives you time to think about it … So far, touch wood, is a tried and tested method for myself." P5*

There was a determination to survive and deal with the distress which could be something to draw on and explore in consultations with clinicians.

Recognising and evaluating strategies

Participants spoke of evaluating their own coping mechanisms and showed insight into their helpfulness. An unhelpful strategy was sometimes the instigator for seeking professional help. Critical appraisal of treatments offered by services, whether that was medication or talking therapies was also included in this theme. A range of agency was captured in the participants' accounts of treatments. Some seemed to be going along with whatever therapy they were offered, others expressed dissatisfaction, and some insisted on an intervention they felt would be helpful for them over what had been offered. For some this meant insisting on a psychological therapy over the usual medication being offered.

Some participants expressed that they did not understand how the therapy would work and there was a sense that person centred care or true collaborative therapy was not taking place.

> *"It were just like 'Do that' and 'Tap your wrist' and 'Tap your nose' and 'Tap your head'. No thanks. … I just told them straight … 'That's not for me. That's definitely not for me'." P10*

Connecting and distancing

A second sub-theme is about the tension of wanting to share their experiences with friends and family but worrying this will cause harm. Participants expressed wanting to shield family from parts of themselves not only for their loved one's benefit but for their own too.

Time and learning together was evident in some accounts of support.

> *"[My family] have learnt over the years, as I have I suppose. So now we've found a way for them to be able to support me." P11*

For others, they didn't have somebody close to love. Others still knew they had to monitor a close connection that could at times be detrimental to their well-being. There was a recognition that even though there were strong relationships, these were not without their issues.

> *"My mum, yeah, we're quite close but I try and take it arm's length when she's in a bad place." P8*

Supportive partners and friends provided consistency and positive regard that gave participants a sense of safety. Some participants had long-serving friends or loved ones who they felt understood them and provided support and there was an unspoken sense that they were lucky in this.

Discussion

This much needed piece of research aimed to give voice to an often unseen and unheard cohort of people living with complex mental health. Findings showed that this group face many barriers to accessing primary care and other sources of support. However, they also reveal a less frequently acknowledged resourcefulness and insight into their difficult circumstances. This was reflected in the overarching theme of "contradiction" which ran through all the themes.

The first theme was "finding and not finding an understanding of the self". This spoke to an urgency with which the participants sought understanding of their predicament and wanted to know “what was wrong with them”. The findings echoed previous work which has shown diagnosis can be a positive or a negative experience depending on how the process unfolds (Moltu et al., 2023). Participants expressed varying reactions to being given a diagnosis with some relieved to have a label. However, this study echoed previous research on the stigma of CEN and the poor attitudes of staff was still very present in services (Ociskova et al., 2017; Stalker et al., 2005; Trevillion et al., 2022). The findings highlight the different attitudes and understandings of help that service users and clinicians bring to sessions (Reder & Fredman, 1996).

The need for an understanding of their distress was universal. Participants researched their own symptoms, brought suggestions to clinicians and persevered when services were hard to access. Finding a recognised label was important for individuals to understand themselves and their sense of place in society, their social identity (Tajfel & Turner, 1979; Turner et al., 1987). However, the consequences of this were varied with some experiencing stigma which in turn was internalised and led to feelings of shame. This sense that participants expressed of being “abandoned by services” (as encapsulated in the sub-theme of the same name) resonates with the work on structural stigma. This points to how prejudice and stereotypes create an organisation that perpetuates mental health stigma and leads to iatrogenic harm by either withholding treatment or using coercive methods to treat individuals (Corrigan et al., 2005b).

The second theme “the predicament creates barriers to care” spoke to the effort and unreasonable expectations that participants experienced when trying to access care. Accessing GPs relied on them being able to ring at a particular time in the morning, tolerate waiting rooms and cope with unexpected changes or delays. These findings suggest that reasonable adjustments are not always being made for people with complex mental health as services are bound to do since The Equality Act (2010). Many of the participants found emotional expression overwhelming and validation was lacking in services.

The sub-themes of this second theme bring further weight to calls for more genuinely co-produced services (Repper & Perkins, 2003). Bringing an understanding that emotions are culturally constructed and experienced relationally may help to guide more collaborative conversations with service users (Fredman, 2004). As many participants had experienced trauma an awareness of how to engage them in collaborative help-seeking is important for all clinicians, particularly those in primary care.

