Exploring the Experiences of Family Caregivers who Support an Individual with a Learning Disability who Engages in Behaviours of Concern

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by

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Overview

This thesis portfolio comprises three parts:

Part One: Systematic Literature Review

Part one is a systematic review of the literature that explores the experiences of family caregivers who support individuals with intellectual disabilities who display behaviours of concern, with a focus on caregivers' general experiences and experiences with support services. 24 papers met the inclusion criteria and thematic synthesis was used to synthesise the findings. Thematic synthesis generated three superordinate themes. The findings highlighted the significance of person-centred support for families and individuals and the need for support specifically for family caregiver's wellbeing. Positive experiences with support services increased the wellbeing of the whole family. Future research should collect demographic data of participants and their family members to enable services to offer support that meets their specific needs.

Part Two: Empirical Paper

Part two is an empirical paper that explores the meaning and experience of compassion for family caregivers who support individuals with intellectual disabilities who display behaviours of concern. Seven semi-structured interviews were completed. Reflexive thematic analysis was used to analyse the data which generated three overarching themes. The findings highlighted the increased difficulties that family caregivers experienced in relation to self-compassion and although they felt showing others compassion was integral to their role as a family caregiver this was not without its difficulties. Caregivers described the importance of self-compassion and receiving compassion from others for their own wellbeing and for enhancing and maintaining their ability to show others compassion. Future research should explore whether interventions to support family caregivers to engage in self-compassion improves their wellbeing and as a result increases the quality of care that they provide to the individual.

Part Three: Appendices

Part three contains appendices relating to both the systemic literature review and the empirical paper, including a reflective statement and an epistemological statement.

Total word count (excluding appendices): 29,853

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Values statement

The term ‘profound and multiple learning disability’ has been used to describe individuals who often require support with significant learning, communication and physical needs, and who may have more than one disability (British Psychological Society, 2015; Doukas et al., 2017). The terminology ‘severe, profound and multiple learning disability’ which is sometimes used by services is a description of an individual’s needs, rather than a clinical diagnosis (Bellamy et al., 2010; Doukas et al., 2017) and is used in the two papers to reflect that the caregivers are supporting individuals who have profound and multiple needs.

Historically behaviours of concern have been described using terminology that has negative connotations and suggests the behaviour is the fault of the individual (Chan et al., 2012). With recognition that behaviours of concern are adaptive and functional and displayed within the context of the individual’s environment, the preferred term of ‘behaviours of concern’ (Chan et al., 2012) is used throughout the two papers.

Throughout the papers, the word ‘caregiver’ is used. There has been a move towards the terminology ‘support with’ rather than ‘cared for’. The term ‘caregiver’ is used for the purpose of the research only.

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Part One

The Experiences of Family Caregivers who Support Individuals with Intellectual Disabilities who Display Behaviours of Concern. A Systematic Review of the Literature.

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This paper is written in the format ready for submission to the Journal of Applied Research in Intellectual Disabilities.

Please see Appendix C for the Guideline for Authors

Word count: 8891 (excluding keywords, figures, tables, figure and table captions and references)

Abstract

Background

Families play a significant role in supporting individuals with an intellectual disability who display behaviours of concern. A previous review identified family caregiver's experiences with support services (Griffith & Hastings, 2014). This review aimed to add to the findings of the existing review, by conducting an international review and broadening the research questions to explore family caregiver's general experiences and experiences with support services.

Materials and Methods

A systematic literature search was completed utilising five databases to explore the experiences of family caregivers who support an individual with intellectual disabilities who display behaviours of concern. 24 studies met the inclusion criteria and thematic synthesis was used to synthesise the findings.

Results

Three overarching themes were generated including 'emotional responses and mental health difficulties: adjustment to a new life', 'preferences for support for my family member' and 'caregiver needs'.

Conclusions

The overarching findings of the review were that caregiver's experiences and needs were not found to differ internationally and in contrast to the existing review caregivers highlighted the importance of their wellbeing and their desire for support to be available to family caregivers. Further research is needed into the demographic factors that might impact on the unique experiences of being a family caregiver. There is a clear need for services to provide more support for family caregivers and to improve the support that services provide to families through person-centred approaches. Services must address the difficulties which impact on access to support and provide opportunities for professionals at all levels to continually develop their expertise.

Keywords

Family caregivers; behaviours of concern; intellectual disability; systematic literature review; experiences; support service

Lay summary

- This study identifies the need for further research into the demographic factors that might impact on the unique experiences of being a family caregiver.
- The study did not identify any clear differences between family caregivers' experiences internationally.
- The study identified a need to improve the support that services provide to families through person-centred approaches.
- The study identified a need for more support to be available for family caregivers' wellbeing which may improve the quality of support family caregivers can provide.

Introduction

Families play a significant role in supporting individuals with an intellectual disability who display behaviours of concern. It is currently estimated that there are 1.5 million people with an intellectual disability in England (Parkin, 2023), many supported by family caregivers within their family home (Foundation for People with Learning Disabilities, 2022). The English population is predicted to rise, potentially resulting in an increase in the number of individuals with intellectual disabilities and family caregivers (Emerson & Hatton, 2008) who with advances in healthcare and longer life expectancy (World Health Organisation, 2000), may remain in caregiving roles for longer.

The prevalence of behaviours of concern is estimated at 10-15% in people with intellectual disabilities (Emerson et al., 2001), which is higher than in the general population (Jones et al., 2008). Behaviours of concern can lead to individuals experiencing a decreased quality of life (Hogan & Bigby, 2024) and can increase the likelihood of caregivers experiencing physical harm and psychological distress (Hastings, 2002).

