Support Systems for People with Developmental Disabilities: Experiences of Grandparents and Psychologists

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List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorders
BPS	British Psychological Society
CASP	Critical Appraisal Skills Programme
CBF	Challenging Behaviour Foundation
CDC	Centre for Disease Control and Prevention
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CP	Clinical Psychologist
DD	Developmental Disabilities
ICT	Information Communication Technology
ID	Intellectual Disability
NHS	National Health Service
NHSE	National Health Service England
NICE	National Institute for Health and Care Excellence
IPA	Interpretative Phenomenological Analysis
UK	United Kingdom
USA	United States of America

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Declaration

This thesis has not been submitted for any other degree or to any other institution and is a record of original work carried out by me. The thesis was conducted under the academic supervision of Dr Magda Marczak (Lecturer in Clinical Psychology/Research Tutor, Coventry University) and Dr Jo Kucharska (Clinical Director, Coventry University). The original idea for this work was my own and followed discussions with the supervisors named above. Data analysis was conducted in discussion with supervisors. The named supervisors also read drafts of the thesis.

Summary

This thesis consists of three parts. Chapter I is a thematic meta-synthesis of 11 qualitative studies of grandparental experience of having a grandchild with a developmental disability (DD). Analysis elucidated three themes: **Adjustment, Blessing and a Curse**, and **Components to Involvement.** Grandparents experienced a period of adjustment following the birth of their grandchild with DD. Grandparenting a child with DD was both rewarding and challenging. A number of factors influenced the level of grandparental involvement. Recommendations are made for promoting grandparental involvement in supporting their families, providing support for grandparents, including access to information about their grandchild's care.

Chapter II is a qualitative empirical study exploring experiences of Clinical Psychologists (CPs) working in Intellectual Disability (ID) settings during the COVID-19 pandemic. Interpretative Phenomenological Analysis (IPA) elicited two superordinate themes. The superordinate theme **Survive or Thrive** highlighted the challenges and successes CPs experienced while working during the pandemic. The superordinate theme of **"Left to their own Devices**" described psychologists' experiences of people with ID as forgotten within society. Psychologists felt abandoned in advocating for their clients. Recommendation include ID services developing robust policies and procedures for remote working; training and supervision for psychologists in the safe and effective delivery of remote interventions; and improved access to mental health support for psychologists.

Chapter III is a reflective paper which encompasses a retrospective look at my research experience to date. Compassion Focussed Therapy's Three Circles Model of Emotion is used as a reflective framework. The account examines challenges encountered in conducting doctoral research in the COVID-19 era.

Total overall word count: 19812 (excluding contents pages, summary and abstracts, tables, figures, footnotes, references, and appendices).

Chapter One: Systematic Literature Review

“A Systematic Review of Grandparents’ Experiences of Having a Grandchild with a Developmental Disability: A Thematic Synthesis”

This chapter was written in preparation for submission to the Journal of Intellectual and Developmental Disability. Appendix A provides details of the author guidelines for this journal.

Overall word count: 8757 (excluding abstract, tables, figures, footnotes and references)

Abstract

Grandparents are an important source of family support for parents of children with Developmental Disability (DD). The appropriate amount of grandparent support may improve parental adjustment and can therefore lead to better quality of care for their grandchildren. Given the increasing life expectancy and its impact on grandparental capacity to support their families, a review of new knowledge in this area is needed.

This meta-synthesis encompassed qualitative research of grandparental experience of a child with DD. A systematic literature search identified 11 studies which were synthesised thematically. Three analytical themes emerged: **Adjustment**, **Blessing and a Curse**, and **Components to Involvement**. **Adjustment** detailed grandparental journey of adaptation following the birth of a child with DD into the family and comprised three themes: *Reactions to Disability*, *Loss* and *Double Burden*. **Blessing and a Curse** analytical theme described grandparenting a child with DD as both rewarding and challenging, and comprised of *Rewards of Grandparenting a Child with DD* and *Challenges of DD*. **Components to Involvement** analytical theme identified a number of facilitators to grandparental involvement in supporting their family and encompassed two themes: *Grandparent-Parent Relationship* and *Social Factors*.

Implications: Grandparents have their own support needs. They require access to information regarding their grandchild’s care. To improve family functioning it may be beneficial for clinicians and educators to promote grandparental involvement in supporting their families.

Key words: grandparent, experience, grandchild, developmental disability.

Introduction

This literature review will synthesise the evidence base of qualitative studies regarding the experiences of grandparents of grandchildren with Developmental Disability (DD). The Centre for Disease Control and Prevention (CDC) defines DD as “a group of conditions due to an impairment in physical, learning, language, or behaviour areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime” (CDC, 2020, para. 1). Some examples of more common developmental disabilities include: Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorders (ASD), Cerebral Palsy and Intellectual Disabilities. Children and young people with developmental conditions, may experience a number of impairments and co-morbidities which, in conjunction with restrictions and barriers to participation, result in complex medical, educational and social support needs (Blackburn et al., 2012). Grandparents are defined, within this review, as the father or mother of a person's father or mother, as per Cambridge Dictionary (n.d.).

Caring for a child with DD can be both a rewarding and a challenging experience that has profound effects on the family. Often one or more family members (usually parents) adopt the role of a ‘carer’ (Kenny & McGilloway, 2007). Parenting a child with DD can be stressful. Parents may experience stress due to the increased caregiving demands such as assisting their child with activities of daily living and co-ordinating their care, accessing specialty education, medical and social care agencies. Stress can be compounded by co-occurring behavioural problems and comorbid health conditions (McIntyre, 2016), and parents leaving employment or reducing their work hours due to the demands, often resulting in financial hardships (Buckner & Yeandle, 2017). Moreover, parents can experience family conflict regarding the child’s impairments, further financial strains due to costly care services and a restriction of their social and recreational activities due to increased care demands (Pearlin et al., 1990). This elevated stress tends to be chronic and persists over long periods of time (Dyson, 1993; Glidden & Schoolcraft, 2003). Furthermore, mothers of children with DD are at an increased risk of poor mental health (Gallagher & Hannigan, 2014; Law & Howie, 2012; Singer, 2006). Social support has been found to help mitigate some of the negative effects of caregiving stress (Weiss, 2002). Such support consists of informal support from family and friends and formal supports provided by professionals. Literature suggests that parents of children with DD tend to have smaller support networks (Kazak & Marvin, 1984). Conversely, large support networks have been found to buffer parental stress (Meppelder et al., 2015). Parents report receiving more help from their family than from friends (Cuzzocrea et al., 2016).

Grandparents of children without disabilities often provide both practical and emotional support for their children's families. The appropriate amount of grandparent support may improve parental adjustment and can therefore lead to better quality of care for their grandchildren (Lavers & Sonuga-Barke, 1997). Grandparents have a variety of established roles such as providing childcare, acting as playmates, and/or providing financial support for their immediate family. In the cases where their grandchild has a disability, roles of grandparents can change drastically, and they may become critical supports in these families. Grandparents can take on additional roles such as emotional support, caregiving to offer respite care and support their children's work related activity, transportation, support with medical appointments and challenging behaviour of the grandchild, and help with household chores (Harris et al., 1985; Hornby & Ashworth, 1994). Furthermore, grandparents can advocate on behalf of the grandchild (Margetts et al., 2006), and with training can provide therapeutic support (Hillman, 2006). Grandparents are an important source of family support for parents of children with DD (Trute et al., 2008) and have been highly ranked in comparison with other support providers (Findler, 2000). Furthermore, grandparent support has been shown to help parents to cope with the demands of a child with DD (Hastings 1997), improve parent psychological adjustment and parental stress (Hastings et al., 2002b; Trute, 2003); thus grandparents are seen as important sources of psychological support for parents of children with DD. Moreover, the prolonged life expectancy and higher quality of medical care means that many grandparents get to experience their grandparental role for much longer (Lee & Gardener, 2010). Despite the many benefits of grandparenting, grandparents report not receiving enough information about the grandchild's disability and are keen to be actively involved in their grandchildren's lives (Katz & Kessel, 2009). However, grandparents are infrequently involved by professionals working with families (Findler & Ben-Ari, 2003). Moreover, grandparents themselves report receiving insufficient systemic support from paediatricians, schools and are dissatisfied with disparity of service availability in different locations (Hillman et al., 2017; Hillman & Anderson, 2019).

Evaluation of Previous Reviews

Hastings (1997) conducted a review of both the qualitative and quantitative literature of grandparents' roles and experiences in relation to their grandchild with disabilities. They found that grandparents report increased involvement in their families, offering both emotional and practical support such as help with domestic chores, providing respite, financial support, help in the education and therapy of grandchildren, among other supports. However, grandparents may be an additional burden to families, particularly because “parents may find it difficult to deal with grandparents' immediate and longer-term emotional responses to their grandchild's disability” (Hastings, 1997, p. 329). This indicates that understanding experiences of grandparents may be helpful to ascertain their involvement and needs when providing support to their families.

Lee and Gardner (2010) synthesised both theoretical and empirical literature, including past reviews on grandparents' involvement and support in families with children with disabilities. They found that grandparents’ initial reactions of learning of the grandchild’s disability were similar to parents’ reactions and that over time, grandparents became more involved in their grandchild’s family system, providing practical and emotional support. Factors that influenced grandparents’ involvement in their grandchild’s care included residential proximity, their understanding of the grandchild’s disability, and the quality of their relationship with their adult child. Additionally, grandparental support was promoted with access to accurate information about disability and access to support groups. Of the included papers 68% were published prior to year 2000. Therefore, there has been no review of more recent research.

Griffiths and Hastings (2015) conducted a meta-synthesis of qualitative research on the experience of caregivers of individuals with intellectual disabilities and challenging behaviour. The authors reviewed 17 studies from Canada, Norway, UK and the USA. They identified five themes: love: as altered identity, crisis management, support is not just ‘challenging behaviour’ services, and the future of low expectations and high hopes. They concluded that caregivers spoke of deep love for their family member and of the chronic strain the demands of caregiving placed upon them. Moreover, support services often caused additional problems and high levels of stress for caregivers, although there were also reports of good practice. The authors noted that the reviewed studies lacked coherent demographic data and therefore it was difficult to draw any conclusions on how caregiving responsibilities may have differed for different family members (Griffiths & Hastings, 2015).

Rationale and Aims of Current Review

The reviews cited above highlight three issues. Firstly, grandparents can play a pivotal role in offering support to their families with a child with DD and as such understating their experiences and ascertaining their needs can help develop effective support strategies to nurture this support. Given the increasing life expectancy and its impact on grandparental capacity to support their families, a review of new knowledge in this area is needed especially, as the last review was published 10 years ago. Therefore, there may be an existing body of research that has yet to be reviewed. Secondly, no review utilising a systematic methodology of grandparents' experiences has been conducted and as such we cannot be confident of the quality of synthesised studies and the reliability of findings from previous reviews. Thirdly, there are currently no reviews of qualitative studies of grandparents' experiences of grandparenting a child with a DD, despite considerable evidence of increased stress, poorer mental health among caregivers of children with DD and the positive impact of grandparental support on parental adjustment.

Thus, understanding grandparents' experiences of having a grandchild with a DD is important to ascertain the needs of grandparents and to develop effective strategies to ensure they can provide optimum support to their families. "Qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (Denzin & Lincoln, 2011, p. 3). As such, synthesising qualitative and mixed method studies, where qualitative data can be extracted will allow to critically appraise the strengths and weaknesses in this area of research, and for the discovery of new insights, which would not be possible through a quantitative study. Therefore, the current review aimed to overcome the highlighted gaps in the literature by synthesising grandparents' views and experiences of grandparenting a child with a DD. This review addressed the following question: "What are grandparents' experiences of having a grandchild with a DD?"

Methods

Systematic Literature Search

Ethical approval was obtained from Coventry University Ethics Committee on 14th of December 2020 (project code P116049, Appendix B). A systematic search of qualitative and mixed method studies, where qualitative data can be extracted, on grandparents' experiences of grandchildren with a DD was carried out between December 2020 and February 2021. To ensure sufficient breadth and depth of literature review, Medical, Nursing and Psychology subject disciplines were reviewed. As such five databases were chosen to search for studies: Cumulative Index of Nursing and Allied Health Literature (CINAHL Complete), Medical Literature Analysis and Retrieval System Online (MEDLINE), PsychINFO, Scopus and Web of Science. The reference lists of extracted articles were manually searched to identify additional relevant articles. Additionally, Google Scholar was searched, due to the highlighted difficulties in searching for qualitative literature using bibliographic databases (Shaw et al., 2004).

Three main concepts used for the search purpose of grandparent, experience and disability, together with their synonyms, which served as key search terms, are shown in Table 1.

Table 1.

Key Search Terms, Synonyms, and Location of Search Within Article

Main Concept	**Synonyms**	**Location**
Grandparent	"grandfather" OR "grandmother"	Title Abstract
Experience	"view" OR "opinion" OR "attitude" OR "perception" OR "perspective" OR "belief"	Title Abstract
Disability	"autism" OR "Asperger" OR "Down" OR "mental retardation" OR "special needs"	Title Abstract

Boolean operators and wild card truncation (as denoted by '*') were used in the search: grandparent OR grandfather OR grandmother AND Experience* OR view* OR opinion* OR attitude* OR percept* OR perspective OR belie* AND Disabil* OR autis* OR Asperger OR Down OR mental retardation OR special needs.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were identified using SPIDER (sample, phenomenon of interest, design, evaluation, research type) model, designed to structure qualitative research questions (Cooke, Smith & Booth, 2012). The inclusion and exclusion criteria for this systematic review are shown in Table 2.

Table 2.

Inclusion and Exclusion Criteria Using SPIDER Model.

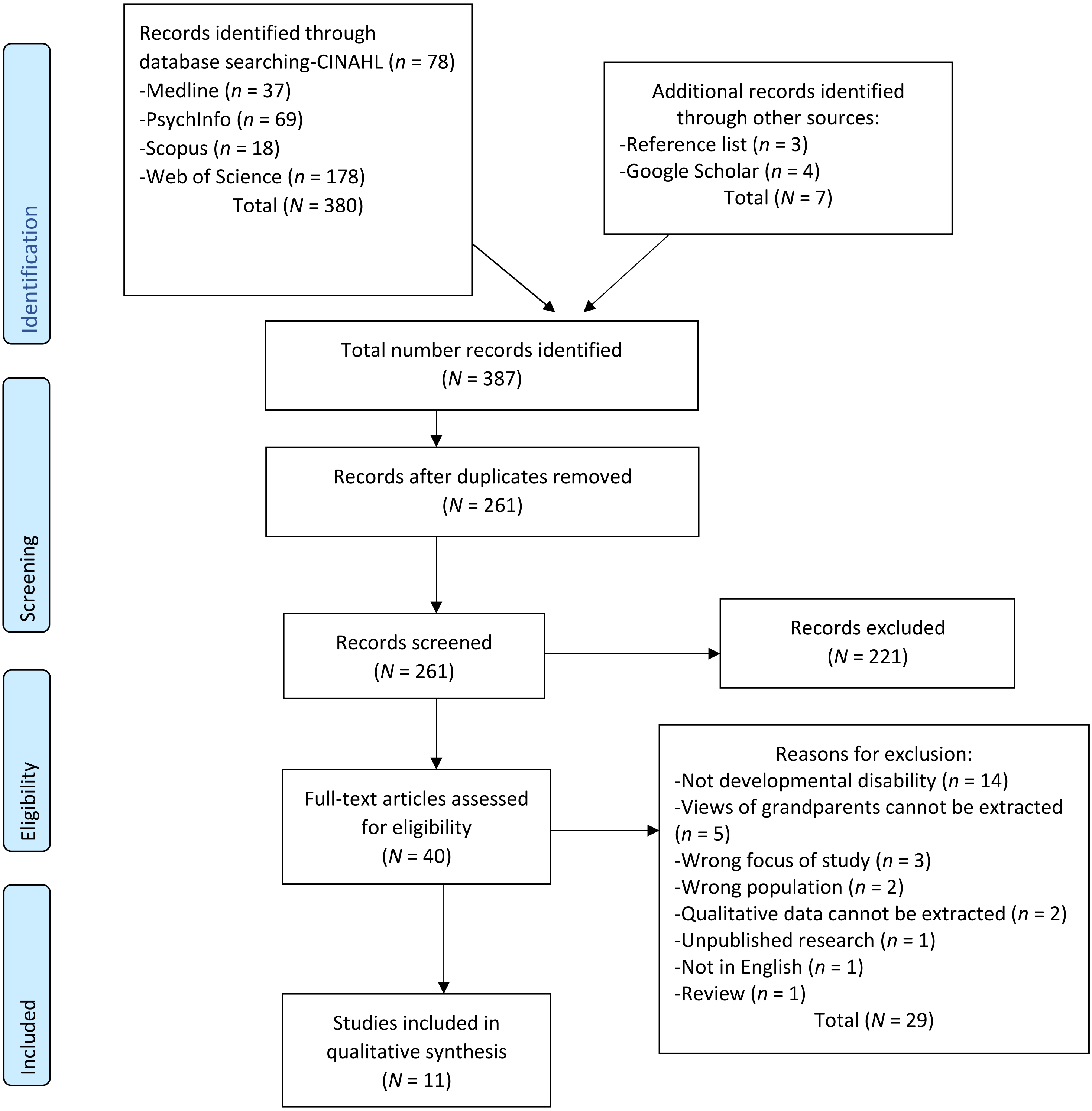
SPIDER Model	**Inclusion criteria**	**Exclusion criteria**
Sample	Grandparent	Other familial relationships
Phenomenon of Interest	Grandchild	Other familial relationships
	Developmental disability	Other types of disability
Design	Qualitative and mixed methods providing qualitative data can be extracted	Quantitative research and mixed methods if qualitative data cannot be extracted
Evaluation	Experiences or perceptions or attitudes or views or feelings	Intervention evaluation
Research type	Empirical, peer reviewed	Non-empirical, non-peer reviewed

Classification of Studies

Articles were screened and retained if they were in English, reported views of grandparents, and described experiences of having grandchild(ren) with DD. In addition, studies were included if they were peer-reviewed and used qualitative or mixed-method designs from which qualitative data could be extracted. The study selection process is documented on a 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' (PRISMA; Moher et al., 2009) flow diagram shown in Figure 1.

Figure 1.

PRISMA Flow Diagram (adapted from Moher et al., 2009)



Database searches identified 380 articles, seven more were found through searching Google Scholar and reference lists, totalling 387 papers. After duplicates were removed, 261 articles remained. Following the initial screening criteria 221 papers were excluded. The remaining 40 articles were screened against the inclusion and exclusion criteria, of these 29 were excluded. Majority of articles were excluded because samples consisted of grandchildren with disabilities other than DD (Figure 1). The initial screening of titles and abstracts, and assessment of full text articles against the eligibility criteria was conducted independently by another reviewer. Any differences were discussed to achieve consensus of paper selection. A total of 11 articles satisfied the inclusion/exclusion criteria.

Quality Assessment Checks

The internal validity of a systematic review relies both on the quality of included studies and the reliability of their findings. As such, the need to critically appraise the quality and reliability of qualitative research has been widely accepted, although strongly debated (Centre for Reviews and Dissemination, 2009). There appears to be no consensus about what constitutes 'quality' within qualitative research. However, Reynolds et al. (2011) review of quality assurance in qualitative research highlighted two main approaches to quality assurance: the output oriented approach, which conceptualised quality in terms of validity and rigor with use of quality checklists, and the process-orientated approach, concerned with principles and values inherent in qualitative research such as on-going self-reflection.

Given the importance of critical appraisal of qualitative papers for systematic reviews and the above findings the Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist (2018) was utilised to assess quality of selected studies for this review. This tool aims to establish validity and usefulness of studies whilst also considering processes inherent in qualitative research. The CASP is a screening measure and consists of 10 questions establishing whether a particular criterion has been met. As no formal scoring criteria for the CASP exist, the reviewer established a scoring system where studies were awarded a score of 2 if they fully satisfied the criteria; a score of 1 if the criteria was partially met/could not tell; and a score of 0 if the criterion was not met. Due to the CASP comprising ten criteria, scores range from 0-20 with higher scores indicating better quality of studies. Quality assessment ratings ranged from 12 (60%) – 20 (100%). No studies were excluded from the review based on quality ratings as research suggest that findings of studies rated as low quality and those of higher quality are not contradictory (Thomas et al., 2004; Noyes & Popay, 2007).

To improve reliability of quality assessment, all included studies were screened by an independent rater, using the CASP. Scores from both raters fell into the same range. Any significant differences in scoring of each paper were reviewed by both raters in order to reach agreement. For the current review raters disagreed on two criteria by one point difference: whether the data collection addressed the research question (Maul & Singer, 2009; Prendeville & Kinsella, 2019); the clarity of findings (Gallagher et al., 2010). Inter-rater reliability analysis was conducted; Kappa coefficients ranged from κ = 0.47-1.0 and an overall inter-rater reliability of κ = 0.93[1]. Please see Appendix C for quality assessment ratings (Table C1), and results of inter-rater reliability analysis (Table C2).

Characteristics of the Literature

The selected papers represent a global sample of predominantly Western countries with five studies conducted in the USA (D'Astous et al., 2013; Gallagher et al., 2010; Hillman & Anderson, 2019; Hillman et al., 2017; Maul & Singer, 2009), with one from each of the following countries Canada (Boyd & Goodwin, 2019), Taiwan (Huang, et al., 2020), Israel (Katz & Kessel, 2002), Australia (Miller et al., 2012), UK (Margetts et al., 2006), and Ireland (Prendeville & Kinsella, 2019). The papers were published between 2006 and 2020.

The focus of studies varied with four studies reporting grandparents' experience of a grandchild with a DD, in general (Hillman & Anderson, 2019; Hillman et al., 2017; Huang et al., 2020; Miller et al., 2012). Miller et al. (2012) investigated the impact of disability on family relationships and quality of life. Three papers explored grandparental involvement in families with a child with DD (D'Astous, et al., 2013; Katz & Kessel, 2002; Prendeville & Kinsella, 2019). The remaining papers explored family experiences of dignity in public leisure settings (Boyd & Goodwin, 2019), the concerns and needs of custodial grandparents

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[1] Kappa results can be interpreted as follows: values ≤ 0 as indicating no agreement and 0.01–0.20 as none to slight, 0.21–0.40 as fair, 0.41– 0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1.00 as almost perfect agreement (McHugh, 2012).

(Gallagher et al., 2010) and the adaptations families make for children with DD and family perceptions of professional support (Maul & Singer, 2009).

All studies utilised qualitative methodology. Purposive sampling was most commonly used (Boyd & Goodwin, 2019; Hillman & Anderson, 2019; Hillman et al., 2017; Huang, et al., 2020; Katz & Kessel, 2002; Margetts et al., 2006; Maul & Singer, 2009; Miller et al., 2012), followed by convenience sampling (D'Astous et al., 2013; Gallagher et al., 2010), and snowball sampling (Prendeville & Kinsella, 2019). The sample sizes ranged from four (Boyd & Goodwin, 2019) to 1870 (Hillman et al., 2017) participants. With the exception of three studies utilising surveys (Hillman & Anderson, 2019; Hillman et al., 2017; Gallagher et al., 2010) the remaining studies used semi-structured interviews to collect data. A range of different approaches were used to analyse findings. Most frequently a thematic approach was utilised (Boyd & Goodwin, 2019; D'Astous et al., 2013; Margetts et al., 2006; Miller et al., 2012; Prendeville & Kinsella, 2019). Hillman and Anderson (2019), Hillman et al. (2017) and Maul and Singer (2009) analysed their data using grounded theory methodology.