The final theme was the “Tightrope of self-care and help-seeking”. This theme encapsulated the sense that participants had an understanding of their needs but at times lacked confidence in their own insight as to why their mental health might be suffering. This finding brings a novel nuance to the idea of health literacy (Drummond et al., 2005). The participants did have insight into their suffering, they understood the social determinants of their distress (Smail, 1993) but when trying to engage in care they were not listened to. The Community Mental Health Framework (Health NCCfM, 2019) recognises the importance of healthy communities with good housing and amenities. Acknowledging the inequalities around access to housing, financial security and healthy spaces destigmatises those suffering psychological distress by externalising the sources of it. Participants provided further weight to previous research that has highlighted the need for longer appointments with GPs and continuity of care so a strong therapeutic alliance between clinician and service user can be built (Patel & Konstantinidou, 2020; Sheridan Rains et al., 2021).

Strengths, Limitations and Future Directions

There is a lack of qualitative research into the experiences of people with complex mental health as understood by MIND (2018) and the Community Mental Health Framework for Adults and Older Adults (NCCfMH, 2021) and with the continued expansion of the framework in England this is a timely piece of research. As a purposefully sampled study, GPs were successful in enabling the recruitment of 19 participants with varying needs that fall under the umbrella term of complex mental health. The recruitment yielded a good number of rich interviews to inform the themes.

Another strength is the design of the study which had involvement from experts by experience and the results were discussed with one of them to aid with the quality of the output and the legitimacy of the findings.

A limitation is that although recruitment was targeted to GP practices with ethnically diverse populations, this did not translate to a diversity in the ethnicity of the participants. Future studies could spend more time in a collaborative approach to the research by building up relationships with community groups, faith groups and charities to increase participation from a wider and more diverse population.

Another limitation was that the researcher did not conduct the interviews so did not experience them first hand. However, in mitigation of this, they listened several times to the audio recordings and read and re-read the transcripts. There was attention paid to reflexivity in the study and this is another strength. The researcher kept a journal and reflected on the first and second listening and reading of the transcripts to enable an interrogation of the analysis and findings (Braun & Clarke, 2014).

Future research could be in the form of focus groups that invite people with complex mental health to explore ideas for ameliorating their experience of primary care. Another under researched area is that of administrative and other support staff in primary care settings. Exploring their experiences of working in what can sometimes be a stressful environment could bring helpful insights.

Clinical Implications

For individuals with CMH these findings add weight to previous research that has called for person-centred and flexible collaborative care with a focus on connection (Kverme et al., 2019; Shepherd et al., 2015; Rains et al., 2021; Adams & Young, 2020). The majority of the participants expressed a preference for continuity of care to enable them to build up a relationship with their clinician. As GPs are the gatekeepers to additional support, trying to develop this continuity of care in GP practices would be beneficial. There are now many health professionals attached to the GP surgeries so there is opportunity for drawing on a wide range of skills for this purpose.

The benefit of continuity of care is that clinicians can begin to notice the signs that someone may be struggling. Many of the participants found it difficult to express their worries or needs, but with appropriate scaffolding in a more trusting collaborative partnership of care, they may be more willing to express themselves and ask for help.

Introducing more flexible care and allowing reasonable adjustments for service users like pre-booked time slots and simpler booking procedures would reduce the onus of responsibility and effort from service users.

Trauma-informed care is an approach that is used varyingly across England with no current NHS-wide policy on its implementation (Emsley et al., 2022). These findings highlight the need for wider recognition of trauma-informed care in primary services as this is where help is initially sought. Trauma informed care for all staff including administrative and support staff would help bring more psychological thinking into services. Receptionists are often the gatekeepers to the GPs and participants often expressed an antagonism towards them and how they were spoken to. Helping all staff understand the impact of trauma on relationships and expectations of relationships would benefit their interactions with all service users, but particularly those with complex mental health. And within the trauma-informed approach is the recognition that staff may also have trauma so considering their well-being would also be advantageous. Introducing clinical psychology consultation or the facilitation of reflective practice groups is also recommended to increase psychological mindedness.

As the Primary Care Networks (PCNs) continue to expand, ensuring that good psychological understanding is embedded in services is essential so that the concerns of a diluted psychological service are not repeated from the Talking Therapies expansion (Bruun, 2023).

A key strength of clinical psychologists is their training in service evaluation. Using the understanding from the work of Corrigan et al. (2005b) and learning from the work on ameliorating the effects of self-stigma from Mills et al. (2020), clinical psychologists can help address the barriers to help-seeking created by shame and self-stigma that some individuals with CMH experience. Meaningful co-production with service users to improve access to care in relation to shame and self-stigma is recommended.

Psychologists holding leadership roles in healthcare settings are in a good position to provide consultation and support to primary care and champion more effective collaboration between primary and secondary care (Naylor 2020). The findings here strengthen the calls for maintaining strong psychological presence in the PCNs and the benefit of local community embedded co-production of services (Hodgson et al., 2022).

Conclusion

Those with complex mental health are still being harmed by stigmatising services and systems. There is an acknowledgement of the social determinants of health, but this has not been fully embraced in primary care where needs are first met. This study gave voice to the resourcefulness and determination of people who were often living in very challenging circumstances. It highlighted the fragmented and inequitable state of services which have failed to give care to those in psychological distress. It strengthened the call for clinical psychologists in primary care to increase psychological understanding and ways of connecting with people who may have learned to mistrust others (“Clinical Psychology in Primary Care - How Can We Afford to Be Without It?: Guidance for Clinical Commissioners and Integrated Care Systems: Cover,” 2022).

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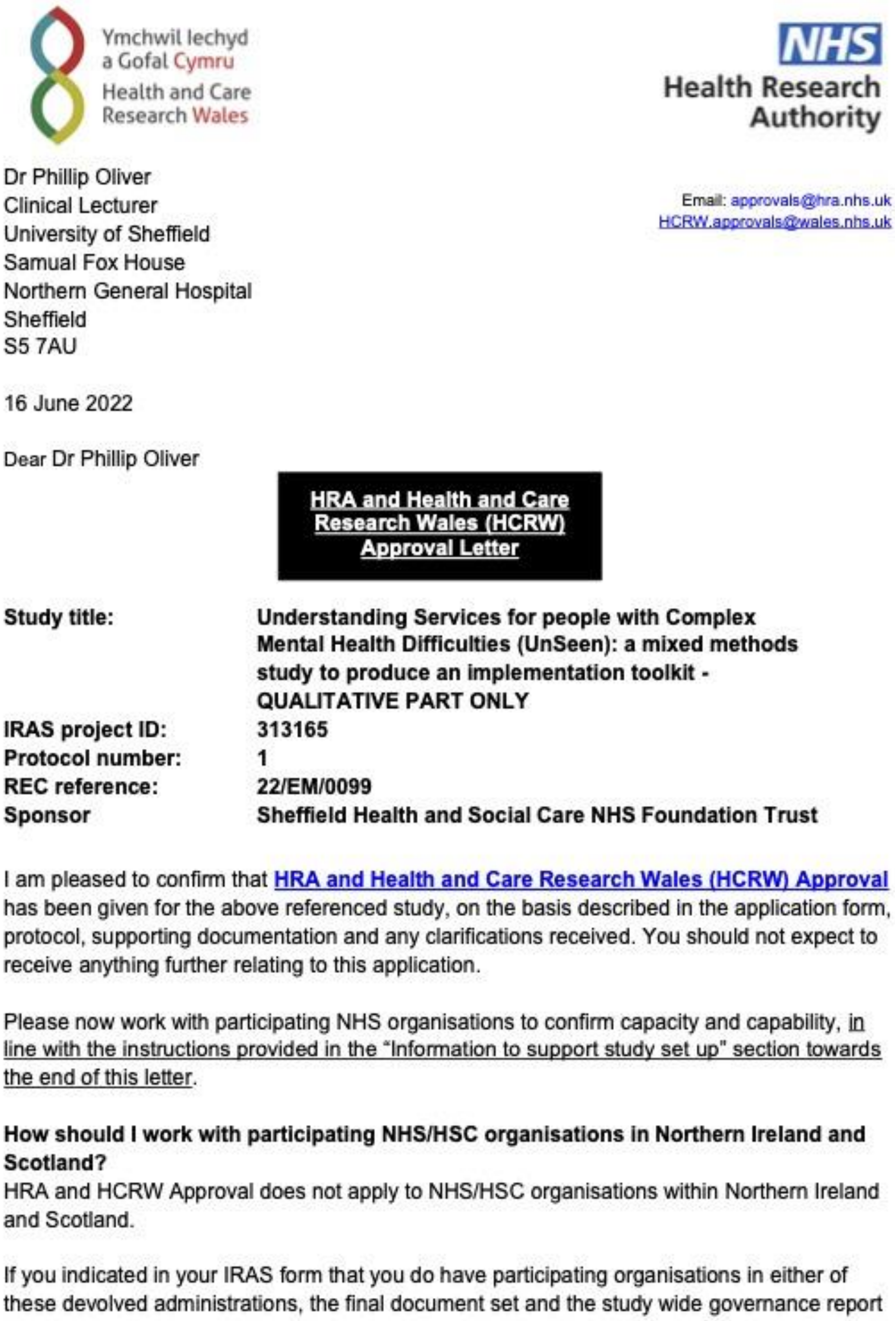
Appendices