Predominantly, participants consisted of grandparents with the exception of three studies which reported views of other family members in addition to grandparents[2] (Boyd & Goodwin, 2019; Maul & Singer, 2009; Prendeville & Kinsella, 2019). Views of grandmothers were over-represented with eight studies reporting mostly grandmothers' views (D'Astous, et al., 2013; Gallagher et al.,2010; Hillman & Anderson, 2019; Hillman et al., 2017; Katz & Kessel, 2002; Margetts et al., 2006; Miller et al., 2012; Prendeville & Kinsella, 2019) and one study focusing only on grandmothers (Huang, et al., 2020). Majority of participants, where race or ethnicity was reported, were Caucasian (D'Astous, et al., 2013; Hillman & Anderson, 2019; Hillman et al., 2017; Maul & Singer, 2009; Miller et al., 2012). The key characteristics of included studies are shown in Table 3.

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[2] These papers were included because grandparental views could be extracted as direct quotes.

Table 3.

Key Characteristics of the Literature

Author, Date, and Country **Quality assessment Rating (QR) & Inter-rater reliability (Kappa)**	**Study Aims**	**Research Design** **Sampling Method**	**Sample Characteristics (where stated)**	**Method of data collection** **Method of data analysis**	**Key findings**
Boyd & Goodwin 2019 Canada QR = 95% $\kappa = 0.474$	To understand how a young family with an autistic child experiences dignity as they engage in community-based family leisure.	Qualitative, instrumental case study Purposeful The first author had an established relationship with the family as a support worker, which led to invitation to participate in the study.	*N*= 4 Mother *n* = 1 (25%) Father *n* = 1 (25%) Grandmother *n* = 1 (25%) Great-grandmother *n* = 1 (25%) *Age range* 29-82 years	Semi-structured, conversational interviews and field notes Thematic analysis (Smith, Flowers, and Larkin, 2009).	Four themes were identified: 1)*'Living under a microscope'* referred to the family's experiences of community-based family leisure as being fraught with feelings of being under the public gaze, being singled out, and judged; 2) *'Screw your microscope, we're going anyway'* described how, over time, the parents developed a commitment to overcome the stares and judgment of others and engage unfettered in leisure settings as a family; 3) *'Emerging stories of belonging'* described how the parents' dignity was restored when they experienced a sense of belonging due to others' shared time, respect for their son, and engagement in social interactions with the family;

					4) *'Retreating, feeling overlooked, and lamenting the future'* talked about the son's communication with strangers replacing Mom and Dad's sense of dignity by experiences of their son being overlooked, ignored, and dismissed by people.
D'Astous, Wright, Wright & Diener 2013 USA QR = 65% κ = 1	To discover the range of engagement within the matrix of intergenerational relationships in families with a child with an ASD.	Qualitative Convenience Grandparents of grandchildren with ASDs, attending a computer workshops at the university were invited to participate in the study.	*N* = 14 Grandmothers *n* = 8 (57%) Grandfathers *n* = 6 (43%) *Marital status* Grandmother's widowed *n* = 3 (21%) Grandparents married *n* = 11 (79%) *Lineage* Maternal grandparents *n* = 7 (50%) Paternal grandparents *n* = 7 (50%) *Employment* Retired *n* = 13 (93%) Employed full time *n* = 1 (7%) *Age range* 56-81 years *Ethnicity* Caucasian *n* = 14 (100%)	Semi-structured interviews Framework analysis (Calzada, Pistrang & Mandy, 2012)	Three main findings include: 1) Social factors such as lineage, proximity, age, health status appeared to influence a grandparent's involvement with a grandchild with an ASD. 2) Factors that influence more engagement: positive communication; appreciation; inclusion; and good understanding of the disability. 3) Factors that influenced less engagement: poor communication; intergenerational tension; including criticism; feelings of exclusion; and lack of understanding of the disability.

Gallagher, Kresak & Rhodes 2010 USA QR = 80% κ = 1	To systematically determine the concerns and needs of custodial grandmothers raising grandchildren with disabilities.	Qualitative Convenience Recruitment during Project GRANDD (Grandparents Raising and Nurturing Dependents With Disabilities) monthly meetings; recruited from two urban hospital medical clinics serving young children with special needs and other Kinship Care programs.	*N* = 20 Grandmothers *n* = 18 (90%) Great-grandmothers *n* = 2 (10%) *Age* 30-40 1(5%) 41-50 4 (20%) 51-60 8 (40%) 61+ 7 (35%) *Ethnicity* African-American *n* = 15 (75%) Caucasian *n* = 5 (25%)	Survey Content analysis (not explicitly stated, Johnson & LaMontagne, 1993; Marchant, 1995).	Four main findings include: 1) Almost all the grandmothers reported they were involved in the planning or implementation of the grandchild's Individualized Education Program. 2) Grandmothers responded that they needed information or help with behaviour issues such as aggression or skill development in areas such as communication. 3) Grandmothers also talked about how hard and challenging it is to raise a child with disabilities. 4) Several grandmothers noted that once they understood what to do, things got easier, and that they had seen improvement for the child. 5) Several also mentioned their joy in raising the grandchild and hope that they were doing the right thing.
Hillman & Anderson 2019 USA QR = 80%	To examine the first-person perspective of custodial grandparents of children with ASD, including their sources of both stress and	Qualitative Purposive (not explicitly stated) Participants recruited via Grandparent	*N* = 117 Grandmothers *n* = 108 (92%) Grandfathers *n* = 9 (8%) *Lineage* Maternal *n* = 83 (71%) Paternal *n* = 34 (29%) *Age*	Survey Grounded theory approach (Strauss & Corbin, 2008)	Four categories of experience and 15 underlying themes were identified: 1) **Issues with adult children** encompassed their challenges and concerns related to one or both of their grandchild's parents and consisted of 3 themes: *Origins of custodial care, Legal issues and Conflict during visitation.*

$\kappa = 1$	joy.	Autism Network, Autism Speaks, the American Association of Retired Persons and IAN research.	44 and younger 5 (3%) 45-54 39 (33%) 55-64 54 (46%) 65-74 18 (15%) 75-84 0 (0%) 85 and older 1 (0.8%) *Race* White $n = 100$ (86%) Black or African-American $n = 8$ (7%) American Indian or Native Alaskan $n = 4$ (3%) Asian $n = 2$ (1%) *Ethnicity* Latino $n = 7$ (6%) Non-Latino $n = 116$ (94%)		2) **Caregiver burden** captured the overwhelming challenges associated with serving as the primary caregiver and consisted of 5 themes: *ASD behaviour problems*, *Insufficient ASD services*, *Finances, 24/7 demands* and *Fear for the future* 3) **Coping** described grandparents coping and consisted of 4 themes: *Celebration of progress*, *Unconditional love*, *Faith/moral imperative*, *Focus on the positive* 4) **Wisdom** represented the integration of grandparents' first-hand knowledge and experience from caring for a child with ASD and consisted of 3 themes: *Personal growth*, *Connection with village*, and *Insight for others*.
Hillman, Wentzel & Anderson 2017 USA QR = 80% $\kappa = 1$	To fill a gap in the literature regarding the unique experience of traditional (i.e., non-custodial) grandparents of children with ASD from the first-person perspective,	Qualitative Purposive (not explicitly stated) Participants recruited via IAN Research, Autism Speaks, the Grandparent Autism Network, and the American Association of Retired Persons.	$N= 1870$ Grandmothers $n = 1533$ (82%) Grandfathers $n = 337$ (18%) *Lineage* Maternal $n = 1178$ (63%) Paternal $n = 692$ (37%) *Age* Less than age 65 $n = 1047$ (56%) Age 65 and older $n = 823$ (44%)	Survey Grounded theory approach (Strauss & Corbin, 2008)	Four overarching categories were identified: 1) **Desire for Connection** which described a basic desire to connect with their grandchild and included 4 individual themes that included *positive*, *negative*, and *mixed emotional states*; 2) **Barriers to Care** described obstacles to their ASD grandchild's care, with 3 underlying themes: *Family Denial of the Diagnosis*, *Instrumental concerns such as living far away and financial burdens* and *Insufficient systematic support*;

	including both positive and negative aspects of grandparenting.		*Race* White n = 1795 (97%) Black n = 37 (2%) American Indian or native Alaskan n = 19 (1%) *Ethnicity* Latino n = 75 (4%) Non-Latino n = 1795 (96%)		3) **Celebration of Progress** included 3 themes: *Recognising progress, no matter how small*, *Recognising Effort of Both Grandchild and Adult Child*, and *Achieving developmental milestones*; 4) **Personal Reactions** represented grandparents' individual responses to their grandchild's ASD, which included 4 distinct themes: *Worry for the Entire Family*, *Despair*, including feelings of hopelessness and helplessness, *Juxtaposition of Extreme Highs and Lows*, in which grandparents attempted to integrate both extremely negative and positive views of ASD and *Resilience* which described the unconditional acceptance of a grandchild with ASD and advocacy for the grandchild).
Huang, Wang, Kellett & Chen 2020 Taiwan QR = 100% κ = 1	To explore the experiences of grandmothers in Taiwan caring for a grandchild with a developmental delay or disability.	Qualitative Purposive Participants were recruited from a medical teaching hospital in central Taiwan.	N = 25 Grandmothers n = 25 (100%) *Lineage* Paternal n = 12 (48%) Maternal n = 13 (52%) *Mean age* 62.68 years *Employment* Retired/homemakers n = 24 (96%)	Semi-structured interview Method of Colaizzi (1978)	Four themes were identified: 1) *Feeling shame upon learning of their grandchild's disability* theme described the grandmothers felt suffering and pain when they realized their grandchild's physical disability, appearance, or language impairment drew attention to being different from other children and threatened their self-identity and self-image and they felt shame; 2) *Building a protective shield for the parent* theme described how grandmothers established a shield by passing on their values and providing support to protect the parent from the feelings of shame and

					suffering and also different support grandmothers provided to the family to maintain functioning and wellbeing; 3) *Worrying about a loss of status in society* theme described concerns that there was no place for their grandchild in the family, the Taiwanese community, or society and worries about the prosperity of the familial kinship; 4) *Believing in the importance of family* theme described how grandparents sought out and maintained positive thinking about their grandparental role and their reflections on their position and limitations as a grandparent.
Katz & Kessel 2002 Israel QR = 60% $\kappa = 1$	To investigate the attitudes of the grandparents toward children with disabilities in general, their perceptions of the impact of their grandchild's developmental disability upon them, and the degree of involvement in his/her care.	Qualitative Purposive (not explicitly stated) Parents of children with disabilities enrolled in programs in the special school were approached to gain permission to interview the grandparents.	$N = 16$ Grandmothers $n = 9$ (56%) Grandfathers $n = 7$ (44%) ($n = 7$ married couples (88%) and $n = 2$ grandmothers (12%) *Lineage* Paternal $n = 12$ (75%) Maternal $n = 4$ (25%) *Age range* 69-78 years	Semi-structured interview	Four categories were identified: 1) *Attitudes and perceptions* described grandparents' positive attitudes and acceptance of the grandchild and their more negative attitudes towards children with disabilities, in general. 2) *Grandparent Involvement* consisted of emotional support, instrumental support, medical care, participating in decision making, and providing financial aid. 3) *Satisfaction with involvement* was a function of grandparents' attitudes towards disabilities in children, their relationship with their adult children and their own life experiences. 4) *Relationship between grandfather and grandmother* demonstrated that

	To investigate the impact of the child's developmental disabilities on the relationship between the grandfather and grandmother and their satisfaction with their role as caregivers.				involvement with their grandchild with developmental disability served to strengthen the relationship between the grandparents and initial and negative feelings about grandchild over time shifted to more positive feelings.
Margetts, Le Couteur & Croom 2006 UK QR = 90% κ = 1	To understand the grandparents' experience for children referred to the second opinion service Pervasive Developmental Disorders (PDD).	Qualitative Purposive Families known to PDD Team were approached to participate.	*N* = 6 Grandmothers *n* = 5 (83%) Grandfather *n* = 1 (17%) (*n* = 1 married couple, interviewed separately) *Lineage* Maternal *n* = 3 (50%) Paternal *n* = 3 (50%) *Age range* 52-74 years	Semi-structured interview Inductive thematic approach (Thomas, 2003)	Three themes were identified: 1) *The Parental Bond* described the protective bonding towards grandchild and adult child; 2) *Striving for Answers* described grandparents' search for meaning by navigating the extent of their input, understanding their grandchild's disability and wanting to find a cause of it; 3) *Keeping Intact* theme described the grandparents' attempts to hold the family together and relinquishing responsibility to their children as their grandchild developed.
Maul & Singer 2009	To determine what specific accommodations families make	Qualitative Purposive	*N* = 17 Parents *n* = 15 (88%) Grandparents *n* = 2 (12%)	Interview Grounded theory	Five themes were identified: 1) *"Just Good Different Things": Lost Opportunities Replaced by New Opportunities* theme described the loss of

USA QR = 80% κ = .706	for their children with DD How families decide on those accommodations The extent to which family members felt that professionals had assisted them in making adaptations to their daily routines.	Participants chosen originally as a comparison group for a larger study. Families who attended or were on a waiting list for speech and language at a clinic at California State University, Fresno, were approached.	*Sex* Female n = 10 (59%) Male n = 7 (41%) *Marital status* Married n = 16 (94%) Divorced n = 1 (6%) *Age range* 31-59 years *Ethnicity* White n = 8 (46.5%) Chinese American n = 3 (18.5%) American Indian n = 1 (5.5%) Pacific Islander n = 1 (5.5%) Latino n = 3 (18.5%) Ukrainian n = 1 (5.5%)	(Charmaz, 1983; Glaser & Strauss, 1970; Strauss & Corbin, 1998).	activities or life plans for grandparents and new opportunities for experiences that were satisfying 2) *“Doing the Tag Team Thing”: The Family as a Team* theme described accommodations for their children with disability that depended on close cooperation among family members; 3) *How Families Adapt Time to accommodate Children With DD* referred to how families adjusted the timings of their daily lives to accommodate needs of children with disability; 4) ‘The Idiosyncratic Nature of Families’ Accommodations’ theme described family-specific adaptations; 5) *“That Can Come Up With Any Child”: Resisting Stigma, Insisting on Normalcy* theme described how parents rejected stigmatisation of their children’s disability and insisted on normalcy.
Miller Buys & Woodbridge 2012 Australia QR = 95% κ =1	To explore grandparents’ experiences of caring for a child with a disability and the impact on their family relationships and quality of life.	Qualitative Purposive Advertisements placed in the newsletters of Council on the Ageing and National Seniors.	N = 22 Grandmothers n = 17 (77%) Grandfathers n = 5 (23%) *Age range* 55-75 years *Employment* Retired n = 19 (86%) Employed n = 3 (14%)	Semi-structured interview Thematic approach (Brantlinger et al. 2005; Liamputtong & Ezzy 2005).	Four themes were identified: 1) *Holding their emotions* theme described the grandparents’ feelings of anger, disbelief and fear and having to be strong for their children, choosing to respond to issues instead of dwelling on own emotions; 2) *Self-sacrifice - putting family needs first* theme described the sacrifices, such as putting plans on hold and reducing their working hours to support the family;

			Origin Anglo-Saxon *n* = 22 (100%)		3) *Maintaining family relationships - being the 'go-between'* theme described grandparents acting as an interface between their grandchild with disability and other family members, sources of conflict and meeting the needs of other grandchildren in the family; 4) *Life for family in the future* theme describe grandparents concerns about the functioning of the family in the future given their declining health and physical ability.
Prendeville & Kinsella 2019 Ireland QR = 90% κ = .630	To explore how grandparents support children with autism and their parents using a family systems perspective.	Qualitative Snowball Participants recruited from inclusive primary schools that had satellite classes for children with autism, and from specialist schools for children with autism and ID.	*N*=24 Mothers *n* = 9 (38%) Fathers *n* = 3 (12%) Grandmothers *n* = 7 (30%) Grandfathers *n* = 5 (20%) (consisting of input from nine families) *Sex* Female *n* = 17 (71%) Male *n* = 5 (29%) *Age range* 35-84 years *Marital status* Married *n* = 19 (79%) Divorced *n* = 2 (8.5%) Widowed *n* = 2 (8.5%) Co-habiting *n* = 1 (4%)	Semi-structured interview Thematic analysis (Braun & Clarke, 2006).	Eight themes were identified: 1) *Family recalibrating* which described the changes to grandparent and parent roles; 2) *Limiting life* theme described the limitations placed on family life due to having a child with ASD; 3) *Impact on family* theme described the impact of a child with ASD on grandparents, experiences of families being brought together and experience of mental health issues; 4) *Strengthening the family system* theme described the role of grandparents in strengthening the family system; 5) *The active role of grandparents* referred to the active roles of grandparents, such as providing respite; 6) *Calming role of Grandfather* referred to grandfathers calming influence on the family and acting as a father figure in instances of marital breakup;

					7) *Current needs and future concerns of grandparents* described the need for grandparents’ roles to be acknowledged by professionals and the concerns of meeting the needs of the family when grandparents will be no longer able to offer support; 8) *Needs of grandparents* theme referred to professionals asking parents if they wished for grandparents to be involved, to offer education to grandparents to facilitate their support of grandchild.

Analytic Review Strategy

Data was analysed using a narrative approach, specifically thematic synthesis. Thematic synthesis has been developed for the purpose of secondary data synthesis of 'thematic analysis' and provides a set of established methods and techniques for the identification and development of analytic themes in primary research data (Thomas & Harden, 2008). Thematic synthesis was selected for the purposes of this review for two reasons. Firstly, it is well suited to the objective of aggregating existing evidence and identifying patterns within data. Secondly, thematic synthesis offers good transparency and accessible outcomes.

The process of thematic synthesis described by Thomas and Harden (2008) was utilised to guide data analysis. This process involves three stages of analysis. Firstly, the findings of primary studies were free coded line by line (Appendix D) whereby the meaning and context was examined and assigned a code. Secondly, the 'free codes' were then organised into related areas to construct 'descriptive' themes (Appendix E). The last stage involved the development of 'analytical' themes which 'go beyond' the content of original studies to give rise to higher order constructs and new interpretations. This process culminated in a meta-synthesis of grandparental experiences of grandparenting a child with DD, whereby themes are evidenced by excerpts from the literature.

Results

The meta-synthesis provided insights into grandparental experiences of having a grandchild with DD, which was nuanced. From the literature three analytical themes emerged: Adjustment, Blessing and a Curse, and Components to Involvement (supported by excerpts in Appendix F). Contribution of papers to themes are evidenced in Appendix G. Table 4. contains analytical themes, themes and subthemes.

Table 4.

Analytical themes, Themes and Subthemes

Analytical themes	Themes	Subthemes
Adjustment	Reactions to Disability	Emotional Response
		Coping
	Loss	Plans Change
		Parent - Grandparent Role Blurring
	Double Burden	Responsibility to Support Family
Blessing and a Curse	Rewards of DD	Personal Growth
		Brings Family Closer Together
	Challenges of DD	Difficulty Making a Connection with Grandchild
		Challenging Behaviour
		Grandparent Support Needs
Components to Involvement	Grandparent - Parent Relationship	Parenting Style Conflicts
		Lineage
		Birth Order
	Social Factors	Age and Health
		Distance

Adjustment

This analytical theme illuminates the grandparental journey of adaptation following the birth of a child with DD into the family. Finding out about their grandchild's disability was often deeply upsetting and was followed by a complex process of coming to terms with this news. Grandparents' retirement plans were thwarted by the substantial demands of supporting their family, often blurring the roles between parent and grandparent. Due to complex needs of a grandchild with DD, grandparents experienced a 'double-dose' of worry both for their child and grandchild. However, grandparents found purpose and meaning in their responsibility to support the family. Adjustment theme comprises of three themes: **Reactions to Disability**, **Loss** and **Double Burden**.

Reactions to Disability

According to the reviewed studies learning about the grandchild’s DD left grandparents in turmoil and necessitated a period of acceptance. **Reactions to Disability** theme represented this journey (Boyd & Goodwin, 2019; D'Astous, et al., 2013; Hillman & Anderson, 2019; Hillman et al., 2017; Huang et al., 2020; Katz & Kessel, 2002; Margetts et al., 2006; Miller et al., 2012; Prendeville & Kinsella, 2019). This theme encompassed grandparents’ *Emotional Responses* upon first learning about their grandchild’s DD (D'Astous et al., 2013; Huang et al., 2020; Margetts et al., 2006) and the various *Coping* mechanisms they employed to make sense of this news (Boyd & Goodwin, 2019; D'Astous, et al., 2013; Hillman & Anderson, 2019; Hillman et al., 2017; Huang et al., 2020; Katz & Kessel, 2002; Margetts et al., 2006; Miller et al., 2012; Prendeville & Kinsella, 2019). These are described below.

Emotional Responses

Grandparents’ immediate experiences of learning about the child’s disability were often painful and profound:

> *“…The doctor brought him to us. We could not bear to see what had happened to him and were all in tears. . . . I was devastated, it was like having a knife cutting my heart when I realized my grandchild was different from other children . . .”*
>
> (Huang et al., 2020, p.55)

Furthermore, this experience was embroiled with uncertainty, as grandparents struggled to envisage their grandchild’s future: *“It’s hardest at the beginning, when things aren’t right, you don’t know why or what will happen”* (Margetts et al., 2006, p.571). Moreover, feelings of utter hopelessness were evident as grandparents *“expressed despair and helplessness with the situation”* (Katz & Kessel, 2002, p.120).

Conversely, for some, receiving a diagnosis brought a sense of relief, in that it fostered an understanding of the grandchild’s condition and offered an insight into the grandchild’s future:

> “*When we found out what was wrong with him, it made it so much easier*”.
>
> (D'Astous et al., 2013, p.140)

Coping

Accepting their grandchild's DD was an agonizing undertaking and manifested in different strategies grandparents used to come to terms with this reality. Some focussed on remaining positive:

> "*You basically think to yourself, well what can I do to contribute to him? Well you know they can't fully recover, but you have to think about how you can approach the situation so that you benefit both the child and the mother by being as positive as you can, particularly for the mother*"
>
> (Miller et al., 2012, p.106)

Others coped by letting go of worries and focussing on the task at hand, which served to maintain their autonomy and maximise quality time with grandchildren:

> "*When you're not conscious of anything, just participating, you don't have your defensive up, in a sense that 'Is something going to go wrong? Is there going to be a melt down and are people going to stare? . . . You have to just let it go. . . . You just keep on keepin' on right? Keep having fun and never let it [stares, glares, comments] stop us from doing an activity*".
>
> (Boyd & Goodwin, 2019, p.232-233)

However, for some grandparents accepting their grandchild's disability was just too painful: *"...I just could not accept this truth*" (Huang et al., 2020, p. 55). Grandparents searched for answers of "*who is to blame*" (Katz & Kessel, 2002, p.121) in trying to make sense of such devastating news. Drawing on their faith helped grandparents make sense of their grandchild's disability:

> "*Maybe it would be easier if our grandson had an entire brain and no seizures, but God gave him to us because he is always looking for someone to help him with the special loving people*".
>
> (Hillman & Anderson, 2019, p.265)

Loss

The literature detailed the considerable sacrifices grandparents made in supporting their grandchild with DD and their parents. *Plans Change* described how the additional caring responsibilities often impeded grandparents' retirement plans, limiting their occupational and leisure opportunities. As a result, grandparents became socially isolated and incurred significant financial burden (D'Astous et al., 2013; Hillman & Anderson, 2019; Maul & Singer, 2009; Miller et al., 2012; Prendeville & Kinsella, 2019). Studies also reported the *Double Burden* grandparents experienced, as a result of supporting the wellbeing of their adult children and their grandchildren. The significant contribution to caregiving often blurred the boundaries between grandparent and parent (D'Astous et al., 2013; Huang et al., 2020; Katz & Kessel, 2002; Margetts et al., 2006; Maul & Singer, 2009; Prendeville & Kinsella, 2019).