Appendix A



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Dr Phillip Oliver
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16 June 2022

Dear Dr Phillip Oliver

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **Understanding Services for people with Complex Mental Health Difficulties (UnSeen): a mixed methods study to produce an implementation toolkit - QUALITATIVE PART ONLY**
IRAS project ID: **313165**
Protocol number: **1**
REC reference: **22/EM/0099**
Sponsor **Sheffield Health and Social Care NHS Foundation Trust**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

Appendix B

The
University
Of
Sheffield.

Interview Topic Guide (for patients)

Version 1.1; 30/06/22

Understanding Services for people with Complex Mental Health Difficulties

(UNSEEN)

---RESEARCH BACKGROUND---
This work aims to narrow the gaps between people with complex mental health difficulties, their GPs and specialist services. Complex mental health difficulties include (but are not limited to) personality disorders, neurodevelopmental co-morbidities, and the consequences of trauma. Complex mental health difficulties are increasingly recognised in NHS policy as important.
---RESEARCH OBJECTIVES---
The overarching research question is "How can general practices better identify people with complex mental health difficulties and provide care in a way which integrates primary care and specialist services?". **Aims:** To understand how people with complex mental health difficulties regard their conditions and how they experience primary care and its interaction with specialist mental health services.

---DISCUSSION GUIDE BEGINS---

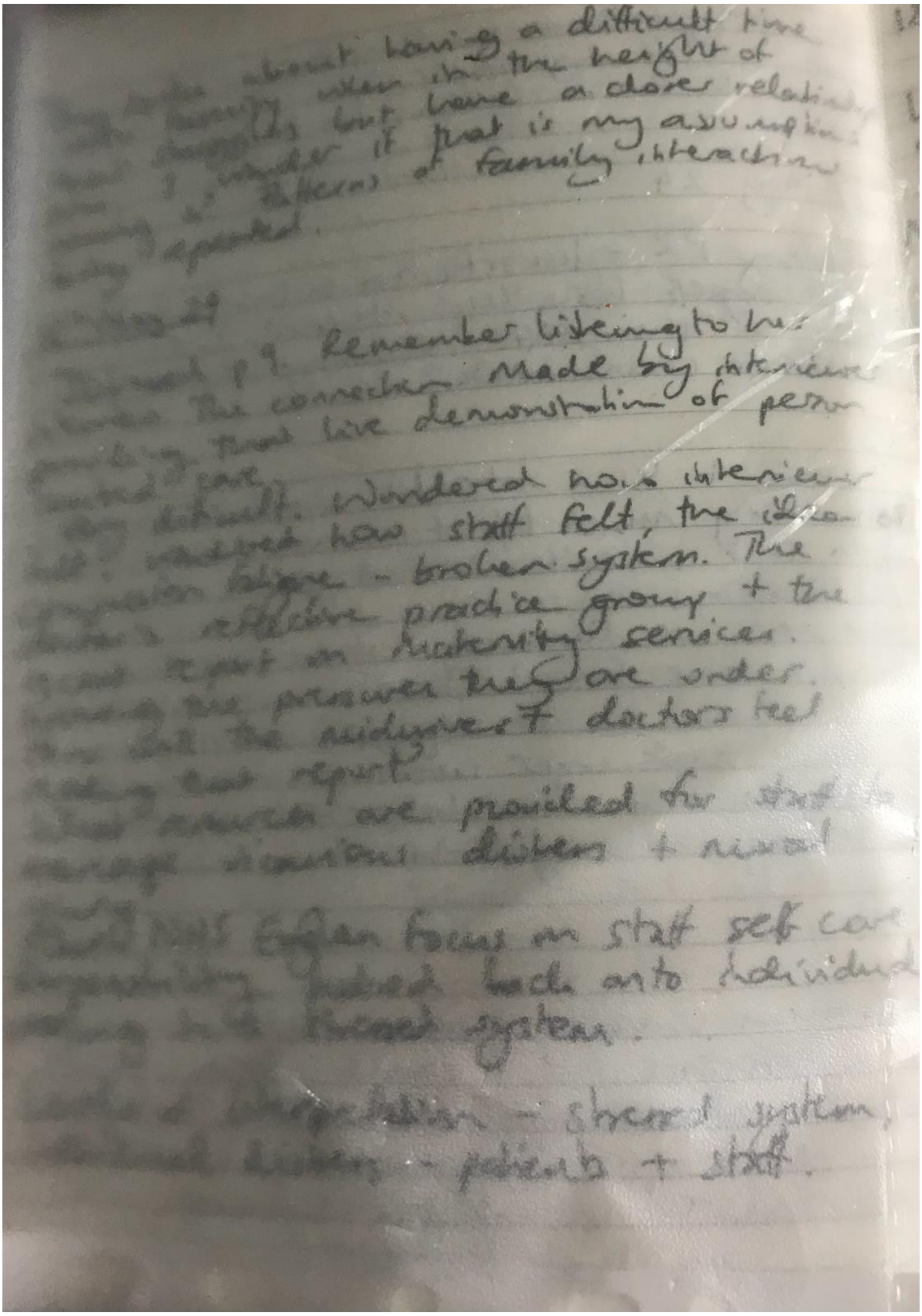
---OVERVIEW OF INTERVIEW FLOW---		
1	**Introduction**	3 MIN
	Objective: To warm-up participants, introduce them to the interview process, and gather initial information about their role. **Interviewer Introduction:**	