Plans Change

Caring obligations came at considerable personal cost to grandparents. Moving closer to their children, abandoning retirement plans and new job opportunities increased financial strain and feelings of loneliness. Part of adjustment to the new role of becoming a grandparent of a child with DD involved navigating an abrupt change to plans grandparents made for their 'golden years': "*grandparents would describe activities that they did or life plans that they had that they felt were no longer possible for them*" (Maul & Singer, 2009, p.159). Grandparents mourned the loss of free time and leisure activities resultant from taking on caregiving roles:

> "*I looked after him from the beginning, I volunteered but my life changed an awful lot, because I used to play pitch and putt every day, and I would be free, I used to enjoy it immensely and after [child's name] being diagnosed I was under pressure then*".
>
> (Prendeville & Kinsella, 2019, p.743)

Grandparents often moved to be closer to their families to provide more timely support:

> "*When I lived in (east of Taiwan), a typical day for me was getting up early in the morning, cleaning the house, going out to exercise, having breakfast, and enjoying afternoon tea with my friends . . . .I moved to xx (center of Taiwan) to look after my granddaughter, because she needs rehabilitation and her parents have to work.*

> *Actually, I don't like to take care of children, but I think I need to come here to give assistance because she is my granddaughter*" .
>
> (Huang et al., 2020, p.57)

Caring for their grandchildren, often resulted in grandparents giving up their employment or passing on job opportunities:

> "*Well, I'm trying to do more, that's one of the reasons I gave up my job. [its created] a bit of constraint about the way we lead our own lives. . . . our life would go in a different direction now if they [grandchildren] didn't exist. I don't think we would stay here but the fact that we're 10 kilometres away and 10 minutes in the car. I think we would head for a little fishing village or something, but it's not an option. There's been once or twice I was offered a job teaching in Japan but I couldn't even contemplate it . . . I'm not saying I'm martyr of the year, at all, but it has been a fact, you know, you sort of think that . . . well it's not an option*"
>
> (Miller et al., 2012, p.106)

The unanticipated consequence of taking on additional responsibilities was *"[the grandparents'] perceived isolation as a result of their reported perceptions of what both grandparents and parents envisaged for grandparents' retirement years*" (Prendeville & Kinsella, 2019, p.742). Furthermore, this was compounded by "*diminished social network causing strain on the relationship between grandparents*" (Miller et al., 2012, p.106), as well as sacrificed social connections that employment provided:

> "*I'm tied down 24/7 and…can't work and my [other] children are busy with jobs and raising their own children, and our friends are busy with their social lives so it can be a very lonely existence*"
>
> (Hillman & Anderson, 2019, p.265).

An additional source of pressure for grandparents was the financial impact of supporting their grandchild and their family: *"My greatest challenge is finances. I didn't plan to support another family"* (Hillman et al., 2019, p.2962).

Grandparent-Parent Role Blurring

Grandparenting a child with DD often encompassed a certain loss of identity. Taking on increasing caregiving demands to meet the complex support needs of their grandchildren often led to roles between grandparent and parent merging: "*I was available for them 7 days a week. She could ring me at work and I'd leave work, or in the middle of the night and I'd go to help*" (Margetts et al., 2006, p.569). Therefore, grandparents engaged in a balancing act of trying to find just the right level of support: "*We help support her children but we do not intrude on her life*" (D'Astous et al., 2013, p.193).

Double Burden

Grandparents felt a strong duty to support their families. This provided purpose and meaning in their lives. Supporting a family with a child with DD placed a dual responsibility on grandparents of caregiving obligations to the grandchild and emotional and practical support to their adult child:

> "*She [daughter] had a nervous breakdown, with her personal problems it is very difficult for her to have a child so severe, she is trying herself to cope, there at times and it's difficult, and I think we could give her a bit more support*" .
>
> (Prendeville & Kinsella, 2019, p.743)

Responsibility to Support Family

Watching their children's, often immense struggles of caring for their grandchild coupled with their grandchild vulnerabilities, ignited a strong sense of duty to support the family:

> "*The parents [of our ASD grandchildren] cannot do all of the lobbying by themselves…These precious children are our responsibility. They cannot fight for themselves and it is up to us.*"
>
> (Hillman et al., 2017, p.2964)

This responsibility to support the family manifested in many grandparents expressing worries about the future: *"The biggest worry that we have is we won't be there for him you now and how will she cope with [child's name] but it's the future that's the problem"* (Prendeville & Kinsella, 2019, p.745).

Therefore, grandparents wanted to pass on skills that will support their grandchild in the future, further evidencing feelings of responsibility to support the family:

> "*I show him how to do things or doing chores. Like I had him mow the lawn, and he was just going all over the place, so I showed him how to go in a pattern and he did." When asked about this grandson's future, he said, "I think he will be okay, and hopefully all that I have taught him and tried to influence him will make a difference*"
>
> (D'Astous et al., 2013, p.141)

Part of the duty to support the family was observed in a conscious intention to support all siblings equally:

> "*I won't love or like her [child with DD] more than her younger sister. No. That would influence their relationship and her younger sister would feel she was being treated unfairly . . . . I think it is important to treat children fairly . . .*"
>
> (Huang et al., 2020, p.58)

Grandparents also encouraged and supported the relationship between their grandchild with DD and their typically developing siblings: "*Grandmother of a child with Foetal alcohol syndrome and his 11 year old brother wanted them "to bond together a little better" noting the turbulence of their relationship*" (Gallagher et al., 2010, p.61).

Blessing and a Curse

The literature described grandparenting a child with DD as both rewarding and challenging. Caring for child with DD promoted family cohesion and the close bond grandparents forged with their grandchild through overcoming difficulties, strengthened their character and brought joy to their lives. However, establishing a bond with their DD grandchild could be difficult and at times, fraught with grandchild's disruptive behaviour. Notably, grandparents wanted to be better equipped to support their grandchildren. This analytical theme comprised of two themes **Rewards of Grandparenting a Child with DD** and **Challenges of DD**.

Rewards of Grandparenting a Child with DD

The rewarding aspects of the grandparenting role included *Personal Growth,* whereby supporting grandchildren was a formative experience for grandparents (Hillman & Anderson, 2019; Hillman et al., 2017; Katz & Kessel, 2002). *Brings Family Closer Together* described how families came together to meet the complex needs of the child and grandparents valued their supportive role. Moreover, the close and meaningful bond between grandparent and grandchild was a source of happiness and pride (D'Astous et al., 2013; Gallagher et al., 2010; Hillman & Anderson, 2019; Hillman et al., 2017; Huang et al., 2020; Margetts et al., 2006; Miller et al., 2012).

Personal Growth

Grandparenting a child with DD provided many life lessons. Overcoming challenges of caregiving fostered personal development and growth, as grandparents were stretched beyond what they thought was possible and attributed the source of their development to their grandchild:

> "*The greatest education I have ever received was from my grandchild; without him speaking a word he has taught me patience, advocacy, unconditional love [and] strength*"
>
> (Hillman et al., 2017, p.2963)

The grandparental journey was a source of strengths and resilience:

> "*The road was winding, filled with misgivings, but with time we learned to cope with the pain and difficulties involved and it has strengthened us all*"
>
> (Katz & Kessel, 2002, p.125)

Brings Family Closer Together

A DD child has complex needs and is therefore dependent on their family for support. Grandparents valued being included in supporting the family and the joy of developing a bond with their grandchild maintained their involvement. Grandparents described the close cooperation of family members and the grandchild's exceptional power to bringing the family closer together:

> “*We have a very close family, we all work in well together, they’re all very supportive of one another whatever the situation but particularly since finding out that young [child with disability] has got autism, so everyone draws together nicely. I think more than anything it’s drawn us closer to him for myself and the rest of the family, his other grandma, we all pull closer together and we do spend as much time with him as we possibly can. If we have family get togethers, he’s just as much cared for everybody looks out for him that he doesn’t hurt himself or anything like that. The other kids all accept that he just the way he is and they understand, even though they’re young themselves, all the other grandchildren, they still look out for him*” .
>
> (Miller et al., 2012, p.107)

Grandparents really valued being involved in family life: “*They include us with family things and they depend on us to ‘fill in.’ I go to his school activities when his mother can’t go to support him*” (D'Astous et al., 2013, p.140). It was through establishing a connection with their grandchild that grandparents found joy in their role. This was achieved through “*vivid recollections of developmental milestones*” (Margetts et al., 2006, p.570) and rejoicing in every bit of progress of their grandchild, no matter how small “*each milestone is celebrated and we celebrate each baby step*” (Hillman & Anderson, 2019, p.265). It was this special connection between grandparent and grandchild with DD that brought happiness to grandparents: “*My greatest joys are getting hugs and kisses [from my ASD grandchildren] when they visit*” (Hillman et al., 2017, p.2962) and grandparents’ love, in turn, benefited the grandchild “*I see the love in his face for me and the love we give him has made a great impact on him*” (Gallagher et al., 2010, p.61). For some grandparents: “*their relationship with their grandchild was seen as a source of pride and something that ‘keeps them young’*” (Gallagher et al., 2010, p.139).

Challenges of DD

The studies evidenced that grandparents experienced a number of difficulties in grandparenting a child with DD. *Difficulty Making a Connection with Grandchild* described how the difficulties inherent in DD presented additional barriers to developing close bonds between grandparent and child (D’Astous et al., 2013; Hillman et al., 2017). Many papers reported grandparents struggling with the *Challenging Behaviour* of their grandchildren, leaving them feeling scrutinised and judged (D'Astous et al., 2013; Gallagher et al., 2010; Hillman & Anderson, 2019; Hillman et al., 2017; Huang et al., 2020; Boyd & Goodwin, 2019; Gallagher et al., 2010). Furthermore, these studies identified a number of *Grandparent Support Needs* (Gallagher et al., 2010; Hillman & Anderson, 2019; Katz & Kessel, 2002; Prendeville & Kinsella, 2019).

Difficulty Making a Connection with Grandchild

Given the importance of connection in maintaining grandparental support, some grandparents struggled to develop a bond with their grandchild due to the communication and social difficulties children with autism can experience. They found their greatest challenge "*was simply trying to connect with [my granddaughter]*" (Hillman et al., 2017, p.2961). At times, the presentation of grandchild's DD impeded relationship building: "…*When he is in a bad mood, he'll say 'Leave me alone and don't touch me.' I find that discouraging*" (D'Astous et al., 2013, p.142).

Challenging Behaviour

Grandparents of children with DD often had to manage a range of complex and often troubling behaviours their grandchildren exhibited as a result of their disability and/or communication impairments. Behavioural difficulties of their grandchild such as "*explosive behaviours that can be destructive and injurious*" (Hillman & Anderson, 2019, p.264) presented another obstacle that grandparents faced often being the victim of physical aggression: "*When I bathed her, she just kept crying and crying and she would bite me sometimes*…" (Huang et al., 2020, p.57).

The obstacle of challenging behaviour was harder to navigate in public. Often, as a result of their grandchild's loud or aggressive behaviour, grandparents felt judged by members of the public: "*can't that old lady control that child?*" (Gallagher et al., 2010, p.61). This negatively impacted their experience of community outings:

> "*Family leisure were remembered as being fraught with feelings of being under the public gaze, being singled out, and judged*"
>
> (Boyd & Goodwin, 2019, p231).

Grandparent Support Needs

Research has identified that grandparents have own support needs, resultant from the additional challenges grandparents of children with DD have to overcome in their caregiving role. Satisfying these needs could equip grandparents to more effectively support their family: "*If I had known more, I would have been able to do more and not feel as guilty as I do now*" (Prendeville & Kinsella, 2019, p.745).

Literature identified a clear need for diagnostic information: "*grandparents felt that they were not given enough information about developmental disability*" (Katz & Kessel, 2002, p.122). In addition, grandparents required professional support as "*they needed help with behaviour issues such as aggression*" (Gallagher et al., 2010, p. 60).

Components to Involvement

The literature identified a number of facilitators to grandparental involvement in supporting their family. The amount of grandparental support was largely dictated by the strengths of their relationship with their child, which was affected by parenting disagreements, lineage of grandparents and the birth order of the grandchild. Grandparent social factors such as age and health and their proximity to their offspring further impacted on the amount of their involvement. This analytical theme encompassed two themes: **Grandparent-Parent Relationship** and **Social Factors**.

Grandparent-Parent Relationship

In supporting families of children with DD relationships are of paramount importance. Research suggests that the level of grandparental involvement was dependent on the quality of their relationship with their adult children (D'Astous, et al., 2013). *Parenting Style Conflicts* impacted this relationship (D'Astous, et al., 2013; Katz & Kessel, 2002; Margetts et al., 2006; Maul & Singer, 2009; Miller et al., 2012). Maternal grandparents tended to be most involved, highlighting *Lineage* as another facilitator to involvement (Katz & Kessel, 2002; Prendeville & Kinsella, 2019). Similarly, *Birth Order* of grandchild also impacted grandparental support (D'Astous et al., 2013; Hillman et al., 2017).

Parenting Style Conflicts

The quality and quantity of involvement of grandparents in the life of their grandchild was dependant on the "*the status of the parent–grandparent relationship*" (D'Astous et al., 2013, p.139), which dictated the contact and closeness of the grandparent's relationship with their grandchild. However, this relationship between parent and adult child was affected by disagreements regarding parenting styles, which grandparents were reluctant to address with their children for fear of disrupting the relationship and in turn their involvement with their grandchild:

> "*When [grandchild] comes to my house he thinks it's the place where we play. I play with him . . . When his dad comes in we have to behave*"
>
> (Margetts et al., 2006, p.570)

Lineage

Depending on whether grandparents were of maternal or paternal lineage their level of involvement differed: "*Maternal grandparents were found to be more involved in the care of the child with developmental disabilities than paternal grandparent*" (Katz & Kessel, 2002, p.122). They tended to provide "emotional and functional support for their families" (D'Astous et al., 2013, p.138).

Birth Order

The order of birth of grandchild with disability impacted grandparental involvement. Where the grandchild with disability was firstborn, grandparents were most involved:

> "*The 13 year-old [grandchild with ASD] is…very lovable and will always have a special place in our hearts as our 1st grandchild" and "He's my first-born grandchild so he's special to me for that reason…My greatest joy is just having him in my life*".
>
> (Hillman et al., 2017, p.2962)

Social Factors

Social factors such as *Age and Health* impacted on grandparental ability to support their families (D'Astous et al., 2013, Miller et al., 2012). Similarly, the *Distance* of how far away grandparents resided from their children impacted on their ability to offer support (D'Astous et al., 2013; Hillman & Anderson, 2019).

Age and Health

Advancing age and declining health impacted on the grandparental ability to support their families:

> "*I don't feel safe going downstairs with him. Upstairs is not so bad, you feel that if you trip…My balance isn't as good as it was and I've told [daughter] that and she doesn't really want to accept that. He's very difficult, it's very awkward. I suppose she thinks I am big and able but you know as you get older, my back isn't that wonderful*".
>
> (Miller et al., 2012, p.108)

Distance

Distance raised a practical barrier to grandparents caring for their grandchild: "*We live far away from our grandchild, so it is hard to support him*" (Hillman & Anderson, 2019, p.2962). Whereby those that lived far away from their grandchild tended to have more infrequent contact: "*maybe once or twice a year*" (D'Astous et al., 2013, p.138).

Critique of Studies

All studies apart from Katz and Kessel (2002) reported how they analysed data. Eight of the 11 studies did not disclose any information regarding the relationship between the researcher and participants, scoring zero on this criterion of the impact assessment (D'Astous et al., 2013; Gallagher et al., 2010; Hillman & Anderson, 2019; Hillman et al., 2017, Katz & Kessel, 2002; Margetts et al., 2006; Maul & Singer, 2009; Prendeville & Kinsella, 2019). Therefore, the level of researcher bias in these studies could not be ascertained. One study partially considered this relationship by acknowledging that the researcher themselves was a grandparent (Miller at al., 2012). Only two studies considered this relationship adequately (Boyd & Goodwin, 2019; Huang et al., 2020).

Two studies did not report any ethical considerations (D'Astous et al., 2013; Katz & Kessel 2002). A further two studies only partially considered ethical issues by referring to obtaining signed consent from participants (Gallagher et al., 2010) or by providing study details to participants (Maul & Singer, 2009).

Discussion

The current meta-synthesis captured the experiences of grandparenting a child with DD through three analytical themes: *Adjustment*, *Blessing and a Curse*, and *Components to Involvement*.

The journey of *Adjustment* in coming to terms with their grandchild's disability, progressed from initial reactions to disability, characterised by emotional responses and finding ways to cope, to mourn the loss of plans made for retirement, navigating the new role of supporting two generations and finding meaning in the responsibility to support their family. Grandparenting a child with DD was both a *Blessing and a Curse* with rewarding experiences of personal growth and family unity despite the challenges that supporting a grandchild with DD entailed. *Components to Involvement* evidenced that grandparental involvement was a function of the grandparent-parent relationship and social factors such as the grandparents health and age and residential proximity to grandchild. Some of these findings related to previous reviews of grandparental experiences of grandchild with disability (Hasting 1997; Lee & Gardner 2015; Griffith & Hastings, 2015). Griffith and Hastings (2015) specifically focussed on the experiences of caregivers of a child with intellectual disabilities and challenging behaviour. However, the current review synthesised grandparental experiences of grandparenting a child with DD, and added to this knowledge base by highlighting the rewarding aspects of grandparenting children with DD. These rewarding aspects included personal growth, which has also been reported by parents of autistic children (Waizbard-Bartov et al., 2019). Furthermore, grandchildren with DD promoted family cohesion. Research suggests that family cohesion is one of the most essential contributors to family resilience (Patterson, 2002; Walsh, 2003).

The grandparents' initial reactions to finding out about their grandchild's disability were painful and characterised by despair and hopelessness. This is not surprising, as the diagnosis of disability in a child is a traumatic event (Simon & Easvaradoss, 2015). This is in line with findings of Lee and Gardner (2010) and Hasting (1997) who also reported grandparents experiencing shock, devastation and loss on learning of the grandchild's disability. However, Hasting (1997) reported that despite grandparents adapting to this reality over time, some remained feeling depressed about their grandchild. In contrast, the current review suggests no long-term impact on grandparents' mental health. Grandparents utilised different coping strategies such as turning to their faith or thinking positively, amongst others, to make sense of their grandchild's disability and find meaning in being grandparent of a child with DD. Scior and Werner (2015) noted policies, service provision and attitudes towards disability have changed over the past 50 years. The current review may suggest this change in attitude may be associated with better grandparental adjustment to grandchild's DD.

Part of the adjustment process involved experiencing a loss of a planned future which comprised of changing retirement plans and relocating to be nearer to their grandchild to provide practical support. This resulted in a loss of an established social network, inadvertently leading to grandparents experiencing social isolation and loneliness. However, this is different to the findings of Hasting (1997) review who conceptualised the loneliness grandparents experienced as arising from grandparental lack of information about the grandchild's disability. The present review noted a desire for more professional support from grandparents and information about their grandchild's DD. This is consistent with findings of other reviews (Hastings, 1997; Lee & Gardner, 2010).

In line with Hastings' (1997) review, the current review highlighted grandparents concerns about the future and the double burden that grandparents encountered in supporting two generations of relatives. This phenomenon arose from the strong sense of responsibility grandparents experienced to support their family. For instance, this sense of duty manifested in grandparents' worries about the future, the need to mediate relationships between the grandchild with DD and their typically developing siblings.

These findings highlight an opportunity for clinicians to ameliorate some of these concerns by providing timely information regarding what to expect following grandchild's diagnosis and the types of support services available to them. The role of mediating between siblings and promoting closer relationships between siblings has not been observed in previous reviews. This can be conceptualised an as additional role grandparents have in supporting the family.

The current review highlighted that grandparents struggled to form an emotional connection with their grandchild. Difficulties developing a connection with the grandchild can decrease grandparental involvement, therefore reducing the support they offer their children. There was an overrepresentation of grandparents of autistic children studies within the present review. The communication difficulties and social impairment inherent in Autism may heighten the challenges grandparents face in establishing a deep emotional connection with their grandchild. A contributing factor to the increased research in this area may relate to the increasing prevalence of Autism Spectrum Disorder in the UK and the USA over the past two decades (Taylor et al., 2013).

This review identified that the primary *Component to Involvement* of grandparents in offering support to their families was the closeness of grandparent-parent relationship, whereby grandparents tended to be more involved if they had a good relationship with their children. Social factors such grandparents' age and health and their proximity to children's residence also impacted level of involvement, consistent with findings of other reviews (Hastings, 1995; Lee & Gardner, 2010). However, one aspect not previously reported in literature, was birth order. Grandparents of firstborn children with DD reported having a closer bond with their grandchild.

Strengths and Limitations of Review

This meta-synthesis is the first review of qualitative literature on the experiences of grandparents of having a grandchild with DD. The current review encompasses studies from across the globe and highlights common themes in grandparental experiences. Moreover, this review provides an update to previous reviews and its findings emphasise that despite previous review recommendations, grandparents support needs are not being adequately met.

It is important to note the limitations of this current review. Due to paucity of qualitative literature of grandparental experiences of grandparenting a child with DD, this review incorporated some studies which reported experiences and views of the whole family, extracting only findings that were based on grandparents' experiences and views. Therefore, this review may not have captured all the nuances of grandparents' multifaceted experiences. Similarly, the views of grandmother's were overrepresented in studies of this review, consistent with other reviews in this area (Hastings, 1997, Lee & Gardner, 2010, Novak-Pavlik et al., 2020). Thus, this meta-synthesis may not adequately represent the experiences of grandfathers.

Furthermore, drawing out of common themes across studies from different countries, may have led to culturally specific themes being underrepresented in the review findings. Similarly, as five of the 11 studies took place in the USA, there remains a risk of bias towards themes predominantly informed by findings on grandparental experiences in a US context. There is also under-representation of studies from non-western countries in this review, which may limit the generalisability of findings to those contexts.

In addition, two of the selected studies reported views of custodial grandparents. Arguably, taking on custodial responsibilities may have predisposed grandparents to have different experiences compared to traditional, non-custodial grandparents. More importantly, the inclusion of those two studies may have influenced the themes that emerged in the review findings, and it remains possible that different themes or subthemes may have arisen if all the reviewed studies had examined non-custodial grandparenting only. As the body of research into custodial grandparents' experiences grows and becomes more developed, a separate review of those experiences may help to gain a better understanding of salient aspects of custodial grandparenting of a child with a DD. Lastly, it is worthy of note that the quality assessment ratings of included studies ranged from 12 (60%) – 20 (100%) and studies of higher quality were not given more weight, making it harder to assess the contribution of each study to resultant themes.

Implication for Policy and Clinical Practice

The loss of social network that results from grandparents taking on additional grandparental responsibilities can lead to isolation. It would help if clinicians are aware of this and signpost grandparents to support groups for grandparents of children with DD in the first instance and periodically thereafter to take account of the initial shock and period of adjustment.

Grandparents valued being involved in supporting their grandchildren. Good practice guidance set out in commissioning service for people with intellectual disability and/or autism (Mansell Report, 1993; Department of Health, 2007) emphasises working jointly with people with disability and their families and carers. However, engagement of carers and family members in the care of the relative with a disability relies on clinicians, locally, to facilitate and promote this engagement. As such, clinicians could endeavour to involve grandparents in their grandchild's care, with parental approval, as a matter of course.

Moreover, to enable grandparents to provide optimum support to their grandchild, they need to be fully informed about the disability, prognosis, local services and care provision. Given that internet use of 65-74 years old age group has increased from 52% in 2011 to 83% 2019 (Office for National Statistics, 2019), this presents another way of disseminating information and signposting to necessary resources.

Grandparents may struggle to connect with their grandchild due to the nature of their disability and clinicians may help nurture this relationship by offering information and training. This can help grandparents better understand the needs of grandchildren and help to identify and practice activities that can promote a deeper connection with their grandchild, aiding family cohesion. Similarly, grandparents where the grandchild with DD is non-firstborn may require support to strengthen their relationship. This has implications for clinicians and educators, who have an opportunity to support the development of close relationship between grandparents and grandchildren with disability by encouraging and promoting grandparent involvement in their grandchild's care and education.

Directions for Future Research

There is a lack of research regarding the coping styles grandparents utilise in their adjustment to having grandchild with DD. Specifically, what coping styles prove to be more effective at facilitating adaptation in the new role. This is of interest as adaptive coping can promote adjustment and reduce the risk of grandparents developing prologued grief reactions and suffering poorer mental health.

This review found that grandparents actively try to promote closer relationships between their grandchild with DD and their typically developing siblings. This has not been observed in previous reviews and can be conceptualised an as additional role grandparents take on in supporting the whole family and may be an important area for further research. Finally, the views of grandfathers of children with DD are underrepresented and as such there is a need to understand their experiences and their specific needs in supporting their families.

The current review extended findings of other reviews by identifying rewarding aspects of grandparenting a child with DD. This warrants further exploration, as understanding what factors contribute to experiences of personal growth as a result of caring for a grandchild with DD can help to improve grandparental experiences and outcomes.

Conclusion

Grandparents play a vital role in supporting their families. Taking on additional challenges of caring for a grandchild with DD comes at a personal cost to grandparents and as such they have their own support needs. The current review has highlighted that despite previous reviews grandparents are still not accessing adequate information and support from professionals. This offers a unique opportunity for clinicians and educators to promote and forester grandparental involvement to improve family functioning.

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Chapter Two: Empirical Paper

“What are the Experiences of Clinical Psychologists Working with People with Intellectual Disabilities During the COVID-19 Pandemic?”

This chapter was written in preparation for submission to Journal of Intellectual Disability Research. Appendix H provides details of the author guidelines for this journal.

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Abstract

Purpose: People with Intellectual Disabilities (ID) are a particularly vulnerable group, at an increased risk of mortality from COVID-19 and of poor mental health due to COVID-19 associated restrictions. The pandemic has compromised the support systems around people with ID. In addition, psychologists who provide mental health support to people with ID report poorer mental wellbeing and higher occupational stress. Moreover, they raise concerns about people with ID engaging with digital technologies to access mental health support in the context of reduced face-to-face psychological provision. Thus, it is important to understand psychologists' lived experiences of working with people with ID and their carers during the pandemic.

Design: Semi-structured interviews were conducted with 11 Clinical Psychologists (CPs) working in community ID services. Interpretative Phenomenological Analysis (IPA) was employed for data analysis.

Findings: Two superordinate themes emerged. The superordinate theme **Survive or Thrive** highlighted the challenges and successes clinical psychologists experienced while working during the pandemic. It includes three subordinate themes of *"I feel like a speck in the base of a tsunami*", "*My head space is filled up*" and *"When the rule book gets thrown out the window".* The superordinate theme of **"Left to their own Devices"** described psychologists' experiences of people with ID as forgotten within society. Psychologists felt abandoned in advocating for their clients. It contains two subordinate themes, *"God only knows what's going on behind the closed doors" and "Lots of red tape to get around".*

Conclusions: The current study demonstrates CPs' ability to adapt to extremely challenging circumstances, and exposes the vulnerabilities of people with ID and the gaps in service provision to adequately meet their needs. ID services may benefit from robust policies and procedures for remote working, training and supervision for psychologists for the safe and effective delivery of remote interventions, and improved access to mental health support.

Key words: Clinical psychologist, experiences, intellectual disability, COVID-19

Introduction

Research Aim and Significance

The current study aimed to explore the experiences of clinical psychologists working with people with Intellectual Disabilities (ID) during the COVID-19 pandemic. The internationally accepted definition of a pandemic is an epidemic that occurs worldwide or over a very wide geographical area, that crosses international boundaries and typically affects a large number of people (Last et al., 2001). The current COVID-19 pandemic is a global crisis.

ID is defined as a disability of intellectual functioning and adaptive behaviour that must manifest before adulthood (Luckasson, 2016). The World Health Organisation Europe (WHO/Europe, 2010) further advises that this results in impaired social functioning with lasting effects on development. People with ID experience higher rates of morbidity and mortality compared to the general population. National Health Service England (NHSE) estimates that 41% of people with ID die from respiratory conditions. Furthermore, they tend to have a higher prevalence of asthma and diabetes and of being obese, making them move vulnerable to COVID-19 (NHSE, 2020), especially at younger ages (Turk et al., 2020). Moreover, people with ID experience higher rates of mental ill-health (Cooper et al., 2015; Cooper et al., 2007; Emerson & Hatton, 2007). Furthermore, carers and family members are recognised as essential to the health and security of people with ID, especially during the COVID-19 pandemic, and are strongly encouraged to be involved in all stages of care and support (Alexander et al., 2020).

The cumulative impacts of stress associated with the fear of contracting COVID-19, social distancing and quarantine measures can negatively impact mental health of some people (Pfefferbaum & North, 2020). Courtenay and Perera (2020) suggest that mental health of people with ID can be similarly affected, possibly to a greater extent, as quarantine measures may trigger an escalation of problem behaviours due to a disruption of familiar routines and restriction on the physical environment. Furthermore, COVID-19 lockdown measures have led to service provision for people with ID being cut back due to staff sickness and closures of day-care and respite services, further compromising mental health of people with ID (Evans, 2020). The greater mental health needs of people with ID, however, misalign with Public Health England (2020) COVID-19 guidance for significantly reduced face-to-face clinical contact, meaning that effective delivery of behavioural and psychological interventions may be reduced, delayed or not implemented.

Due to increased vulnerability of people with ID to COVID-19 and the wider impacts of the pandemic, Alexander et al. (2020) recently published detailed guidance for the treatment and management of COVID-19 among this population. The authors identify a vital role for CPs in delivering specialist psychological intervention in community settings to mitigate any impact of the pandemic on mental health and challenging behaviour. CPs are registered mental health professionals who deal with a wide range of mental and physical health problems with a principal aim to reduce psychological distress and promote psychological wellbeing (The British Psychological Society [BPS], n.d.).

Previous Literature

People with ID often rely on family and paid carers for support. Carers of family members with ID manage day-to-day general care demands and the stresses associated with challenging behaviour such as physical injury and fear. Moreover, they often battle with services regarding the lack of suitable support and worry about the future of their relative with ID when they would no longer be able to provide care and support to them (Griffith & Hastings, 2013). Caring for an adult with ID has been shown to negatively impact parents' quality of life. Caring led to restricted relationships, leisure activities and employment opportunities, and was associated with financial insecurity and frustrations with the service system (Yoong & Koritsas, 2012). The measures implemented to manage COVID-19 pandemic such as self-isolation and quarantine have affected the day-to-day activities and livelihoods of all people that may lead to increased loneliness, anxiety and depression (Brookes et al., 2020; Kumar & Nayar, 2020; Patel, 2020; Razai et al., 2020).

Willner et al. (2020) utilised an online questionnaire to compare coping styles and levels of anxiety and depression of informal carers of children/adults with ID to parents with children/adults without disabilities. Carers of people with ID reported higher levels of anxiety and depression compared to parents of people without disabilities. These rates were two to three times higher than those reported prior to the start of the pandemic. Moreover, the authors highlighted that despite greater mental health needs of carers they reported receiving less social support from friends and family and a loss of support from care providers (Willner et al., 2020). Families provide an essential safety net for their relative when the systems around them shut down, at a time when they are already experiencing great strain in providing 24-hour care that was usually shared with paid carers (Courtney & Parera, 2020).

McMahon et al. (2020) investigated the wellbeing of paid carers working in ID services during the pandemic in the Republic of Ireland. Carers reported moderate levels of personal and work-related burnout and mild levels of anxiety and depression. The authors noted higher mean scores across measures used for staff who worked in independent living settings and those that supported individuals with challenging behaviour. The changes in service provision and the withdrawal of social care during the pandemic has resulted in additional challenges for people with ID. Therefore, it is important to understand their needs and the needs of their informal and paid carers.

Langdon et al. (under review) conducted a cross-sectional survey (*n*=97) exploring the changes to job role of psychologists working with people with ID and the impact of such changes on mental wellbeing and occupational stress as a result of the COVID-19 pandemic[3]. Their results indicate that greater occupational stress of COVID-19, caused by changes to job role and additional demands at home, was associated with poorer mental wellbeing. In addition, role uncertainty, shortages of personal protective equipment (PPE) and poor mental wellbeing were associated with greater occupational stress. Furthermore, almost a quarter of their sample were redeployed away from working with people with ID or into non psychology roles. Moreover, qualitative analysis of open-ended responses highlighted psychologists' concerns that people with ID may encounter more barriers to service provision such as making use of technology to access services in the context of reduction or withdrawal of support including education and social care support. Psychologists in the study stated that COVID-19 related policies and changes to usual practice did not adequately consider the individual needs of their clients (Langdon et al., under review).

Emmerson (2007) highlighted that the average family caring for a child or adult with ID is likely to live in poverty. Similarly, the author's review of available evidence regarding the socio-economic position of adults with ID point to high levels of poverty. Moreover,

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[3] hereinafter referred to as pandemic.

experiencing stressful events makes falling into poverty more likely and less likely to escape it (Emerson et al., 2010). Burgess' (2020) research investigating the use of technology during the COVID-19 lockdown highlighted a clear link between poverty and digital exclusion that is understood as the lack of access to and use of information and communication technology (ICT) resources. Macdonald and Clayton (2012) examined the impact of digital technologies on improving the lives of disabled people in deprived neighbourhoods. They found that only 29% of disabled people had used a computer and 73% of people with impairments had reported never to have connected to the internet. Similarly, use of mobile phones among disabled people was extremely low, with 50% of responders using the device. In addition, the authors highlighted that major barriers for access to ICT disabled people faced were financial constraints and lack of confidence in their own skills and knowledge in using ICT. Macdonald and Clayton's research although dated, provides a baseline for uptake of technology among people with ID. This research highlights the difficulties people with ID may have in accessing psychological provision using digital technologies.

Thus far no qualitative, in depth research to understand how the pandemic has affected the mental health provision for people with ID has been conducted. Given the digital exclusion faced by people with ID, it is not known how psychologists working in ID services experienced delivering mental health and behavioural interventions in the context of reduced face-to-face contact, using digital technologies.

Rationale and Research Question

A review of empirical literature has highlighted people with ID as a particularly vulnerable group, at an increased risk of mortality from COVID-19 and at increased risk of poor mental health due to COVID-19 associated restrictions. The family and carers, people with ID rely on for support, are reporting poorer mental health resultant from the pandemic and withdrawal of social care support services, impairing the levels of care they provide to their relative with ID. Furthermore, research highlights that psychological provision for people with ID in community settings has decreased due to redeployment of staff into other areas. In addition, psychologists who provide mental health support to people with ID in community settings also report suffering poorer mental wellbeing and higher occupational stress. Moreover, they raise concerns about people with ID engaging with digital technologies to access mental health support in the context of reduced face-to-face psychological and behavioural interventions. Understanding psychologists' experiences of working with people with ID and their carers during the pandemic will help to identify more effective ways of tailoring service provision to the needs of people with ID and consider how to support clinicians in the delivery of care.

Therefore, the current study will attempt to address these limitations by investigating the following research question: "What are the lived experiences of clinical psychologists working with people with intellectual disabilities during the COVID-19 pandemic?"

Methods

Research Design

The epistemological position of this research project is interpretivist. The central tenet of interpretive epistemology is to understand the subjective world of human experience. This position states that "the world does not exist independently of our knowledge of it" (Grix, 2004, p. 83). Furthermore, it posits that meaning is not discovered but "constructed through the interaction between consciousness and the world" (Scotland, 2012, p.11), meaning that reality is socially constructed (Bogdan & Biklen, 1998).

In accordance with the epistemological position, this study employed IPA to interpret and make sense of participants' responses. IPA is a qualitative approach, particularly concerned with how the participants make sense of their personal and social world and the personal meaning they ascribe to those events (Smith et al., 2009). IPA is a two-stage interpretative process, known as double hermeneutics. Whereby, "the participant is trying to make sense of their world and the researcher is trying to make sense of the participants trying to make sense of the world" (Smith & Osbourne, 2015, p.53).

Because IPA has been specially developed to understand the lived experience of individuals (Smith, 1996), it is a method that best lends itself to answer the research question and illuminate the personal meaning making of CPs of working during the pandemic in ID, community services. Furthermore, IPA is most suited to examining topics which are complex and emotionally laden (Smith & Osbourne, 2015). This is pertinent, given the high levels of psychological distress observed among healthcare workers during the COVID-19 pandemic (Man et al., 2020). IPA has not previously been utilised to explore the proposed research topic. Lastly, IPA is not wedded to existing theoretical perceptions and allows for the construction of lived experience in its own right.

Sampling Design

Participants

The present study employed non-probability sampling. A sample of CPs working in community services for people with ID, in England was recruited using purposive sampling method. Purposive sampling is widely used in qualitative research and enables the identification and selection of information rich cases to ensure most effective use of resources (Patton, 2002). This sampling method is particularly helpful in identifying and selecting individuals or groups of people who are particularly knowledgeable about a particular subject or have experience in the phenomenon of interest (Cresswell & Plano-Clark, 2011). Furthermore, this sampling method allows for a selection of a homogenous sample of CPs working in intellectual disability services, in line with IPA requirements.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria are presented in Table 5.

Table 5.

Inclusion and Exclusion criteria

Criteria	Inclusion	Exclusion
Job role	Clinical Psychologist HCPC registered	Any other job role Trainee psychologists
Setting	NHS service England Community	Private providers Any other country of the UK Primary or tertiary care, inpatient settings
Patient group	ID and/or autism[4] Adults	Any other patient group Children

COVID-19 management strategies have detrimentally impacted on the wellbeing of people with ID. Many adults with ID who reside in the community are primarily cared for by parents

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[4] It is acknowledged that NHS Intellectual Disability services also provide support to people with autism.

or other family carers (Gilbert et al., 2008; McConkey, 2005). Due to parents' advancing age, they may be less able to provide the type and amount of care that their adult child with ID requires (Baumbusch et al., 2017). Moreover, adults with ID have greater needs for their independence and wellbeing to be supported creating a greater role for professional input (The Health Foundation, 2020). Therefore, adult services for people with ID have been selected for this study, excluding children's services. Given the role of CPs in delivering psychological interventions to this group (Alexander et al., 2020), the current research was conducted with practicing, qualified CPs and other clinicians who support in delivery of mental health care were excluded.

IPA requires participants from a homogenous group in order to make meaningful interpretations of a perspective (Smith et al., 2009). Given the variability of learning disability services across local areas, participants employed by the NHS were recruited, as published best practice guidance offers some national consistency in what services should look like across local areas (NHSE, 2015). Following devolution of the National Health Service in 1999, the policies and structures in the four countries of the UK have diverged (Jeffrey, 2007; Walshe & Davies, 2013). Therefore, this research study focussed on CPs working in England, excluding other countries in the UK. Due to Public Health England (2020) guidance for reduced face-to-face contact and other COVID-19 management strategies, significantly affecting delivery of mental healthcare within community services, the current research captured experiences of psychologists practicing in community settings.

Recruitment

The sample was recruited via the academic supervisors' professional networks. A research poster and the participant information sheet were disseminated via email among professional networks. The poster and participant information sheet clearly outlined study's aims, purpose, provided a general outline of the study, and advised participants to express interest in the study by contacting the researcher via email.

Smith et al. (2009, p.26) indicate that in IPA research, "there is no right answer to the question of... sample size". However, due to IPA's idiographic commitment, smaller concentrated samples are typically used. Smith et al. (2009) stipulated a sample size of 4-10 for professional doctorates. A total of 11 participants made up the sample of this research.

Sample characteristics

Participants were assigned pseudonyms to preserve their anonymity (*Table 6*). Of the 11 participants, majority were female (*n* = 10, 91%), with an age range of 32-54 years (*M* = 41). All except one identified as belonging to white ethnic group (*n* = 10, 91%), with one participant belonging to mixed/multiple ethnic groups: White and Asian. The sample consisted of psychologists of all grades from Clinical Psychologists to Consultant. Time spent in ID service they were employed at the time of interview ranged from 14 month to 27 years (*M* = 10 years).

Table 6.

Participant Pseudonyms and Gender.

Pseudonym	**Gender**
Charlie	Female
Alex	Female
Jamie	Female
Sam	Female
Max	Female
Ashley	Female
Jules	Female
Chris	Female
Andy	Female
Billie	Male
Pat	Female

Materials

Data was collected using semi-structured interview. The aim of the semi-structured interview is for the researcher to immerse themselves in the participant's meaning making and understanding of the phenomenon being studied. An interview guide (Appendix I) was devised using IPA principles, as discussed in Smith et al. (2007). See Table 7 for a summary of this process.

Table 7.

Process for Developing Interview Guide

Stage	Description
1	A literature review was conducted to identify the broad areas of interest. The overarching experience of working during the COVID-19 pandemic and themes of process and relationships emerged with an additional phenomenological and psychosocial focus.
2	A range of topic areas to be covered in the interview then emerged as COVID-19 management strategies, coping, client engagement and carer engagement.
3	Next, the sequence of questions in the most 'logical' order was established with a view that more 'sensitive' questions are introduced later in the sequence once the researcher has had the opportunity to establish rapport and the participant feels more at ease. In addition, a warm-up question and prompt not specifically related to the interview question was included to aid rapport building by giving the participant an opportunity to talk about something familiar like their job role, allowing them to relax into the interview.
4	The initial phasing of questions was developed along with prompts to elicit the participants, feelings, thoughts, and actions.
5	Once an initial interview guide was developed a mock interview with the supervisory team helped to restructure the order of the questions, the phrasing of questions and fine tune follow up questions and prompts.

Methods of Data Collection

Data was collected via one-to-one, semi-structured interviews. Due to COVID-19 Public Health restrictions, interviews were conducted remotely via MS Teams, a secure digital video conferencing platform utilised by the NHS. Participants engaged with interviews from their homes or places of work. The interviews lasted between 43 and 62 minutes, with an average of 52 minutes.[5]

Ethical Considerations

Ethical approval was sought and obtained from Coventry University Ethics Committee between the 5th and 11th February 2020 (project code P117341, Appendix J). All research activities were bound by the BPS Code of Ethics and Conduct (2018)[6].

To maintain ethical standards the participant information sheet (Appendix K) and informed consent form (Appendix L) were emailed to participants[7]. The debrief sheet (Appendix M) with signposting information was emailed to participants following verbal debrief.

Method of Data Analysis

The audio data was transcribed verbatim and analysed using IPA. The premise of IPA analysis is to learn something about the participant's internal world. Thus, the researcher must immerse themselves in the meaning making of the participant. "Meaning is central and the aim is to try and understand the content and complexity of those meanings" (Smith, 2007, p.66). Thus, the researcher engages in an interpretation of the transcript. There are six stages of IPA analysis (Smith, 2007); they are described in Table 8.

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[5] Interviews allowed for a dialogue to develop between researcher and participant with the researcher being led by the participant's experience with reference to the interview guide (Smith et al., 2007).

[6] All participant data was processed in accordance with the GDPR 2016 and the Data Protection Act 2018 and all participant data has been stored securely on a password protected Coventry University OneDrive folder.

[7] These documents informed participants about why they were asked to participate in this research, their right to withdraw from the study and outlined mechanisms to ensure anonymity and confidentiality. Prior to engaging in the study participants provided written consent, electronically, to participate in the study and to being audio recorded. A signed copy of the consent form was returned to them along with the reiteration of withdrawal procedure. During the interview a distress procedure was implemented. The couple of instances where participants were observed experience strong emotions (eyes welling up) the researcher asked the participant if they were ok and offered them an opportunity to pause. However, this was declined in both instances. Following the interview participants were debriefed verbally.

Table 8.

Stages of IPA Analysis and Description of Process.

Stage of analysis	**Procedure**	**Description**
1	Reading and re-reading	The first stage involved the researcher immersing themselves in the data by reading and re-reading the transcript. The researcher noted what thoughts and perceptions the interviewee invoked in them.
2	Initial noting	Exploratory phase, where the researcher examined language, connections and contradictions in the transcript and noted down interviewee's descriptions and implicit meanings.
3	Developing emergent themes	The researcher looked for emerging theme titles within each transcript, resulting from analysis, reviewing and collating responses that supported these themes.
4	Searching for connections across emergent themes	The emerging themes were merged into clusters producing a table of themes where clusters were given names and formed several subordinate and superordinate themes.
5	Moving to the next case	The researcher underwent the same process for each transcript however, some transcripts offered richer content and therefore more interpretation or themes. In moving from one transcript to another the researcher attempted to bracket ideas from previous transcript in an effort to be idiographic.
6	Looking for patterns across cases	The final stage of the process was to organise themes and identify patterns across all transcripts by identifying what themes were more prominent and consistent across participants which led to the development of superordinate themes.

Validity

Coding, interpretation and analyses conducted by the researcher were reviewed by the supervisory team to triangulate perspectives and ensure validity. Analysis annotation and thematic mapping is evidenced in Appendix N. Participant contribution to themes is presented in Appendix O and Appendix P presents additional quote excerpts to support the themes presented in the Results section. This commitment to rigour, transparency and impact is consistent with Yardley's (2008) recommendations for demonstrating validity in IPA research.

Researcher Reflexivity

The researcher is considered an integral part of the qualitative research process, therefore, awareness of the impact of one's own background and perceptions is an important consideration (Houghton et al., 2013).

The researcher aimed to remain mindful of biases and preconceptions that may have impacted study design, development and data collection to capture a true representation of the participant experience. The researcher was on placement during training and had previously volunteered in an ID service. During these times the researcher observed clinical psychologists to be, often, strong advocates for people with ID and very creative in their clinical approach which relied heavily on systemic principles to meet the needs of their clients. It is also important to point out that three participants were previous colleagues/acquaintances of the researcher which may have affected the interview process compared to other participants. The bracketing interview was conducted to identify any prior biases or preconceptions about the research topic[8]. The identified position of the researcher and its impact on the research process was mitigated via the use of reflective journal, discussion with the supervisory team and inclusion of prompt questions in the interview guide to elicit impact of feelings from participants.

Results

Analysis elicited two superordinate themes and five subordinate themes (Table 9), supported by excerpts in Appendix I. Representations of themes across transcripts are evidenced in Appendix J.

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[8] Bracketing interview assumptions: COVID-19 pandemic would have caused significant disruption to ID services and psychologists would have experienced significant struggles and frustrations in supporting their clients due to the initial suspension of face-to-face work; psychologists would have felt that their clients have not been adequately considered in government guidelines and by services; some clients may benefit from remote ways of engaging with service provision; psychologists would avoid talking about the emotional impact, on themselves, of working through the pandemic.

Table 9.