	Name of interviewer Introduce the purpose of the study Reassurance on confidentiality and consent to record the conversation. - To start, can you tell me a little bit about yourself? o Probe: Age, Family, Occupation and/or Key responsibilities	
2	**Perception of CMH**	10 MIN
	Objective: To examine the ways people with complex mental health currently describe, understand, and make sense of their problems. **Possible questions:** ⇒ Can you share with me some experiences of your mental health difficulties? Probe: How have you made sense of this or how do you understand this	
3	**Opinions on collaboration**	10 MIN
	Objective: To gather examples from the patient's perspective of constructive working with primary care, particularly in relation to integration with community mental health services. **Possible questions:** ⇒ Thinking about your mental health condition/difficulty, have you sought any form of support for it? If Yes: Where they chose support from and why that place/person was chosen. If No: Why did they decide against it? What is the benefit of this to you? ⇒ Have you had any support from your GP or some other primary care providers? Probe: Was this positive or negative? ⇒ Can you share this experience of poor care or support from your primary care provider with me? ⇒ Have you experienced any transition between primary to secondary care or vice versa? Can you share how this experience was for you with me?	
4	**Opinions on existing & future generations**	10 MIN
	Objective: To understand ways in which people with complex mental health difficulties think of intergenerational mental health issues and how primary care teams should address these. **Possible Questions:** ⇒ How, if at all, do you feel your mental health difficulties has affected your family or the people around you in anyway? If No: How have you managed to separate it/ detach your mental health difficulties and your social life? ⇒ Do you think your mental health difficulties may influence your grandchildren in anyway? If Yes: How do you rationalise it? How does it make you feel? If No: How do you justify it? Probe: Impact on Carers, impact on children, impact on family & friends	

	Thank you for your answers so far- we are nearly at the end of this conversation. Now we would like to look towards the future. **Possible Question:** ⇒ In an ideal world, if there weren't the current issues you stated earlier, what do you think GP's, or your GP could do better for you and people like you. - Probe: Continuity, Time, Wellbeing-checks, Effective collaborations	
5	**Summing-up**	2-3 MIN
	Objective: To summarise and close discussion - Interviewer to summarise and reiterate important points and interesting insights gathered from the discussion. - Any further points to add? - Thank you for your time and for helping us out with our study.	

Appendix C

Reflective Journal Extract



[redacted] about having a difficult time
[redacted] when in the height of
[redacted] but have a closer relati
[redacted] I wonder if that is my assumptions
[redacted] patterns of family interaction
[redacted] operated.

[redacted]
[redacted] p9. Remember listening to her
[redacted] the connection made by interviewee
[redacted] that live demonstration of person
[redacted] care.
[redacted] difficult. Wondered how interviewee
[redacted] how staff felt, the idea of
[redacted] blame - broken system. The
[redacted] reflective practice group + the
[redacted] report on maternity services.
[redacted] the pressures they are under.
[redacted] the midwives + doctors feel
[redacted] report.
[redacted] are provided for staff to
[redacted] distress + moral

[redacted] NHS often focus on staff self care
[redacted] back onto individual
[redacted] system.

[redacted] - shared system,
[redacted] - patients + staff.