Superordinate and Subordinate Themes

Superordinate Themes	**Subordinate Themes**
Survive or Thrive	"I feel like a speck in the base of a tsunami"
	"My headspace is filled up"
	"When the rule book gets thrown out the window"
"Left to their own devices"	"God only knows what's going on behind the closed doors"
	"Lots of red tape to get around"

Survive or Thrive

The superordinate theme ***Survive or Thrive*** highlighted the challenges and successes clinical psychologists experienced while working during the pandemic. Clinical psychologists within ID services endured an emotional onslaught throughout the pandemic, impacting their practice. They survived by utilising defence mechanisms and by connecting with others. The surreptitious blurring of boundaries between work and home hindered their ability to navigate challenges, insidiously encroaching on psychologists' personal lives. However, despite this some psychologists flourished working in new ways. Working through the pandemic brought about a number of unanticipated benefits. This superordinate theme includes three subordinate themes of *"I feel like a speck in the base of a tsunami*", "*My head space is filled up*" and *"When the rule book gets thrown out the window",* described below.

"I feel like a speck in the base of a tsunami"

The impact of the pandemic was recounted as "*quite seismic to start with*" (Billie, 102), describing the abrupt shift from face-to-face to remote working. The initial uncertainty about the new way of working, limited availability or capacity of technology, and significant concerns about clients' wellbeing in the context of suspension of social care provision and reduced carer support was described as "*the mind melting level of nightmare*" (Charlie, 153-

154). The stresses and uncertainties of working during the pandemic took a significant emotional toll on psychologists' wellbeing:

> "*I've sort of said that kind of anxiety, I noticed, sort of, before going into work each week, the day before feeling that, that sense of real anxiety and almost like panic within me of not, not really knowing what we're doing and when is this going to end*" (Pat, 190-193).

Psychologists' commitment to provide adequate psychological services to their clients via telephone or digital videoconferencing platforms left them feeling like their "*formulations are missing a big piece of the puzzle*" (Ashley, 341) and they struggled to connect with clients "*because I'm missing so much in terms of um, that visual feedback, I guess, what's going on for a person*" (Alex, 321-313), often experiencing feelings of guilt and inadequacy:

> *"That kind of makes me think you know, I'm not doing my job right because like, you know, I don't think I'm actually able to sort of provide the service I want to provide to people"* (Max, 251-252).

The lack of connection was also evident in psychologists feeling cut off and disconnected. Feelings of disconnection from colleagues and clients arose due to barriers remote working presented. Alex "*found remote working to feel quite isolating*" (Alex, 66), while for others the physical, social distancing restrictions and use of PPE provided additional barriers to connection:

> "*The experience of going into any of the bases but all being very separate and in separate rooms and the screens between you and the service users*" (Jamie, 160-161).

Witnessing the impact of the pandemic on their clients, "*risk increasing and a lot of people hitting crisis*" (Ashley, 111), coupled with the protracted impact of the pandemic, led to feelings of burnout "*like you're walking through treacle*" (Chris, 92-93) which "*wasn't at all sustainable*" (Max, 295-296). This resulted with some psychologists having to "*take some emergency annual leave*" (Jamie, 289) to survive. Surviving the emotional onslaught of the pandemic was evident in the language psychologists used when recalling their experiences: "*we have made our way around that*" (Jules, 258), "*we've ridden the storm*" (Andy, 365-366), and "*muddle through it*" (Billie, 103).

While psychologists discussed overcoming these obstacles by actively establishing means to connect with one another: "*there's all these kind of things that we've put in place to sort of be able to support each other*" (Max 219-220), there was evidence of some psychologists using defence mechanisms such as denial to survive:

> *"There have been points where I thought, I don't know why I feel so stressed (laughs)"* (Jamie, 164-165).

"My headspace is filled up"

Enduring the pandemic was hindered by psychologists reporting a merging between their working selves and their personal identities due to the blurring of boundaries between work and home life which remote working appeared to perpetuate. Shifting boundaries and the demands of juggling home and work life often left psychologists feeling exposed and unsafe, inevitably encroaching on their personal lives.

Remote working left CPs in a perilous state, feeling exposed an unsafe as they struggled to "*separate work from home*" (Ashley, 226). The lack of a physical boundary between work and home left no space to decompress after work:

> "*When you're kind of working on your kitchen table, and all you're doing at the end of the day is closing your laptop and taking a few steps to the sofa. It's, it's a bit, um, it feels a bit trickier to have that kind of work/ home separation"* (Alex, 150-152).

Furthermore, the increased demands of juggling looking after children, home schooling and remote working further impaired capacity to maintain professional boundaries:

> "*At first children were still in school. And so you could kind of maintain a little bit of work life balance. But then when I've got three young boys and dogs, and parrots and all that stuff in the background, actually maintaining that professionalism and keeping that kind of barrier, that boundary between home and work life balance became a little bit more challenging"* (Jules, 130-133).

Work was insidiously invading psychologists' personal lives:

> "*Because you're not leaving the office anymore in closing the door. That's difficult because it infiltrates into your house*" (Chris, 336).

Work intrusions such as carrying out therapeutic work in the home with children present was felt to be "*a real invasion of my privacy*" (Sam, 150). Another psychologist described feeling uncomfortable at bringing work home "*so, there's groups and then forensic sorts of issues and I didn't like bringing any of that into my home*" (Jamie, 77-78). Moreover, psychologists encountered feeling vulnerable as the grip on professional boundaries appeared to slip "*I have shared with one, one particular carer, perhaps more than I feel happy with having shared*" (Max, 432). The unwanted intrusions of work into home life left CPs feeling consumed by work:

> *"There's not such clear distinctions…. and that, that has quite a negative impact because it means that outside of work I'm not devoting my attention and my energy to the things that I think are important"* (Sam, 262-266).

"When the rule book gets thrown out the window"

The experience of surviving the pandemic was contradicted by some psychologists, for whom the pandemic "*opened doors*" (Jules, 187) allowing them to thrive in new ways of working:

> "*It's just expanded our repertoire really in a way that we can engage with people differently which, across LD we get to be creative anyway, but it's just an area that we haven't really played around with. It's forced us to step out of our comfort zones and get used to this technology and see who it might work for."* (Ashley, 374-377)

Some clinicians flourished during the pandemic because working from home better suited their lifestyle:

> "*I've been given a flexibility that I never would have been afforded before this pandemic hit*" (Andy 277-278).

The change to usual practice brought about a number of "*silver linings*" (Andy, 301) which helped psychologists to navigate the challenges they encountered and, in some cases, conferred significant benefits. Clients with ID were empowered by remote technology "*it's* *given them a real sense of accomplishment and an independence*" (Sam, 290-291). Another unanticipated benefit of remote technology was how "*clients (with ASD) engaged above and beyond any level they've previously engaged with [using remote technology]"* (Jules, 53-54). When commenting on this a number of psychologists said they were "*surprised*" (Jamie, 312) indicating that psychologists themselves underestimated their clients' abilities of working in new ways.

"Silver linings" of working remotely benefited psychologists and in turn carers, as one clinician described:

> "*Carers have seen a real benefit, like the fact that we're not having to travel all the time for meetings, we get a much better attendance, they're getting more professionals there for meetings about the person they're supporting, when previously they, they would really struggle*" (Ashley, 289-292).

The pandemic impacted everyone, and the collective experience "*something that our clients are going through at the same time as us*" (Max 34-35) was unifying. Working together through adversity provided opportunities for closer networking and "*more joined up thinking*" (Alex 222-223) between professions and services, fostering "*a definite kind of sense of camaraderie*" (Billie, 207). This helped to develop closer relationships "*we are even more kind of bonded than we were before*" (Ashley, 139). Counterintuitively, working remotely provided new avenues for connection:

> *"Looking at other's lives and actually the first time that somebody else's doorbell rang and everyone else's dogs went crazy and all that was actually quite an opportunity for bonding and establishing relationships in different ways"* (Jules, 168-170).

"Left to their own Devices"

This superordinate theme described psychologists' experiences of people with ID as insignificant and forgotten within society and the systems around them during the COVID-19 pandemic. Psychologists felt abandoned in their battle with services in advocating for their clients, at times feeling powerless to help. This superordinate theme contained two subordinate themes, *"God only knows what's going on behind the closed doors"* and *"Lots of red tape to get around*", described below.

"God only knows what's going on behind the closed doors"

Psychologists discussed, throughout, their experiences, of people with ID and their needs being completely disregarded:

> "*They 've [clients with ID] been very much overlooked in this pandemic, you know, once again, in societies they have been subjugated, and so many of the guys we're supporting, just, don't just don't have those other support networks out there*" (Pat, 86-88).

The pandemic brought into sharper focus how cut off people with ID generally are in society:

> "*It has really become apparent to me, as well, how isolated some of these people are. For some people, it [the pandemic] hasn't really changed what they do"* (Jamie, 305-306).

This exacerbated psychologists' concerns that their clients were "*left just to try and make sense of this with no support*" (Pat, 318-319). One psychologist remarked how closure of day services and other social supports in response to managing spread of COVID-19 compounded this situation further, adversely impacting client's mental wellbeing:

> *"A lot of people had things that they really relied on, completely stopped. So day services and um… their support workers… stopped coming to be able to take them out and then, I suppose smaller things, as well, like one person I knew, used to wander along to the local hairdressers and he'd spend sort of 20 minutes just chatting up, um, chatting and gossiping. But it was a really important part of keeping him healthy and well*" (Jamie, 32-36).

Feelings of abandonment and loss were particularly poignant when clients' lives were lost due to COVID-19:

> "*And there's times when, when we are going into seeing people who are at the end of life, or we've got people we've known for many years, who were in hospital, and we know they're going to die. And previously, we, team members, would have gone, seen*

> *them and we haven't been able to, or we've known of clients of ours, who've died alone*" (Charlie, 336-336).

Vehemently advocating for their clients, psychologists highlighted their vulnerabilities and emphasised that they "*are more in need than ever*" (Pat, 152) during the pandemic. Some commented on inadequacies of government communication of COVID-19 guidance, in meeting the needs of people with ID "*many of our guys, they don't, sort of follow what's going on in, in the media*" (Pat, 287-288) leaving them cut off and unable to look after themselves:

> "*They're not following government guidelines. They've had one mask the whole pandemic, and they've never changed it or washed it. They don't get it*" (Chris, 350-351).

CPs appeared resentful of the indifference their client group were subjected to. Government COVID-19 management strategies were inconsiderate of the needs of their clients and presented a multitude of obstacles with one psychologist describing masks as "*definitely a hindrance and a barrier to relationship forming*" (Andy, 549-550). So much communication was missed when part of the speaker's face was covered, communication that their clients heavily relied on. Another clinician reflected that "*service users have really struggled to understand this concept [social distancing], or have worried about it excessively*" (Jules, 345-346), again highlighting government guidance as insufficient to adequately meet the needs of people with ID. Another psychologist pointed out that COVID-19 management strategies could in themselves be traumatising to clients:

> "*And for one lady, particularly, PPE was such a trigger, she had a trauma around a hospital admission, not COVID related, but any kind of medical equipment, gloves, masks, aprons, was quite a trigger to her trauma*" (Ashley, 322-324).

Similar to government directives, CPs were disappointed with the local, service guidance for remote working which "*hasn't necessarily attended to kind of what it might be like in learning disability settings*" (Alex, 29-30). Moreover, NHS Trusts' response to stop face-to-face visits and the "*abandonment that elicits [in clients with complex trauma] has often sent people off into crisis positions*" (Pat, 444), highlighting not only the lack of consideration of clients' needs but the disastrous impacts of poor service decisions.

In addition to the inequity of government and service COVID-19 response, the pandemic exposed the social inequalities people with ID experienced, as reflected by Ashley:

> *"A lot of our folks don't have access to laptops and smart phones and if they do have access even through their own means or family or carers they're not very used to using them and it can be really hard with a learning disability to learn new stuff"* (Ashley, 38-40).

Reliance on staff or family to facilitate remote assess added extra complexity, exposing "*issues around confidentiality and safety and security*" (Charlie, 75) that presented an additional challenge to therapeutic work. Whereas, telephone contact, due to lack of visual cues, presented additional "*issues around risk and monitoring risk*" (Jamie, 48),

"Lots of red tape to get around"

Psychologists felt they were left on their own, to navigate the challenges of the COVID-19 crisis in a system ill equipped to meet the needs of its client group, often having to fight the bureaucracy of the system. Feelings of abandonment were evident in psychologists' narratives: "*doesn't feel like they've [senior management] been particularly present in any of this*" (Pat, 163) with Chris vividly describing being forsaken:

> *"I remember being in the office at the start and it was just like, I was there on the first day. None of…. the... higher, our manager wasn't there. I think I was the only senior member in the in the office, and there were just loads of us there all going: 'what are we meant to do'? (laughs) So, because all of the, my Trust's, like directors, everyone were in a meeting all day trying to plan what to do, they've forgotten to tell the people on the ground: 'hey, go home, like or at least some of you go home*'" (Chris, 143-148).

Moreover, psychologists described how the lack of "*clear guidance*" (Charlie, 140) elicited feeling directionless, underscored by a sense of "*who is kind of steering this ship, really*?" (Billie 119), leaving clinicians to manage alone.

Advocating for their clients' access to digital technology to access support, one psychologist described as "*having to almost fight with social care to get them to give some funding*" (Chris, 49). Having to "*have to justify why we want to see people face to face*" (Billie, 95-96) and battling with care providers to meet clients' needs was recounted as "*coming up against brick walls*" (Chris, 58).

The needs of people with ID amplified significantly during the pandemic: "*our referral rates to psychology have rocketed, and the level of complexity, the level of need is just dreadful*" (Charlie, 252-253). Furthermore, CPs feared for their clients' safety due to their increased vulnerability to COVID-19 and clients "*dying disproportionately, compared to the general population*" (Ashley, 63-64). Moreover, the support that people with ID and their families relied upon to keep the person with ID well were no longer available:

> "*All their activities have gone. Um… you know, they've, they've no, they've no day support, they have no jobs, they have no… um… social interaction. Some of them um… won't leave the house and going for their daily exercise and do their walking. Um…, you know, I fear for what's coming"* (Max, 264-266).

Feeling abandoned and working in a flawed system increased pressure on psychologists to help their clients, which was evident in the pressure to make rushed decisions:

> "*This gathering sense that we need to rush in, rush -in, rush -in, rush -in and now because we're not travelling, we can, you know, we can do more, we should see more people, we should do more"* (Jules, 211-213).

To help those in distress clinicians resorted to subverting referral criteria and accepting clients whom they knew were not eligible to access ID services because of the level of need and no other support available:

> "*So, I know that over the summer, between myself and my colleagues, we've probably each had at least one to two clients who we knew didn't have a learning disability. But because we couldn't establish that very clearly at the beginning, we've ended up picking those pieces of work up. Um… because there's a distressed person at heart of it. And, they've been quite complex and quite involved. And, we're now in the position of probably having a caseload that is much bigger than we should have because of it"* (Jules, 379-384).

Navigating the bureaucracies of the system, some psychologists appeared utterly powerlessness to help people with ID, as implied by feeling unable to "*do anything about* *that*" (Billie, 372) and experiencing being called upon to intervene and feeling somehow responsible at not being able to help, as powerfully described by Chris:

> "*What it is, is at the crux of all of this, I think is… that you don't have a magic wand, you can't take COVID away, you can't allow your service users to go back to day services and their activities, but people are still looking at you to come to come fix this problem*" (Chris, 282-284).

Feeling powerless was amplified by processes within the system such as possible redeployment: "*a looming threat of you might be pulled out of this job any minute*" (Ashley, 217) and Pat describing feeling unsupported by the service and senior management:

> *"And I think, particularly when you feel like you've not got the, maybe the backing of management, when there's these other pressures coming down on you, I think that's been really, really hard and really frustrating, really, and not always feeling that understood or valued by the service, I think, particularly at management level when there's more pressures being put on at a time when we're already struggling so much. I think that's quite hard"* (Pat, 425-429).

Discussion

The current study aimed to explore CPs' experiences of working with people with ID during the COVID-19 pandemic. Two superordinate themes emerged: Survive or Thrive and "Left to Their Own Devices".

The start of the pandemic was experienced as assault of emotions by CPs. The prolonged exposure to stress and uncertainty of working during the pandemic inevitably, had a deleterious effect on CPs mental wellbeing, leading to burnout. This in consistent with findings of Langdon et al.' (under review), and McMahon et al.' (2020) surveys of psychologist and healthcare workers, respectively, working in ID settings and numerous other studies reporting burnout in healthcare providers (Sharifi et al., 2021). It is unsurprising given the multitude of challenges CPs experienced in their role as a direct impact of COVID-19 related changes to usual practice.

CPs reported shortcomings of conducting psychological interventions remotely due to reduced visual cues, resulting in incomplete assessment and formulation. These concerns were noted by Langdon et al. (in print) and are consistent with findings of a survey of 335 psychotherapists delivering remote therapy who also reported reduced visual cues as one of the challenges of remote working (McBeath et al., 2020). The authors also reported psychotherapists' reduced confidence in remote work. Similarly, CPs in the current study reported finding remote interventions inferior to delivering therapy in person. However, the current study also found that CPs experienced feelings of inadequacy and guilt when conducting therapy remotely. These feelings may be conceptualised as arising from lack of familiarity of delivering psychological interventions remotely and may be reflective of the broader issues of NHS digitisation. Particularly, the shortcomings of the National Programme for IT, with persistent use of outdated systems and chronic underinvestment (Controller and Audit General, 2020). A large sample study by Pierce et al. (2021) conducted in USA, found that registered psychologists conducted only 7.07% of their clinical work using remote digital technology prior to the pandemic and during the pandemic this figure rose to 85.53%, indicating a rapid uptake of remote interventions. The NHS has lacked the infrastructure to respond swiftly to such huge demand for remote technology.

Despite the challenges of delivering remote interventions CPs unequivocally found that this mode of therapy was preferable to some client groups, such as people with autism. Similarly, a recent survey of front line staff working with people with ID and/or autism found staff widely endorsing remote delivery of services (Sheehan, et al., 2021). Moreover, CPs experienced remote consultation as fostering a sense of empowerment for these individuals as they succeeded in mastering remote technologies. This offered clients, who may not have been offered interventions remotely a choice and ensures parity of mental health interventions for all clients. Interestingly, a number of CPs were surprised by their clients' ability to adapt to new ways of working. This may highlight a larger issue of people with ID, their abilities and their resilience being underestimated.

Current findings suggest that the abrupt shift to remote working presented unforeseen challenges to maintaining a work / life balance. The absence of a physical boundary between work and home negatively impacted CPs, leaving them feeling unsafe, exposed and intruded upon. Similar concerns were noted by Butler et al. (2021) and Langdon et al. (under review). This is of concern, as work/home balance represents an overall appraisal of personal effectiveness and satisfaction with work and home roles (Greenhaus & Allen, 2011). As remote working and blended approaches become the norm in healthcare, there is a need for greater consideration of how boundaries can be implemented successfully to ensure staff effectiveness and wellbeing. The BPS has produced guidance for sustainable working from home, emphasising the need to set boundaries and how this can be achieved (BPS, 2020).

Findings of the current study exposed the loneliness and disconnection CPs felt as a result of remote working. Clinicians instinctively coped by seeking out connection with their colleagues, by setting up peer support groups and informal supports. The BPS recognise that working from home can be isolating and that loneliness can lead to stress, anxiety and depression and recommends seeking out and maintaining social connection at work (BPS, 2020).

The pandemic has significantly disrupted CPs work environments and practices. While some clinicians felt galvanised by this disruption, making connections and developing new ways of working, others felt demotivated and alienated from their colleagues. Similar dichotomies in responses of healthcare staff have been reported by Butler et al. (2021). The current study, however, offers no indication on what internal or external factors contributed to CP's ability to flourish or struggle during the pandemic. Literature suggests that in responding to complex and unpredictable disruptions to clinical practice a team based approach can be beneficial. Effective team-based approach comprises of collaboration, open communication, shared vision and goals and mutual trust and respect (Choi & Pak, 2007; Mitchell et al., 2012). Established team working processes were significantly impaired by staffing shortages due to redeployment, clinicians shielding and move to remote working. Moreover, CPs experienced confusing communication and lack of direction from senior management, feeling abandoned, unvalued and unsupported. Extreme stress has been shown to negatively impact leadership style (Sandler, 2012) which can impair the quality of support provided by leaders. Moreover, supportive managers foster better mental health in their teams (Brooks et al., 2018), this may be a contributing factor to burn out reported by CPs.

This study highlighted the vulnerable position of people with ID during this pandemic. CPs experienced people with ID as completely neglected by governmental policy and changes to mental health service provision, emphasising the digital poverty and exclusion people with ID encountered. These issues have been well documented in recent literature (Alexander et al., 2020; Burgess, 2020; Courtenay, 2020; Embregts et al., 2020) and suggests that people with ID may require additional adaptations to support effective use of technology and therefore access mental health provision. In addition, CPs in the current study struggled to navigate the bureaucracy of systems that were not fit to meet the needs of people with ID, often feeling powerless. Willner at al. (2020) and Patel et al. (2021) highlighted similar feelings of powerlessness as expressed by carers of people with ID during the pandemic, highlighting the need for robust policy and service processes for ensuring adequate mental health support for clinicians and carers.

Strengths and Limitations

The current study supports the body of literature on the negative impacts of the pandemic on the wellbeing of CPs. However, it adds to the evidence base by demonstrating CPs ability to adapt to extremely challenging circumstances. This study exposes the vulnerabilities of people with ID and the gaps in service provision to adequately meet their needs. Despite this, it is important to note the limitations of this study. Firstly, the study consisted of majority female participants, which although representative of the field of clinical psychology, may not adequately capture experiences of male CPs. Secondly, the small sample size, which is appropriate for IPA methodology, limits generalisability of findings to the broader experiences of CPs. Lastly, the self-selecting recruitment process may have inadvertently resulted in a sample of respondents being skewed towards those with higher levels of distress which may have motivated them to respond.

Implications: Policy and Practice

Given that going forward the NHS is likely to adopt a blended style of healthcare delivery, offering both in person and remote intervention options there is a great need for policy to address the digital poverty of people with ID. Policy may need to focus on improving digital literacy of clients and their carers, as well as ensuring financial provision to ensure equity of access to technology.

ID services may benefit from developing policies and procedures for delivering remote interventions that better meet the diverse needs of people with ID. It may be beneficial to explore adaptations to digital technology to accommodate client's needs. Additionally, ID services may benefit from investing in leadership training and bolstering support processes for managers. This will help to ensure they are able to support their teams effectively in the future.

CPs may benefit from continued support in use of digital technology in order to conduct remote interventions safely. Similarly, CPs may need robust protocols in place for assessing and monitoring risk during telephone consultations. As such, CPs may benefit from increased supervision to manage process and risk issues that may arise from remote working.

There is a clear need for improved access to mental health support for clinicians. This need has been acknowledged by NHS England, who in collaboration with NHS Improvement have pledged to invest an extra £15 million to strengthen mental health support for nurses, paramedics, therapists, pharmacists, and support staff. The implementation of staff mental health support hubs by NHS Trusts has commenced.

Suggestions for Future Research

This research provides a perspective on how people with ID engaged with remote delivery of services through the CPs' lens. However, research into people with ID's experiences and those of their carers will be helpful to truly understand their views of remote delivery of mental health care services.

Given the variability of CPs’ response to the challenges presented by COVID 19, it may be pertinent to examine factors affecting individuals’ stress and resilience to develop more effective strategies to support clinicians.

Conclusion

The pandemic has significantly disrupted CPs capacity to provide mental health care to people with ID, whose needs have been neglected during the pandemic. Going forward, this presents an opportunity to adapt mental health service provision to support CPs to adequately meet the needs of this client group in the digital age of treatment delivery.

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Chapter Three: Reflections on my Research Experience

Overall word count: 2981 (figures and references)

Introduction

The aim of this chapter is to reflect on my experiences of research to date, with particular emphasis on conducting my doctoral research and the challenges that I encountered during this process, what I have learnt from this experience and where this learning will take me in the future.

Reflection is defined as “a generic term for those intellectual and affective activities in which individuals engage to explore their experiences in order to lead to a new understanding and appreciation” (Boud et al., 1985, p.19). The concept of the ‘reflective practitioner’ was introduced by Schön (1983) to describe an aspect of clinical practice that utilises reflection as a tool for revisiting experience both to learn from it and for the framing of complex problems of professional practice. Research is an essential component of clinical training and practice, even when the clinician is not actively engaged in conducting research, as research knowledge is essential to understand and appraise the evidence base which guides clinical practice. Moreover, the reflective scientist-practitioner model dominant in UK clinical psychology doctoral training emphasises “self-awareness and sensitivity” (BPS, 2019, p.16), which resonates with me. Personally, reflection allows me to develop of a deeper self-awareness through engaging in reflective processes with particular focus on the emotional experience and exploring the role of my collective past.

I will be using Compassion Focussed Therapy (CFT) and in particular, the Three Circles Model of Emotion (Figure 2; Gilbert, 2009) to structure my reflections. The model describes a tripartite emotion regulation system, based on evolutionary psychology and comprises the Threat System, the Drive System and the Soothing System. Balanced use of all three systems is essential for effective emotional regulation and an underdeveloped Soothing System can make it harder to regulate emotions such as anxiety, anger and self-criticism. This is something I have experienced to varying degree throughout my doctoral research. As a therapeutic approach, CFT teaches purposeful cultivation of the Soothing System, by caring for self and others, which helps one to feel safe and confident in navigating challenging emotions and life’s difficulties (Kolts, 2016). This appeals to me personally, as this approach fosters courage to face challenges and promotes personal agency and autonomy.

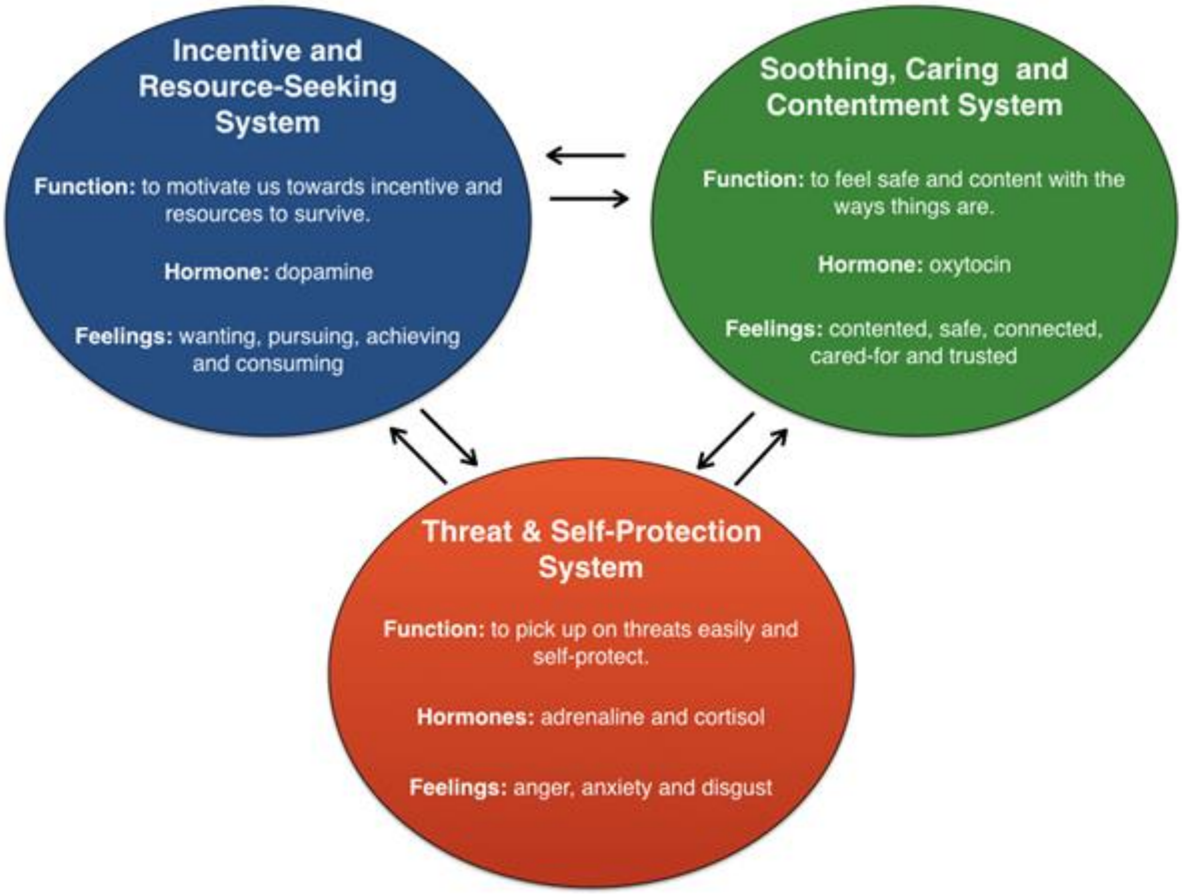

Figure 2.

Three Circles Model of Emotion (Gilbert, 2009).

The Research Journey: The origins

Incredulously, my research experience spans sixteen years from undergraduate degree, through to, studying at MSc level in Forensic Psychology and culminating in my doctoral research. However, I have never felt completely confident in my research skills and abilities. I saw myself as an imposter, whose accomplishments were achieved through luck and contingency, and who will inevitably lose all credibility and be exposed as a charlatan. Clance and Imes (1978) coined the term “imposter syndrome” which refers to “a pattern of behaviour wherein people (even those with adequate external evidence of success) doubt their abilities and have a persistent fear of being exposed as a fraud” (Mullangi & Jagsi 2019, p.403). Hutchins (2015) has demonstrated that imposter syndrome is more prevalent in those with advanced degrees, those with traits of conscientiousness, achievement orientation, perfectionistic expectations and those who work in highly competitive and stressful occupations.

Looking back, this academic insecurity emerged from an idealisation of academia. I remember learning about the classic psychological experiments of Pavlov, Milgram, Zimbardo, and Asch amongst others, at college. I was captivated by their studies and how they shaped our understanding of human behaviour and research ethics, given the controversies surrounding some of the experiments. I really felt that academics had some real value in terms of making positive contributions to our understanding of the world and their effort, curiosity, courage and discovery were inspirational to me. Scientific rigour and the unending quest to learn and generate new thinking were the things that really stirred my passion. This elevated academia to some unattainable pedestal. I believe, that coming from a non-academic family, the principles and values one had to uphold to conduct research ethically were captivating and seen as a great responsibility, that was hard to achieve. In fact, research suggest that imposter behaviours are linked to family background, and are more prevalent those people who are the first of their family to exceed norms or expectations for success in career, financial or educational goals (Harvey & Katz, 1985). This is true in my case.

Publishing my Masters thesis was an achievement of a life’s goal. However, the experience was one of hollow victory diminished by my perceptions of my work being published due to a lack of research in the field and the low impact factor of the journal. All the while I anticipated some public refutation of my findings, at any moment. Thus, going into my doctoral research I wanted to do a ‘good job’, I wanted to ensure that I provided a decent platform for my participants where their voices will have some impact.

Doctoral Research and Practical Problems

Empirical study

I had an idea I was passionate about: doing research with carers of forensic inpatients, exploring their experiences of the admission of their relative to forensic inpatient services. I hoped that by giving a voice to this group through research, perhaps in some small way, carers’ experiences would improve. I felt confident about my research because I knew how I would access participants, I have gone through the process of obtaining approval from the

Health Research Authority and I did not anticipate any major challenges. For someone who procrastinated with academic pieces of work, I was, for once, ahead with my research.

However, I soon encountered recruitment difficulties, namely red tape from the additional sites I approached to ensure viable recruitment opportunities. COVID-19 pandemic impacted on this process further with some sites unable to further support my research due to reduced capacity. Because I am so driven to get things done, I sprang into problem solving mode and took these challenges in my stride, persevering with recruitment, despite feeling irritated with these setbacks. My Drive system was dominating here. I continued to approach other sites. In the process, I developed a deeper understanding of research ethics by exploring the ethical dilemmas inherent in my research. An ethical review committee raised concerns about the potential detrimental impact carers discussing their experiences of their relative's admission may have on the service user's mental health. Despite developing protocols to mitigate this risk, this resulted in carers being selected by the responsible clinician based on service user approval and other criteria, impacting participants free choice to take part in this research. Thereby, making the participant selection unethical and my research unpublishable. Although debating ethical issues with service users, heads of service and with input from their legal teams were a great learning opportunity, such scrutiny of my project made me feel out of my depth, raising my anxiety, activating my Threat System. I noted feelings of anger rising, towards the people I was dealing with. These feelings were exacerbated by lack of progress and a fast approaching thesis deadline. I found myself having to soothe more with increased social contact, getting out into nature and incorporating increasingly more treats.

I approached another site for participant recruitment. I had the opportunity to present my research proposal at their trust wide research meeting. This again was a great opportunity for development. Presenting my research to a large group of clinicians was nerve-racking but allowed me to convey my passion for my project and to advocate for this group of carers. I was also able to discuss broader research issues such as difficulties recruiting in this population and considering possible barriers such as overrepresentation of carers from minority backgrounds. It felt good to share my ideas with other clinicians conducting research in forensic settings and helped me to develop it further. I felt like I had grown from the initially, anxiety inducing experience, building my confidence. However, these positive research experiences were soon overshadowed by the lengthy local NHS Research & Development (R&D) processes of getting approval to conduct my study. In my experience, NHS trusts do not differentiate student research from commercial studies, which tend to have much longer time frames for completion and as such the bureaucracy is overwhelming. Despite emphasising that this was a student project and the short timescales involved, the process dragged from July to December, with no R&D approval in sight. Thankfully, the UK government has now launched an independent review of UK research bureaucracy with a view to removing unnecessary red tape in the UK research system (Department for Business, Energy & Industrial Strategy, UK Research and Innovation, and Amanda Solloway MP, 2021).

By November I had already conducted two interviews with carers I recruited from a non-NHS organisation. Despite recruiting the required number of participants being crucial to the success of clinical research many studies fail to achieve the desired recruitment rate (Newington & Metcalfe, 2014). However, two participants were considerably short of my recruitment goal. I had no other possible avenues for recruitment and during a research supervision meeting in December we discussed the possibility of terminating my study and considered an alternative project that could be accomplishable by the thesis deadline. I was in turmoil, I felt that I had made a commitment to carers, this is what I was passionate about and the thought of ending my project was deeply upsetting, especially as two carers had already given up their time to share their difficult experiences with me and were extremely keen to improve the system for others. I had a duty and a responsibility to have their stories heard and I also needed to graduate. I had to be pragmatic, there were no other means of recruiting carers and the thesis deadline was only three months away. I really struggled to inform my participants that I was terminating the first project and procrastinated for a fortnight, feeling like I was letting them down. I felt it was unethical to delay informing them and had to really push myself to find the courage to turn towards the difficult feelings. Utilising my compassionate self to talk through this helped me self-soothe and lessen my discomfort.

I felt like I had let the participants of my first study down. This feeling intensified my desire to represent my new participants (CPs working in ID services during the COVID-19 pandemic) and as such I was very keen to publish my new project, right from its conception.

Especially, given the lack of research within ID field and the enthusiasm from my research participants to disseminate the findings within ID forums. Moreover, I am aware of the gender bias in publication of psychological sciences, with men publishing more articles per year than women across most career stages. Also, the prevalence of women authors declines linearly as the impact factor of journals increases (Odic & Wojcik, 2019), further intensifying the drive to publish. However, knowing that I am aiming to write for publication meant writing to, in my mind, some unattainable standard, I perceived academic writing to be. This raised my anxiety, and feeling like an imposter, which, to some degree, lingered throughout.

However, commencing a new project presented an opportunity to switch off the Threat mode, of feeling continually anxious about recruitment and feeling irritated and angry with processes and people, which was exhausting, and engage the Drive System. This was appealing because the drive mode is probably my preferred way of being and when a deadline is looming I am very adept at just 'powering' through and getting things done. I find the achievement of goals very motivating and it makes me feel in control. I had a lot to do, starting from the beginning but having a tight deadline galvanised me into action and having a new direction made me feel like I was making progress. Conversely, restarting a project and feeling behind inevitably led to me comparing my progress to that of my course mates which raised my anxiety, significantly. I continued working and became more and more stressed, feeling an overwhelming sense of dread about the work, giving up on exercise, one of the few things that personally keeps me well, and working longer hours, having less time for relationships and rest.

The most challenging period of writing the thesis was the last month before submission during which I analysed my data and was writing up the results. I found myself overwhelmed with detail, describing the data instead of interpreting it. The long and complex process of attempting to make sense of what my participants have said and the added pressure of some internal integrity to do this process justice, felt overwhelming. The more I immersed myself in data the more consumed I became with detail until codes refused to aggregate into themes. Smith et al. (2009, p.114) recommend using small samples of "up to six participants" for novice IPA researchers. I do believe that having a sample of nearly double that figure complicated the process. The reality of time running out only compounded the problem. I found myself continually oscillating between operating from the Drive system to the Threat system, as pressure of the impending deadline increased. My experiences appear to be consistent with other researchers. A recent survey conducted at Kings College London, of doctoral student and research staff about the impact of COVID-19 pandemic on the research community found more than three quarters of respondents reported experiencing a negative impact of lockdown on data collection (Byrom, 2020). More than half also reported a negative impact on data analysis and writing. Moreover, three-quarters of respondents reported low levels of mental wellbeing (Byrom, 2020).

It was very helpful in the earlier stages to see my supervisors modelling a calm and planned approach to help me manage my project, which, in the latter stages helped to utilise supervision to discuss pressures I encountered. The supervisory team was validating and advised me to step back from the work and practice some self-care. It was this distance from the data and an opportunity to process the information that helped with the interpretation and emergence of themes. The interpretations were made initially, with much trepidation as I did not want to eclipse the experiences of my participants with exaggerated claims and it took a few iterations of this process to feel confident in my interpretations. Practicing self-care helped to replenish my resources and ultimately improved the quality of my work. This is something that I have had to consciously do, give myself the permission to take time away from the work to improve my endurance and prevent myself from burning out.

Systematic Literature Review

I was apprehensive about my Systematic Literature Review (SLR) due to the process being an unknown quantity. I felt overwhelmed with the initial literature search and struggled to find a suitable review topic but one did emerge and I felt really interested in reviewing psychiatric nurses’ experiences of workplace violence. Given the unfamiliarity of the task and the rigorous process of conducting a systematic review coupled with thoughts of writing for publication made me perceive the task as exceedingly complex and superlative. The imposter feelings resurfaced, raising my anxiety, leaving me feeling doubtful of my abilities. This activated my Threat System. Wanting to protect myself I avoided starting this daunting task altogether. Thus, months passed without me daring to commence the SLR. When I finally did start, I came across a published protocol for a similar systematic review with a much wider scope. I had to concede that I will need to find a new SLR topic. Similarly, to the empirical paper, I had to choose a new area to review, that was related to my research topic. This left me feeling less enthused about this part of the thesis. Thus, the progress on the project was quite slow. However, despite perceiving the SLR as an onerous task, breaking it down into smaller activities really helped to speed up the process and achieving each small section became quite motivating. This really helped me to appreciate how useful this technique is in managing a large project. I was surprised to enjoy this part of the thesis, especially learning about interrater reliability and kappa coefficients. Having a dabble at statistics again, reminded me that I really quite enjoy the methodical nature and well-established process within statistics. Having chosen qualitative methodology for my empirical paper I found myself yearning for a quantitative project.

Conclusion

Overall, I have found the doctorate thesis a stressful experience, at times, imbued with many negative emotions. Emotions stemming from perfectionistic tendencies and self-criticism, wanting to be good at what I was doing and struggling. I have had to remind myself, on several occasions, that I am learning new skills and this is effortful and tiring but facing the challenge by ‘chipping away’ bit by bit, instead of avoiding, helped boost confidence in my abilities. I am currently on placement, in a service that is very research focused. Having sat in some meetings it feels incredibly reassuring that I understand all of the projects discussed and can offer some insights into how to improve them, but also develop my research skills in other areas by learning from other clinicians/researchers. This is a very nice feeling and I am really keen to pursue research further in my career.

Completing my research thesis has led to the important discernment of my research skills and competencies and has demonstrated my capability and competency in conducting doctoral level research. Although, I have always wanted to continue doing research in the future, despite the imposter niggles, surviving the thesis solidified in my mind that I can overcome whatever challenge I encounter. This process emphasised the importance of self-care, the essentiality of supportive relationships and of pacing myself to successful completion of large-scale projects. Furthermore, reflecting on the research process allowed me to appreciate how much I have learnt and developed from this experience, something I usually pay little attention to in my pursuit of goals.

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Appendices

Appendix A

Journal of Intellectual and Developmental Disability Author Guidelines

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Appendix B

Certificate of Ethical Approval, Systematic Review

“A Systematic Review of Grandparents’ Experiences of Having a Grandchild with a Developmental Disability: A Thematic Synthesis” P116049

Coventry University

Certificate of Ethical Approval

Applicant:	Nataliya Chemerynska
Project Title:	“A Systematic Review of Grandparents’ Experiences of Having a Grandchild with a Developmental Disability: A Thematic Synthesis”

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:	14 Dec 2020
Project Reference Number:	P116049

Nataliya Chemerynska (D62PY) Page 1 14 Dec 2020

Appendix C

Table C1.

Quality assessment ratings, percentile representation of total scores.

Study	**Boyd & Goodwin, 2019**		**D'Astous, et al., 2013**		**Gallagher, Kresak & Rhodes, 2010**		**Hillman & Anderson, 2019**		**Hillman, Wentzel & Anderson, 2017**		**Huang, et al., 2020**		**Katz & Kessel, 2002**		**Margetts, Le Couteur & Croom, 2006**		**Maul & Singer, 2009**		**Miller, Buys & Woodbridge, 2012**		**Prendeville & Kinsella, 2019**	
Rater	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
Q1	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Q2	2	2	2	2	2	2	2	2	2	2	2	2	1	1	2	2	2	2	2	2	2	2
Q3	2	2	2	2	1	1	1	1	1	1	2	2	1	1	2	2	2	2	2	2	2	2
Q4	2	2	1	1	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Q5	2	2	2	2	2	2	1	1	1	1	2	2	1	1	2	2	2	2	2	2	2	2
Q6	2	2	0	0	0	0	0	0	0	0	2	2	0	0	0	0	0	0	1	1	0	0
Q7	2	2	0	0	1	1	2	2	2	2	2	2	0	0	2	2	0	1	2	2	2	1
Q8	2	2	0	0	2	2	2	2	2	2	2	2	1	1	2	2	2	2	2	2	2	2
Q9	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Q10	1	0	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Total /20	19	18	13	13	16	16	16	16	16	16	20	20	12	12	18	18	16	17	19	19	18	17
% Score	95	90	65	65	80	80	80	80	80	80	100	100	60	60	90	90	80	85	95	95	90	85

Appendix C

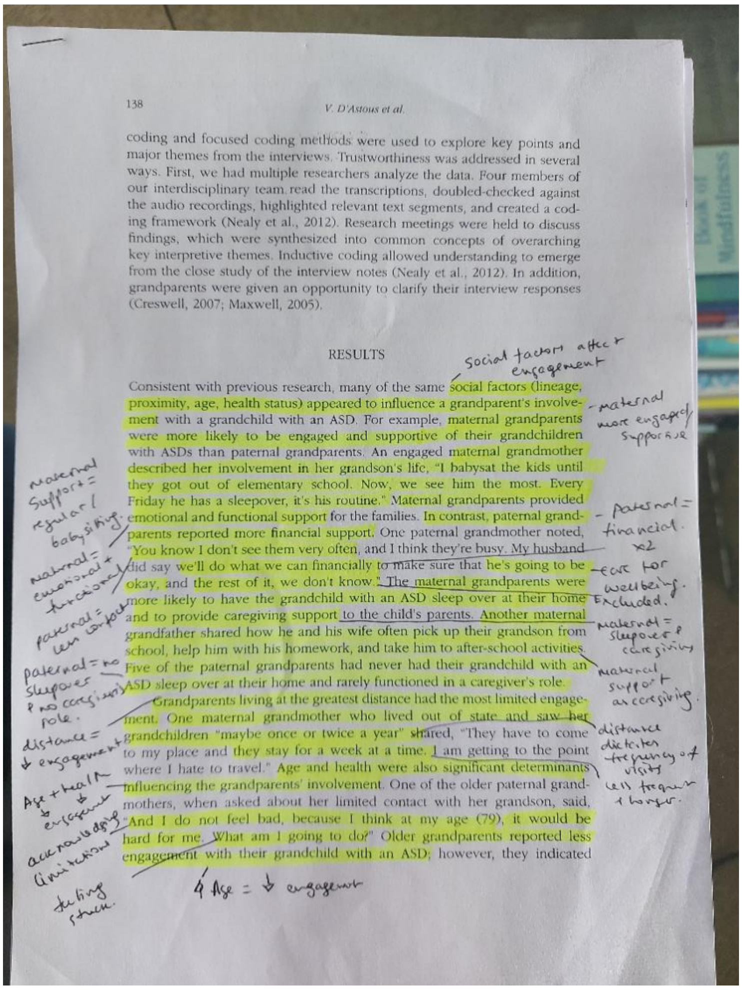
Table C2.

Inter-rater reliability of quality assessment and approximate significance.

Authors	*Kappa Coefficient κ*	*Significance level p*
Boyd & Goodwin, 2019	0.47	0.002
D'Astous, et al., 2013	1	0.001
Gallagher, Kresak & Rhodes, 2010	1	0.001
Hillman & Anderson, 2019	1	0.001
Hillman, Wentzel & Anderson, 2017	1	0.001
Huang, et al., 2020	1	0.001
Katz & Kessel, 2002	1	0.001
Margetts, Le Couteur & Croom, 2006	1	0.001
Maul & Singer, 2009	0.71	0.003
Miller, Buys & Woodbridge, 2012	1	0.001
Prendeville & Kinsella, 2019	0.63	0.005
Overall inter-rater reliability	0.93	0.001

Appendix D

Example of Line by Line Coding



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coding and focused coding methods were used to explore key points and major themes from the interviews. Trustworthiness was addressed in several ways. First, we had multiple researchers analyze the data. Four members of our interdisciplinary team read the transcriptions, doubled-checked against the audio recordings, highlighted relevant text segments, and created a coding framework (Nealy et al., 2012). Research meetings were held to discuss findings, which were synthesized into common concepts of overarching key interpretive themes. Inductive coding allowed understanding to emerge from the close study of the interview notes (Nealy et al., 2012). In addition, grandparents were given an opportunity to clarify their interview responses (Creswell, 2007; Maxwell, 2005).

RESULTS

Consistent with previous research, many of the same social factors (lineage, proximity, age, health status) appeared to influence a grandparent's involvement with a grandchild with an ASD. For example, maternal grandparents were more likely to be engaged and supportive of their grandchildren with ASDs than paternal grandparents. An engaged maternal grandmother described her involvement in her grandson's life, "I babysat the kids until they got out of elementary school. Now, we see him the most. Every Friday he has a sleepover, it's his routine." Maternal grandparents provided emotional and functional support for the families. In contrast, paternal grandparents reported more financial support. One paternal grandmother noted, "You know I don't see them very often, and I think they're busy. My husband did say we'll do what we can financially to make sure that he's going to be okay, and the rest of it, we don't know." The maternal grandparents were more likely to have the grandchild with an ASD sleep over at their home and to provide caregiving support to the child's parents. Another maternal grandfather shared how he and his wife often pick up their grandson from school, help him with his homework, and take him to after-school activities. Five of the paternal grandparents had never had their grandchild with an ASD sleep over at their home and rarely functioned in a caregiver's role.

Grandparents living at the greatest distance had the most limited engagement. One maternal grandmother who lived out of state and saw her grandchildren "maybe once or twice a year" shared, "They have to come to my place and they stay for a week at a time. I am getting to the point where I hate to travel." Age and health were also significant determinants influencing the grandparents' involvement. One of the older paternal grandmothers, when asked about her limited contact with her grandson, said, "And I do not feel bad, because I think at my age (79), it would be hard for me. What am I going to do?" Older grandparents reported less engagement with their grandchild with an ASD; however, they indicated

Social factors affect engagement

- maternal more engaged/ supportive

maternal support = regular babysitting.

maternal = emotional + functional

paternal = less support

- paternal = financial. x2

- care for wellbeing.

Excluded.

maternal = sleepover & caregiving

maternal support as caregiving.

paternal = no sleepover & no caregiving role.

distance = ↓ engagement

distance dictates frequency of visits

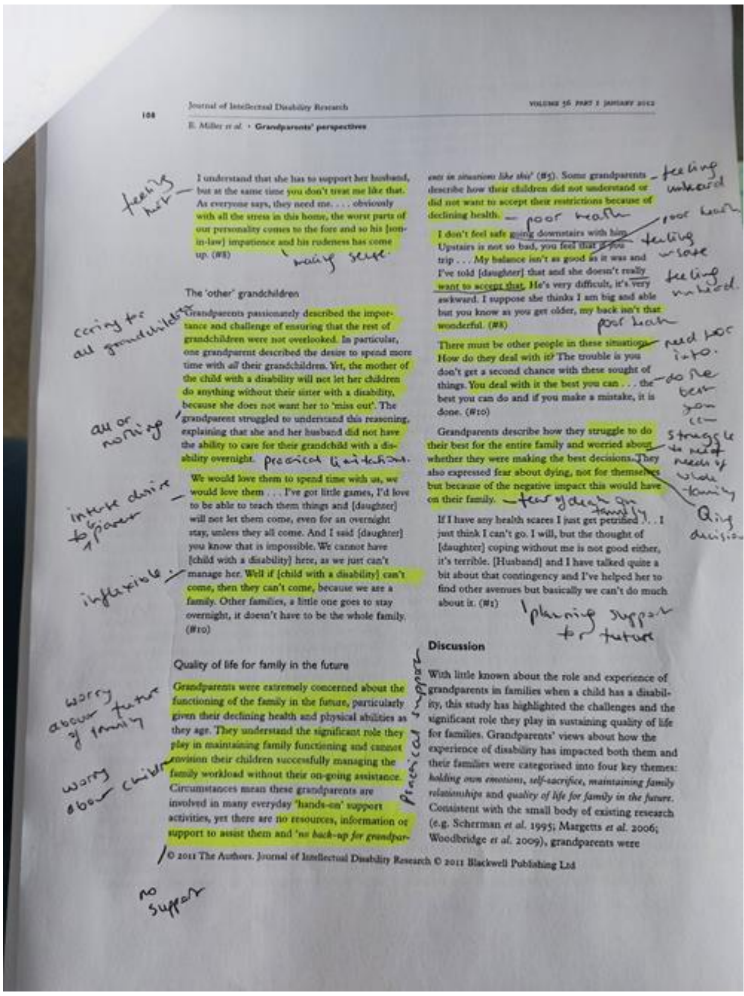
less frequent + longer.

Age + health ↓ engagement

acknowledging limitations

feeling stuck.

↑ Age = ↓ engagement



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E. Miller et al. • Grandparents' perspectives

I understand that she has to support her husband, but at the same time you don't treat me like that. As everyone says, they need me. . . . obviously with all the stress in this home, the worst parts of our personality comes to the fore and so his [son-in-law] impatience and his rudeness has come up. (#8)

The 'other' grandchildren

Grandparents passionately described the importance and challenge of ensuring that the rest of grandchildren were not overlooked. In particular, one grandparent described the desire to spend more time with all their grandchildren. Yet, the mother of the child with a disability will not let her children do anything without their sister with a disability, because she does not want her to 'miss out'. The grandparent struggled to understand this reasoning, explaining that she and her husband did not have the ability to care for their grandchild with a disability overnight.

We would love them to spend time with us, we would love them . . . I've got little games, I'd love to be able to teach them things and [daughter] will not let them come, even for an overnight stay, unless they all come. And I said [daughter] you know that is impossible. We cannot have [child with a disability] here, as we just can't manage her. Well if [child with a disability] can't come, then they can't come, because we are a family. Other families, a little one goes to stay overnight, it doesn't have to be the whole family. (#10)

Quality of life for family in the future

Grandparents were extremely concerned about the functioning of the family in the future, particularly given their declining health and physical abilities as they age. They understand the significant role they play in maintaining family functioning and cannot envision their children successfully managing the family workload without their on-going assistance. Circumstances mean these grandparents are involved in many everyday 'hands-on' support activities, yet there are no resources, information or support to assist them and '*no back-up for grandparents in situations like this*' (#5). Some grandparents describe how their children did not understand or did not want to accept their restrictions because of declining health.

I don't feel safe going downstairs with him. Upstairs is not so bad, you feel that if you trip . . . My balance isn't as good as it was and I've told [daughter] that and she doesn't really want to accept that. He's very difficult, it's very awkward. I suppose she thinks I am big and able but you know as you get older, my back isn't that wonderful. (#8)

There must be other people in these situations. How do they deal with it? The trouble is you don't get a second chance with these sought of things. You deal with it the best you can . . . the best you can do and if you make a mistake, it is done. (#10)

Grandparents describe how they struggle to do their best for the entire family and worried about whether they were making the best decisions. They also expressed fear about dying, not for themselves but because of the negative impact this would have on their family.

If I have any health scares I just get petrified . . . I just think I can't go. I will, but the thought of [daughter] coping without me is not good either, it's terrible. [Husband] and I have talked quite a bit about that contingency and I've helped her to find other avenues but basically we can't do much about it. (#1)

Discussion

With little known about the role and experience of grandparents in families when a child has a disability, this study has highlighted the challenges and the significant role they play in sustaining quality of life for families. Grandparents' views about how the experience of disability has impacted both them and their families were categorised into four key themes: *holding own emotions*, *self-sacrifice*, *maintaining family relationships* and *quality of life for family in the future*. Consistent with the small body of existing research (e.g. Scherman *et al.* 1995; Margetts *et al.* 2006; Woodbridge *et al.* 2009), grandparents were

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feeling hurt

walking secure

caring for all grandchildren

all or nothing

practical limitations.

intense desire to ↑ grandparent

inflexible

worry about future of family

worry about child

no support

practical support

- feeling awkward

- poor health

poor health

feeling unsafe

feeling unheard.

poor health

need for info.

- do the best you can

struggle to meet needs of whole family

Q-ing decision

- fear of death on family

planning support for future

Appendix E

Emerging descriptive themes

Authors	Codes	Descriptive themes
Boyd and Goodwin, 2019	Socially excluded by reactions of others	Challenges of DD
	Scrutinised and judged by others	Challenges of DD
	Ignore other's reactions	Reactions to disability
	Grandchild at the centre	Rewards of DD
	Positive interactions = dignity	
	Let go of worries/coping?	Reactions to disability
	Valuing being involved	Grandparent parent relationship
	Learning from child	Rewards of DD
	Preparing for activities	
	Disregarding negative comments = control/coping	Reactions to disability
	People that make an effort are good	
	Acceptance of others feels good	
D'Astous, et al., 2013	Maternal more involved	Grandparent parent relationship
	Maternal = emotional and functional support	Grandparent parent relationship
	Paternal = financial support	Grandparent parent relationship
	Paternal less contact	Grandparent parent relationship

Appendix F

Additional Quote Excerpts to Support Themes

Analytical Theme: Adjustment

Reactions to Disability

"I saw her the day after the MMR. I feel it was the cause. 99% of people seem to deny [it] . . ." (Margetts et al., 2006, p.571).

"I still feel great shame and sadness that I didn't recognize [my grandson's] condition earlier. Clearly, I was in denial. I haven't forgiven myself for this to this day" (Hillman et al., 2017, p.2962).

"My greatest challenge now is to figure out what happens to my granddaughter when I die and her mother dies" and "[I have great] concern about how this dear child will be able to make his way in the world" (Hillmen et al., 2017, p.2963).

"They [child with DD] changed everything in the home" (Katz & Kessel, 2002, p.121).

"The birth of a child with a developmental disability came from above" (Katz & Kessel, 2002, p.121).

Loss

"I feel that once you accept that you've got a child or a grandchild with a disability, then your whole concept of what lies ahead of you completely changes, because you know then that your life isn't going to pan out the way you thought it would, because there is this so much extra responsibility involved with a child with a disability . . . because they need you. This is why I feel I can't just walk away. I can't afford to say, well I'm sorry you've got all these problems, I'm going to walk away and retire" (Miller et al., 2012, p.106).

"We had no other interest, no other people and we are both quite outgoing and always had a huge circle of acquaintances and people and what have you, and we had no one there and we started to get cross with each other" (Miller et al., p.106).

"I have depleted my retirement funds" (Hillman & Anderson, 2019, p.265).

Double Burden

"We help support her children but we do not intrude on her life" (D'Astous, et al., 2013, p.193)

"There were phone numbers at the end of each chapter [of a book]. I didn't ring them. I left it to (daughter) – you think you're not directly involved" (Margetts et al., 2006, p.570).

"*We are old and are merely offering our opinions . . . . Taking care of children at an old age is remarkably tiresome . . . . Worries do our body no good and we should learn to just let things be . . . . As grandmothers, we should not bear so much burden . . . . We need to take care of our health. This way, we can provide them timely help . . . . After all, parents should be the ones most responsible for raising their children"* (Huan et al., 2020).

"Every child needs someone who cares enough about them. Someone they know that they can depend on" (D'Astous, et al., 2013, p.140).

"I'm concerned for [my grandson's] future. We will not always be alive to care for him or provide a home for him… I don't want him abandoned or neglected when we're not here to care for him anymore" (Hillman & Anderson, 2019, p.265).

"[We make] sure we do not give our other [non-ASD] grandchild more attention because we can interact with him more" (Hillman et al., 2017, p.2963).

<u>Analytical Theme: Blessing and a Curse</u>

Rewards of DD

"[My granddaughter with ASD] has taught me much and stretched me beyond what I ever thought I was capable of" (Hillman & Anderson, 2019, p.266).

"It truly does take a village… This little guy… has in important ways made the family more kind and cohesive. In-laws, outlaws, exes, all come together … and focus on… this child" (Hillman & Anderson, 2019, p.266).

[I receive joy from] the child-like love that is showered on me often [between tantrums & melt-downs] but I wouldn't have it any other way" (Hillman & Anderson, 2019 p.265-266).

"Such a trauma for all of us. . . . Never in my life did I believe I'd have to go through something like this. . . . I am disappointed with myself . . . I feel I should have been able to do more, to be

more understanding. In the beginning I very often got slapped in the face by our children. . . . Sometimes I would be judgmental or critical, and they would feel I did not trust them and realize that they were doing their best . . . I never realized how much it hurt them . . . I have had to learn a lot, a major life experience, but we have all learnt to deal with it and with each other" (Katz & Kessel, 2002, p.124).

Challenges of DD

"He just pulls away" (D'Astous et al., 2013, p142).

"… asked for information about a specific diagnosis. She said: There's a lot for a grandparent to know and do" (Gallagher et al., 2010, p.61).

"At the age of 3 [our grandson] got out of bed unlocked the doors and went out in a rainstorm" (Hillman & Anderson, 2019 p.264).

"Even a simple trip out for ice cream can go wrong in a heartbeat" (Hillman et al., 2017, p. 2962).

In almost all cases grandparents felt that they were not given enough information about the developmental disability (Katz & Kessel, 2002, p.122).

Analytical Theme: Components to Involvement

Grandparent - Parent Relationship

"The child's father will not let us interfere at home. . . . He insists on us doing as he says. For example, he is very demanding of the boy and does not want us to spoil him. We have candies in the car and would like to give him some, but the father says no. We don't approve of them [the parents] being so strict with the child, but we only discuss our disagreements in the car where the parents can't hear"

"One paternal grandmother noted, "You know I don't see them very often, and I think they're busy. My husband did say we'll do what we can financially to make sure that he's going to be okay, and the rest of it, we don't know" (D'Astous, et al., 2013, p.138).

Social Factors

"And I do not feel bad, because I think at my age (79), it would be hard for me. What am I going to do?" (D'Astous et al., 2013, p.138).

"We live far away from our grandchild, so it is hard to support him" (Hillman et al., 2017, p.2962).

Appendix G

Contribution of Papers to Themes

Superordinate themes		Adjustment			Blessing and a Curse		Components to Involvement	
Theme		Resections to disability	Loss	Double burden	Rewards of grandparenting a child with DD	Challenges of DD	Grandparent-parent relationship	Social factors
Author	Boyd & Goodwin, 2019	√				√		
	D'Astous, et al., 2013	√	√	√	√	√	√	√
	Gallagher, Kresak & Rhodes, 2010			√	√	√		
	Hillman & Anderson, 2019	√	√		√	√		√
	Hillman et al., 2017	√		√	√	√	√	
	Huang, et al., 2020	√	√	√	√	√	√	
	Katz & Kessel, 2002	√	√		√	√	√	
	Margetts et al., 2006	√	√	√	√		√	
	Maul & Singer, 2009		√				√	
	Miller et al., 2012	√	√	√	√		√	√
	Prendeville & Kinsella, 2019		√	√	√	√	√	

Appendix H

Journal of Intellectual Disability Research Author Guidelines

Impact factor: 1.755

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Qualitative Studies are only considered if they have strong theoretical underpinnings and use an established method of data synthesis. International reporting guidelines should be used (e.g., https://www.equator-network.org/reporting-guidelines/coreq/).

Systematic Reviews

The maximum word length for systematic reviews is 6,000 words. Authors submitting a systematic review are encouraged to assess the quality of their reporting against the PRISMA checklist prior to submission (http://www.prisma-statement.org/2.1.2 - PRISMA 2009 Checklist.pdf) or MOOSE guideline (https://www.equator-network.org/reporting-guidelines/meta-analysis-of-observational-studies-in-epidemiology-a-proposal-for-reporting-meta-analysis-of-observational-studies-in-epidemiology-moose-group/).

Brief Reports

Brief Reports of up to 2,000 words are encouraged especially for replication studies, methodological research and technical contributions.

4. PREPARATION OF THE MANUSCRIPT

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Prior to submission, we encourage you to browse the ‘Author Resources’ section of the Wiley ‘Author Services’ website here. This site includes useful information covering such topics as copyright matters, ethics and electronic artwork guidelines.

Free Format Submission

The Journal of Intellectual Disability Research now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.
- The title page of the manuscript, including statements relating to our ethics and integrity policies (if applicable):
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    - o conflict of interest disclosure
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Spelling

- Spelling should conform to The Concise Oxford Dictionary of Current English.
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- Where applicable the journal standard is to use words ending in –ise as opposed to –ize. For example, use ‘analyse’ ‘standardise’ as opposed to ‘analyze’ and ‘standardize’

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Terminology

It is important that the term 'intellectual disabilities' or ‘intellectual disability’ is used when preparing manuscripts. The term ‘person’, ‘people’, ‘children’ , ‘participant(s)’ or other appropriate term should be used as opposed to, for example, ‘patient(s)’.

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The manuscript should be submitted in separate files: title page; main text file; figures.

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(iv) the full postal and email address, plus telephone number, of the author to whom correspondence about the manuscript should be sent;
(v) acknowledgements;
(vi) conflict of interest statement.

The present address of any author, if different from that where the work was carried out, should be supplied in a footnote.

Acknowledgements

Contributions from anyone who does not meet the criteria for authorship should be listed (including any advisors/consultees with intellectual disability), with permission from the contributor, in an Acknowledgments section. See section on Authorship for more detail. Material support should also be mentioned Thanks to anonymous reviewers are not appropriate.

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The main text of the manuscript should be presented in the following order: (i) structured abstract and key words (ii) text, (iii) references, (vi) endnotes, (vii) tables (each table complete with title and footnotes), and (ix) figure legends. Figures should be supplied as separate files. Footnotes to the text are not allowed and any such material should be incorporated as endnotes.

Abstract

For all submissions, a structured summary should be included at the beginning of the article, incorporating the following headings: Background, Method, Results, and Conclusions. These should outline the questions investigated, the design, essential findings, and the main conclusions of the study.

Keywords

The author should also provide up to six keywords. Please think carefully about the keywords you choose as this will impact on the discoverability of your paper during literature searches (**https://authorservices.wiley.com/bauthor/seo.asp**)

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- The journal follows the Harvard reference style.
- References in text with more than two authors should be abbreviated to (Brown et al. 1977).
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- Authors are responsible for the accuracy of their references.

The reference list should be in alphabetical order thus:

Giblett E.R. (1969) Genetic Markers in Human Blood. Blackwell Scientific Publications, Oxford.

Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. Journal of Mental Deficiency Research 24, 137- 41.

Seltzer M. M. & Krauss M.W. (1994) Aging parents with co-resident adult children: the impact of lifelong caregiving. In: Life Course Perspectives on Adulthood and Old Age (eds M. M. Seltzer, M.W. Krauss & M. P. Janicki), pp. 3–18. American Association on Mental Retardation, Washington, DC.

Endnotes

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Figure Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

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Author Guidelines updated 20 February 2020

Appendix I

Interview Guide

Interview Schedule

"What are the Experiences of Clinical Psychologists Working with People with Intellectual Disabilities During the COVID-19 Pandemic?"

The purpose of this interview is to explore what your experiences are of working with people with intellectual disability during the COVID-19 pandemic. I am interested to hear how **you** found this experience and how you made sense of it. I would encourage you to be as open as you can during the interview. I will be asking you some questions, however, I hope to be led by you and your experiences. I may ask you, at times, to explain what you mean in more detail or ask to clarify something, this is to ensure that I am able to try to understand your experiences in as much detail as you are comfortable to share. Generally, the questions will focus on your experiences of working during the pandemic.

1. **Can you tell me about yourself and the job you are currently doing?**
    - What has drawn you to this research?

2. **Can you describe your experiences of working with people with ID during the COVID-19 pandemic? How has this changed from March 2020 till now?**
    - What was you experience of working with your colleagues during this time?
    - What was happening for you both at work and at home?
    - What was your experience of the service at that time?
    - How has your practice changed as a result of the pandemic?
    - What images come to your mind?

3. **What was your experience of COVID-19 management strategies at work? How has this changed from March 2020 till now?**
    - Can you tell me about your experience?
    - Can you tell me about experiences with your clients? How did that leave you feeling?
    - Can you tell me about experiences with your colleagues? How did that leave you feeling?

4. **How did you navigate the COVID related changes to your practice? How has this changed from March 2020 till now?**
    - What helped you manage?
    - What were the challenges you faced?
    - How did that leave you feeling?
    - Personal vs outside (colleagues/ organisational etc.) resources

5. **Can you describe to me your experience of how people with ID engaged with changes to service delivery? How has this changed from March 2020 till now?**
    - What did that mean to you?
    - How did that leave you feeling?
    - How did you make sense of it?

6. **Can you describe to me your experience of how carers and family of people with ID engaged with changes to service delivery? How has this changed from March 2020 till now?**
    - Strengths
    - Difficulties
    - What did that mean to you?
    - How did that leave you feeling?
    - How did you make sense of it?

7. **Is there anything else you would like to tell me about your experience of work during the pandemic, that we did not get a chance to talk about?**

Thank you for taking part in this interview

General prompts:

- Can you tell me what you mean?
- Can you tell me more about that?
- What did that mean to you?
- How did that leave you feeling?
- How did you make sense of it?

Appendix J

Certificate of Ethical Approval, Empirical Paper

"What are the Experiences of Clinical Psychologists Working with People with Intellectual Disabilities During the COVID-19 Pandemic?" P117341

Coventry University

Certificate of Ethical Approval

Applicant:	Nataliya Chemerynska
Project Title:	"What are the Experiences of Clinical Psychologists Working with People with Intellectual Disabilities During the COVID-19 Pandemic?"

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:	11 Feb 2021
Project Reference Number:	P117341

Nataliya Chemerynska (D62PY) Page 1 11 Feb 2021

Appendix K

Participant Information Sheet

"What are the Experiences of Clinical Psychologists Working with People with Intellectual Disabilities During the COVID-19 Pandemic?"

PARTICIPANT INFORMATION SHEET

You are being invited to take part in research on Psychologists' experience of working with people with ID during the COVID-19 pandemic. This study is part of Doctorate in Clinical Psychology educational project and has been reviewed by Coventry University Ethics. Nataliya Chemerynska, Trainee Clinical Psychologist at Coventry University is leading this research. Before you decide to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The purpose of the study is to accurately capture and interpret the lived experience of registered clinical psychologists working with people with intellectual disabilities (ID) during the COVID-19 pandemic. The study will explore how the working environment has changed as the result of the pandemic and how psychologists adapted to these changes. Ultimately, the desired outcome is to identify how to support clinical psychologists working with people with (ID) and improve service provision.

Why have I been chosen to take part?

We are inviting registered clinical psychologists who work in community, NHS services for people with intellectual disability in England, to take part in this study.

What are the benefits of taking part?

By sharing your experiences with us, you will have an opportunity to have your voice heard and to contribute to research which might inform future service provision.

Are there any risks associated with taking part?

This study has been reviewed and approved through Coventry University's formal research ethics procedure. There are no significant risks associated with participation. However, discussing personal experiences may lead to psychological distress, in this case the interview will be paused and you can choose if you would like to continue, reschedule the interview for another time or withdraw from the study. If you are still experiencing distress please speak to your line manager or clinical supervisor or alternatively contact your GP or the Samaritans on 116 123.

Do I have to take part?

No – it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you seek to withdraw from the study at a later date. You are free to withdraw your information from the project data **up to two weeks** after your interview. If you decide to withdraw, any data you have provided will be securely destroyed. To withdraw, please contact the lead researcher (contact details are provided below). Please also contact the Research Support Office (ethics.hls@coventry.ac.uk;

telephone +44(0)247 765 8461, so that your request can be dealt with promptly in the event of the lead researcher's absence. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

What will happen if I decide to take part?

Consent

Informed consent will be sought from all participants, before engaging in the study by either providing written consent digitally where participants are emailed the forms to complete and return by email. Participants can either sign electronically or print, sign and scan (or take a photo of) the forms. A return email will be deleted from the inbox and from the deleted folder; the transcript will be retained as a record of a participant's informed consent.

Initially, you will be asked to provide some demographic information about you and your service. You will then be invited to answer a number of questions regarding your experiences of working with people with ID during the pandemic. The interview will take place over the telephone or via secure videoconferencing platforms such as Skype Business, Microsoft teams or WebEx at a time that is convenient to you. Ideally, we would like to audio record your responses (and will require your consent for this), so the location should be in a reasonably quiet area. The interview should take around 60-90 minutes to complete. However, if you find the experience distressing and wish to have a break or reschedule the interview times will vary accordingly.

The audio data from interviews will be transcribed verbatim, including questions from the interviewer, any unfinished words, pauses or hesitations, as well as laughter. All audio recordings will be destroyed once they have been transcribed. Once the interviews have been transcribed, the lead investigator will email transcripts to participants to check and return by email.

Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consent to being audio recorded, all recordings will be destroyed once they have been transcribed. Any identifiable data i.e. names, places, etc., will be removed from transcripts. Everything you share in your interview will be treated confidentially, however, if you disclose some information that means you or someone you know may be in danger I will have to notify a relevant agency such as the police. Data will only be viewed by the researcher/research team. All electronic data will be stored on a password-protected Coventry University OneDrive folder. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. Your personal data be stored digitally by Coventry University for up to five years after the study has ended and Coventry University will take responsibility for data destruction in line with its policies and procedures.

Data Protection Rights

Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

What will happen with the results of this study?
The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name. If you decide to take part in this study a summary of the results will be emailed to you.

Making a Complaint
If you are unhappy with any aspect of this research, please first contact the lead researcher, on chemeryn@uni.coventry.ac.uk. Alternatively, you can contact Nataliya's supervisory team:

Dr Jo Kucharska
Clinical Director/Senior Lecturer Tutor
Clinical Psychology Doctorate Course
Coventry University
Charles Ward Building

CV1 5FB
Tel: +44(0)24 7765 8769
E: Jo.Kucharska@coventry.ac.uk

Dr Magda Marczak
Lecturer in Clinical Psychology/ Research

Clinical Psychology Doctorate Programme
Coventry University
Charles Ward Building

CV1 5FB
Tel: +44(0)24 7765 5819
E: Magdalena.Marczak@coventry.ac.uk

If you still have concerns and wish to make a formal complaint, please write to:
Prof. Nigel Berkeley
Associate Dean of Research
Coventry University
Coventry CV1 5FB
Email: Nigel.Barkeley@covnetry.ac.uk

In your letter please provide information about the research project, specify the name of the researcher and detail the nature of your complaint.

Appendix L

Informed Consent Form

Participant No.

INFORMED CONSENT FORM:

"What are the Experiences of Clinical Psychologists Working with People with Intellectual Disabilities During the COVID-19 Pandemic?"

You are invited to take part in this research study for the purpose of collecting data on psychologists' experiences of working with people with intellectual disabilities (ID) during the COVID-19 pandemic. Participating in this research will give an opportunity to have your voice heard and to contribute to research which might inform future service provision.

Before you decide to take part, you must read the accompanying Participant Information Sheet.

Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by putting your initials against each of the below statements and then signing and dating the form as participant.

		Initials
1	I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions	
2	I understand my participation is voluntary and that I am free to withdraw my data, without giving a reason, by contacting the lead researcher and the Research Support Office at any time within two weeks of my interview. Withdrawal from the study will lead to the data I have provided being securely destroyed.	
3	I understand that all the information I provide will be held securely and treated confidentially	
4	I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs	
5	I am happy for the interview to be audio recorded	
6	I agree to anonymised, direct quotes from the interview to be included in the publication of this study	
7	I agree to take part in the above study	

Thank you for your participation in this study. Your help is very much appreciated.

Participant's Name	Date	Signature
Researcher	Date	Signature

Appendix M

Debrief Sheet

"What are the Experiences of Clinical Psychologists Working with People with Intellectual Disabilities During the COVID-19 Pandemic?"

Participant debriefing sheet

Thank you for participating in this interview. I hope that you have found it interesting and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing and you wish to speak to someone like your line manager, clinical supervisor, or contact staff support services offered by your Trust. Alternatively, please contact your GP in the first instance. If you need to speak to someone outside of working hours, please contact:

Our Frontline
Frontline offers round-the-clock, one-to-one support, by call or text, from trained volunteers for healthcare workers.
To talk by text, text FRONTLINE to 85258 any time. To talk by phone for free, call 0800 069 6222 from 7am to 11pm if you're in England, or call 116 123 any time if you're elsewhere in the UK.

Samaritans
Samaritans is available for anyone struggling to cope and provide a safe place to talk 24 hours a day. Phone: 116 123 or Email: jo@samaritans.org.

Study aims and design: The purpose of the study was to accurately capture and interpret the lived experience of clinical psychologists working with people with intellectual disabilities during the COVID-19 pandemic. The study explored how the working conditions changed as a result of the pandemic and how psychologists navigated these changes. Ultimately, the desired outcome is to identify how best to support psychologists working with people with intellectual disability and to improve service provision.

What if I have a question? Please contact the researcher (Nataliya Chemerynska) if you would like some more information about this study at chemeryn@uni.coventry.ac.uk.

What if I want to withdraw from the study? You are free to withdraw your information from the project data set up to two weeks following your interview. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study. To withdraw, please contact the researcher (chemeryn@uni.coventry.ac.uk) and provide your participant number which is listed on the consent form. Please also contact the Research Support Office (ethics.hls@coventry.ac.uk; telephone +44 (0)247 765 8461, so that your request can be dealt with promptly in the event of the lead researcher's absence.

Data Protection and Confidentiality: Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consented to being audio recorded, all recordings will be destroyed once they have been transcribed. Your data will only be viewed by the researcher/research team. All electronic data will be stored on a password-protected computer file on the lead researcher's computer. All paper records will be stored in a locked filing cabinet at Coventry University premises. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. Coventry University will take responsibility for data destruction in line with its policies and procedures.

How will I find out the results of the study? Once this paper has been awarded a mark (July 2021), a research summary could be requested by contacting the researcher Nataliya Chemerynska on chemeryn@uni.coventry.ac.uk.

What if I wish to make a complaint? If you are unhappy with any aspect of this research, please first contact the lead researcher, Nataliya Chemerynska on chemeryn@uni.coventry.ac.uk. Alternatively, you can contact Nataliya's supervisory team:

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If you still have concerns and wish to make a formal complaint, please write to:

Prof. Nigel Berkeley
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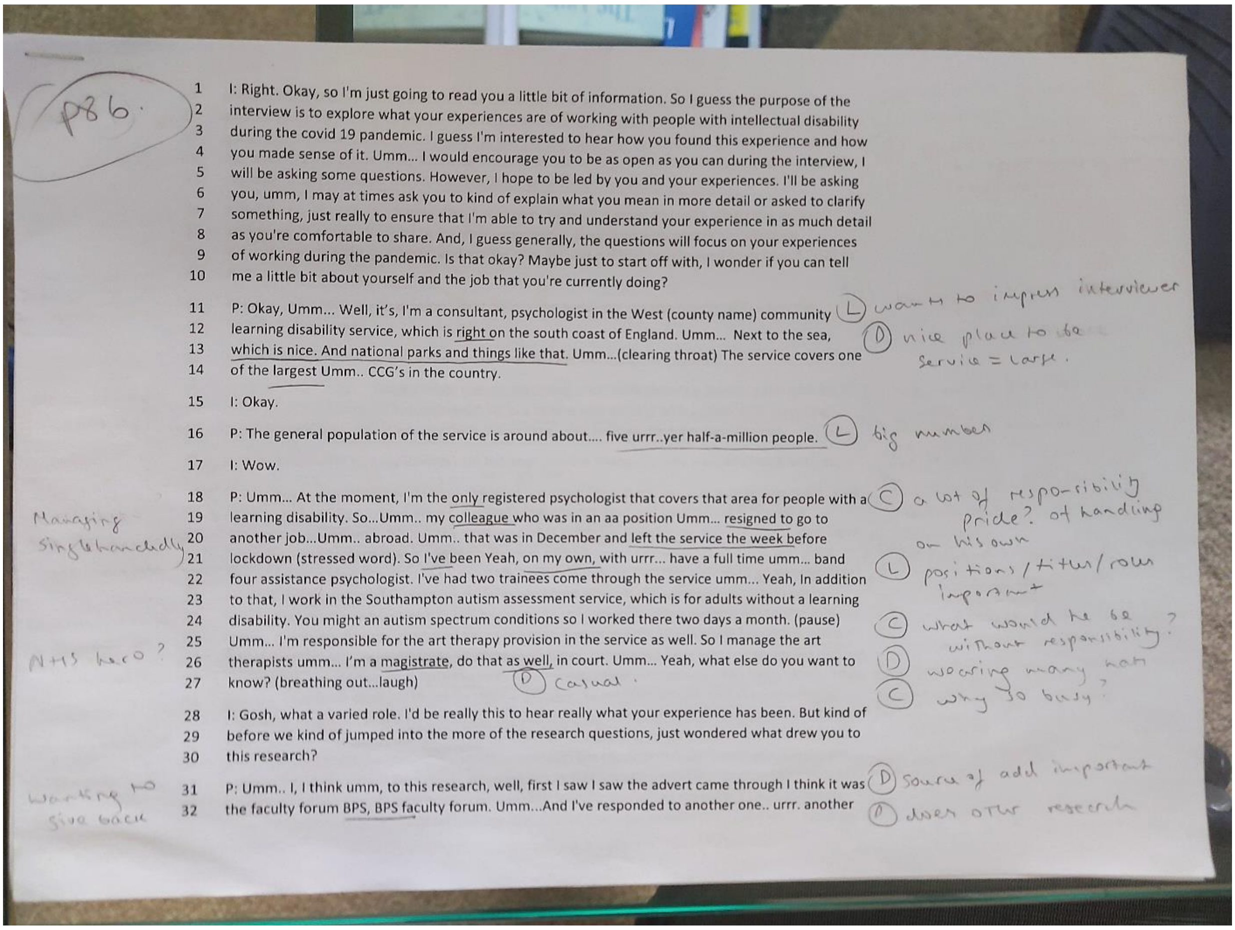
In your letter please provide information about the research project, specify the name of the researcher and detail the nature of your complaint.

Thank you so much for taking part!

Appendix N

Analysis Annotation and Thematic Mapping



P86.

I: Right. Okay, so I'm just going to read you a little bit of information. So I guess the purpose of the interview is to explore what your experiences are of working with people with intellectual disability during the covid 19 pandemic. I guess I'm interested to hear how you found this experience and how you made sense of it. Umm... I would encourage you to be as open as you can during the interview, I will be asking some questions. However, I hope to be led by you and your experiences. I'll be asking you, umm, I may at times ask you to kind of explain what you mean in more detail or asked to clarify something, just really to ensure that I'm able to try and understand your experience in as much detail as you're comfortable to share. And, I guess generally, the questions will focus on your experiences of working during the pandemic. Is that okay? Maybe just to start off with, I wonder if you can tell me a little bit about yourself and the job that you're currently doing?

P: Okay, Umm... Well, it's, I'm a consultant, psychologist in the West (county name) community learning disability service, which is right on the south coast of England. Umm... Next to the sea, which is nice. And national parks and things like that. Umm...(clearing throat) The service covers one of the largest Umm.. CCG's in the country.

Ⓛ wants to impress interviewer
Ⓓ nice place to be
Service = large.

I: Okay.

P: The general population of the service is around about.... five urrr..yer half-a-million people. Ⓛ big number

I: Wow.

P: Umm... At the moment, I'm the only registered psychologist that covers that area for people with a learning disability. So...Umm.. my colleague who was in an aa position Umm... resigned to go to another job...Umm.. abroad. Umm.. that was in December and left the service the week before lockdown (stressed word). So I've been Yeah, on my own, with urrr... have a full time umm... band four assistance psychologist. I've had two trainees come through the service umm... Yeah, In addition to that, I work in the Southampton autism assessment service, which is for adults without a learning disability. You might an autism spectrum conditions so I worked there two days a month. (pause) Umm... I'm responsible for the art therapy provision in the service as well. So I manage the art therapists umm... I'm a magistrate, do that as well, in court. Umm... Yeah, what else do you want to know? (breathing out...laugh) Ⓓ casual.

Managing singlehandedly

NHS hero?

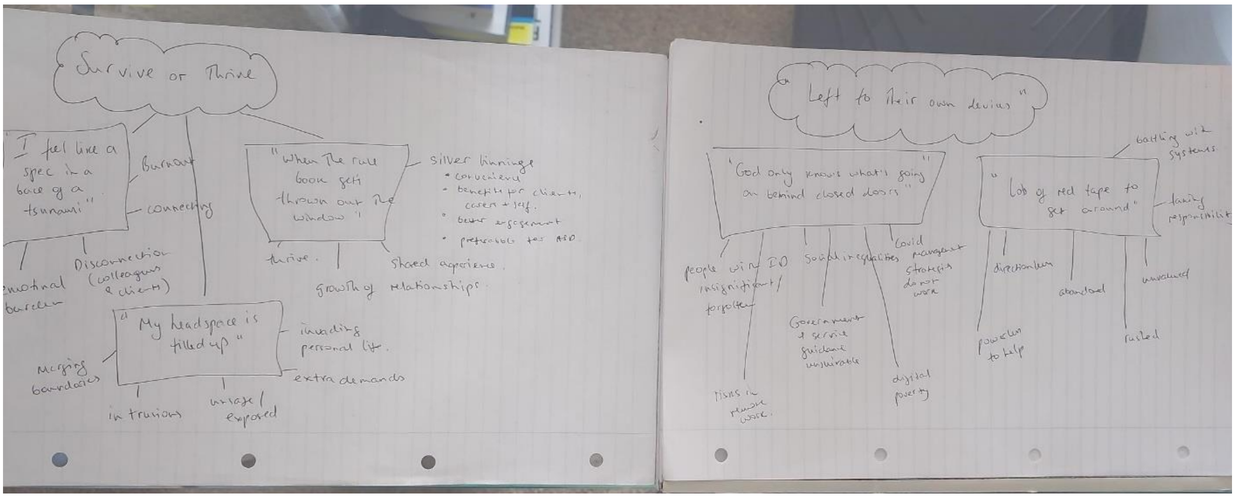
Ⓒ a lot of responsibility
pride? of handling on his own
Ⓛ positions / titles / roles important
Ⓒ what would he be without responsibility?
Ⓓ wearing many hats
Ⓒ why so busy?

I: Gosh, what a varied role. I'd be really this to hear really what your experience has been. But kind of before we kind of jumped into the more of the research questions, just wondered what drew you to this research?

P: Umm.. I, I think umm, to this research, well, first I saw I saw the advert came through I think it was the faculty forum BPS, BPS faculty forum. Umm...And I've responded to another one.. urrr. another

Wanting to give back

Ⓓ source of add important
Ⓓ does other research



Appendix O

Participant Contribution to Themes

Superordinate Theme	**Survive or Thrive**			**“Left to their own devices”**	
Subordinate theme	“I feel like a speck in a base of tsunami”	“My head space is filled up”	“When the rule book gets thrown out the window”	“God only knows what’s going on behind closed doors”	“Lots of red tape to get around”
Charlie	√	√		√	√
Alex	√	√	√	√	√
Jamie	√	√	√	√	√
Sam	√	√	√	√	√
Max	√	√	√	√	√
Ashley	√	√	√	√	√
Jules	√	√	√	√	√
Chris	√	√	√	√	√
Andy	√		√	√	√
Billie	√		√	√	√
Pat	√		√	√	√

Appendix P

Additional Excerpts from Transcripts to Evidence Themes

Superordinate theme: Survive or Thrive

Subordinate theme: "I feel like a speck in the base of a tsunami"

Emotional toll

Sort of that that shell shock (Charlie, 166).

I felt really anxious going into work (Ashley, 186).

It sort of felt like there wasn't an end in sight (Jamie, 277).

Disconnection

I mean, personally, for me, I work quite psychodynamically. So again, trying to do that over, over video or phone is… it can be really difficult, particularly, sort of time lags in technology and things like that, when you you're trying to sort of be, be with somebody, it can be quite a challenge (Pat, 43-45).

Yeah, definitely. So yeah, I think it's felt a little bit like um, I don't know what's made me think of it, at Christmas time, there was like a celebrity Master Chef thing, but they did it, there was an exercise where they were split into pairs, and they had to make the same thing but communicate to each other through a wall. Sometimes, I think it feels a little bit like that. And that you're kind of, you're still trying to work towards the same thing. But there's a bit more of a barrier to being able to… um, see the same things and sometimes quite literally (Alex, 51-56).

Guilt and inadequacy

It's just because I'm a bit limited in this situation and what I can do, but I think it really risks making you feel really useless (Ashley, 353-354).

And so, it feels like there's a really important part of that person's story and what, what happens for them, and what makes things more difficult for them that we're not really able to work with effectively(Alex, 336-338).

Well, it felt, I suppose always that sense that I couldn't do enough. And they were more on the front line. So, I'd like a complete fraud during all the clapping. Because, yeah, there were all these people working more on the front line (Jamie, 111-113).

Isolation

You kind of just become a bit of a lone wolf in this situation (Chris, 82).

Like an island (Pat, 108).

One of the things that we really miss is the bits around the edges of meetings, you know, when you're waiting, having a cup of tea or the walking down the corridor or the bits where you kind of bond and catch up with each other. That's all disappeared off when you are working remotely (Charlie, 277-280).

Burnout

And there's just there's a lot of anxiety. There's a lot of frustration and just tiring (Chris, 71-72).

I've sort of had a period kind of last year of just of having to be kind of off work for a few weeks (Pat, 408-409).

Seeking connection

So… yeah, I guess I've got a… yeah a few psychologists, friends from training and things. So, it's been really helpful to link up with them. One of whom also works in learning disabilities and another of my friends works in older adults. So, I think we've kind of shared some similar, similar themes, similar challenges in terms of trying to kind of… continue doing work that feels helpful. Um… So, that's been really useful to kind of have them to… lean on (Alex, 232-236).

So, I think, for me, it's kind of like, you know, something that our clients are going through at the same time as us, we're all going through it together (Max, 34-35).

<u>Subordinate theme: "My headspace is filled up"</u>

Merging boundaries

So, I guess it's a mix of the boundaries being blurred with working at home and also the… dealing with that overwhelming work demand (Sam, 250-251).

I think that, that sort of, like blurring of boundaries is, is not very healthy (Max, 203).

Actually maintaining that professionalism and keeping that kind of barrier, that boundary between home and work life balance became a little bit more challenging (Jules, 132-133)

Extra demands

The expectations are that you're available all the time. And I think we've placed that expectation on ourselves, you know, because we're working from home. So we need to be available all the time, and umh… doing something all the time to prove that we're working (Max, 236-238).

Feeling vulnerable/exposed

Actually, people can do a lot at home and actually there's a risk of overworking because people don't switch off in the same way (Ashley, 367-368).

There was still that kind of overlap of, of home and work and clients or other professionals being able to see or hear a snapshot of your, your personal life that they wouldn't usually… (Sam, 153-154).

Personal lives consumed

I think in many ways, it's probably been a case of umh… I think I've been running on adrenaline for a very long time. And it's probably been impacting things out of work a lot more than I've probably realised (Pat, 220-222).

Well, I'm way busier now than I've ever been. And I work way longer hours than I ever have. And I've accrued more toil now than I can ever take back. which for me is, is not how I've worked. I, I've worked um, I, I've been very sort of boundaried about my work before and I'm not so boundaried now because, because, like, I've got annual leave, but there's nothing else to do (Max, 198-201).

To begin with, it would just be like everything strewn across all the time. And you… I'd noticed I'd go back in the evening and start looking at emails again (Chris, 333-334).

<u>Subordinate theme: "When the rule book gets thrown out the window"</u>

Thrive

None of our work is textbook or manualised (laughs) its all a bit, kind of, have a go and fly by the seat of your pants, so this has just been like another challenge on top of that we were really up for taking (Ashley, 141-143).

I mean, I really enjoyed being innovative, innov-inovative, I can't talk this morning. And, yeah, I really enjoy kind of finding new ways to do that (Sam, 211-212).

Silver linings

Working in alternative ways with people has proven quite helpful, and has proven to be actually improved, has improved engagement for some particular patient groups (Andy, 64-65).

There have been some families and some individuals for whom moving to remote provision has been, has had some positive benefits. There are some people who have really got a lot from that, and certainly moving forward, we will be retaining, delivering some or having that as an offer for some people, you know, they're people who, for whatever reason be autism or whatever it is, is just easier, and better and all around a good thing for that. So, for some people that have been real bonuses (Charlie, 298-303).

So, bearing in mind that a lot of my long term clients probably have autism and or ADHD and learning disability, they actually find engaging face to face a little bit overwhelming, distracting sometimes. And it does affect the consistency of engagement. Whereas those clients have engaged above and beyond any level that they've previously engaged with (Jules, 50-54).

So, there's been something lovely I find about being in my home (Chris, 311).

We've been able to work from home, that we've got all the technology we need to do that, so I think there was a real sense of kind of, we were able to stay safe and were really, really grateful for that (Ashley, 107-109).

Closer relationships

I guess I've built a stronger relationship with the ward manager than I perhaps would have done, because we have informally caught up, a lot and I suppose he's in a similar situation, really (Jamie, 170-172).

We became quite, quite close, I guess, because we were seeing each other every day and sitting in that same large room every day (Billie, 180-181).

Superordinate theme: "Left to their own devices"

Subordinate theme: "God only knows what's going on behind the closed doors"

People with ID disregarded and abandoned

And seemed like, we had to use it because they paid for it. Rather than we've got to use something because it works (Billie, 84-85).

I think a lot of my clients that I've worked with have felt a bit forgotten maybe, as a, as a learning disabled kind of population (Ashley, 21-22).

Umh… so there's a general sense of… the services can't meet the need, our referral rates to psychology have rocketed, and the level of complexity, the level of need is just dreadful. And there's… I can't… possibly meet that need (Charlie, 251-253).

There's also a frustration there because it feels like you know, these individuals have been referred with presenting issues that are now sort of being overlooked (Pat, 320-321).

PPE and social distancing barriers

But it (masks) was particularly for more moderate LD or particularly with people with more severe autism that it, it just was such a barrier (Ashley, 318-319).

As a psychologist, you're there to build a rapport with someone and show empathy. I find it really hard to show appropriate empathy with a mask on (Chris, 216-217)

But I guess the general reflection is that actually our service users have really struggled to understand this concept (social distancing), or have worried about it excessively (Jules, 345-346).

Digital poverty

Everything went remote which is a real challenge in LD because a lot of our folks don't have access to laptops and smart phones and if they do have access even through their own means or family or carers they're not very used to using them and it can be really hard with a learning disability to learn new stuff (Ashley, 37-40).

And I don’t think there’s that understanding of our service users or who they are or the limitations that they might have? Kind of how impoverished they are as well. So…, a lot of people would say, “well, everyone's got a smartphone, haven’t they these days”. Well “no” (laughs) they haven’t. It's quite a lot of people. There's quite a lot of people that can't use a smartphone in our service (Jamie, 300-303).

Subordinate theme: “Lots of red tape to get around”

Psychologists abandoned

I think that's been a struggle because our corporates have been stripped bare in places and we still need those basic support functions to do our job (Andy, 229-230).

Because no one else is gonna to care for me (Max, 102).

Umh, and so I felt like there was a real lack of understanding of what we were doing, to be totally honest (Pat, 152-153).

Directionless

So, it feels very much like there's not been a clear strategy within either psychology or, or the trust really about what we're doing and very much this view of we're not doing face to face, we don't know when we're going to be doing face to face and, and a sort of reluctance to think about… how we navigate that (Pat, 173-176).

But it does feel bizarre to be going into the office to essentially do Teams calls, but from a slightly different location (laughs). Um… So that's always kind of… um, jarred a little bit…. I don't know how much of it is kind of, well, this is the way that we said we're going to do it. So, we're just going to continue to do it. I think we, think we have sort of raised it a couple of times (Alex, 187-195).

Feeling powerless

I think it's quite heart breaking when you're on the phone to them and you're thinking I want to, I want to be able to come out and help but I can't at the moment, I’m being told by my service, I can't and I also can't give you a date of when I'm going to be able to (Pat, 364-366).

Yeah, and I think sometimes it has felt a bit overwhelming, actually, more the staff….. More the supporting the staff or that, the kind of helplessness of not being able to do anything (Jamie, 180-182).