Family caregivers supporting an individual often describe the rewards that they experience, including love and admiration for their family member as well as the challenges they experience (Sheldon et al., 2021). Family caregivers who support an individual who displays behaviours of concern report experiencing stress, anger, guilt, shame, and social isolation and report a lack of support from services, impacting on their physical health and relationships (Challenging Behaviour Foundation, 2022). Feeling increased stress and powerlessness may be associated with the inadequate support they receive (McGill et al., 2006). It is therefore important for services to understand family caregivers’ personal experiences and experiences of services in order to provide support for both their physical and emotional health.

Throughout this review, the word ‘individual’ will refer to an individual with an intellectual disability who displays behaviours of concern and is supported by a family caregiver. An existing literature review (Griffith & Hastings, 2014) explored the experiences of family caregivers of individuals, with a focus on their experiences of support services. Whilst the findings of the review reflected the rewards of being a family caregiver and the positive impact that becoming a caregiver had on their identity whilst adapting to a new way of life, it also identified the challenges family caregivers experienced within their role. Caregivers mainly described their experiences of professionals and services, but also described the physical and emotional impact of behaviours of concern, including physical injuries and the distress that they experienced in relation to witnessing their family member engage in self-harm. They expressed appreciation for services in which professionals were proactive, collaborative and showed a genuine care for the individual, and described the positive impact that these services had on the whole family’s wellbeing. However, caregivers largely described support services as inadequate, frustrating and difficult to navigate and obtain, resulting in feelings of exhaustion, anxiety and stress. Caregivers described feelings of being ‘on call’ when individuals accessed respite services limiting the potential benefits of the support. They described their relationships with professionals as difficult and that those who were supportive lacked the power to affect the changes required. Services and professionals were mainly described as increasing the level of difficulties that families were experiencing (except for five studies that evaluated the support provided by their own service). Caregivers highlighted the importance of all services and professionals having expertise and knowledge to manage behaviours of concern. Where services lacked expertise, it further increased caregivers lack of trust and resulted in individuals being excluded from support services. Worries about the future were reported in relation to caregivers’ ability to support their family member as they became older and their significant distrust of services to adequately support the individual. Caregivers rarely spoke of their own needs throughout the review but did refer to the positive impact of professionals offering encouraging and affirmative statements. The review however had several limitations: it predominately included studies from the United Kingdom (UK), was unable to explore any patterns in demographic data due to limited information reported and did not include a quality assessment.

Since Griffith and Hastings' (2014) review, policies have been introduced to create standards of care and new frameworks have been introduced for support services. The updated policies and frameworks have highlighted the importance of personalised care and the role of family caregivers within the lives of individuals with an intellectual disability. The Care Act was introduced in England in 2014 entitling caregivers to a person-centred assessment of their emotional and/or physical needs which may have resulted in an increase in support services for caregivers and further research to evaluate this. In addition to The Care Act, Positive Behaviour Support (PBS) has increasingly become an important model within services to support individuals (PBS Coalition, 2015). An updated definition and framework for PBS was proposed by Gore et al., (2013) which aimed to increase the quality of life of the individual and their caregivers and National Policy statements have recognised the importance of PBS in providing effective support for individuals (National Health Service, 2013). As PBS recognises the key role that caregivers play in supporting families and the importance of their role in the assessment and intervention of behaviours of concern (Hastings et al., 2013), this may have also resulted in additional research exploring caregivers' experiences of support services, interventions and professionals.

Policies supporting people with intellectual disabilities and their carers vary internationally potentially impacting on the experiences of caregivers. Policies recognising the role of carers have been in place in Australia and Canada for a number of years and recent changes have been made in the USA to increase the support to family caregivers. Differences exist within Europe as Norway has had a policy in place to support informal caregivers since 2011 whilst the Netherlands implemented a policy in 2015 to protect and increase the wellbeing of caregivers. Scotland and Wales have also had support in place since 2013 and 2014 to increase and protect the wellbeing and quality of life of family caregivers. Overall, to the best of the researchers knowledge, the UK and Australia appear to have the largest support available for family caregivers. The inclusion of international studies may highlight themes reflecting the impact of policy on caregivers' experiences and wellbeing and identify the need for different approaches to intervention as a result of this.

The current review will add to the existing review. The existing review had access to limited demographic data, mainly explored caregivers' experiences in the UK and did not include a quality assessment. The current review will therefore include an increased number of studies conducted outside of the UK to consider a wider demographic and explore any patterns that might arise, include a quality assessment to highlight the quality of the papers and will widen the use of qualitative research to explore both the general experiences of being a family caregiver and the experiences of support services. The inclusion of a higher number of international studies may highlight cultural differences in approaches and understanding towards support, services and relationships with professionals. The exploration of demographic data may highlight differences in support needs dependent on life circumstances and the impact of additional diagnoses and behaviours of concern which research has suggested can be associated with greater difficulties in family wellbeing (Douma et al., 2006; White & Hastings, 2004).

The aim of this review is to explore the experiences of family caregivers who support an individual with an intellectual disability who displays behaviours of concern. This review is needed to update research to reflect the current experiences of caregivers following changes in service provision and to identify if there have been any changes since the previous review was published in 2014. This review aims to inform practice within intellectual disability services that are delivering support to families. It will provide insight into the lived experience of family caregivers, the support services available and support options that could be developed. It will help professionals to understand and support the emotional wellbeing of family caregivers which may have long term benefits for their wellbeing and the quality of life of the individual they support. The research question was: what are the experiences of family caregivers who support an individual?

Method

Search strategy

An electronic search was undertaken in December 2023 using databases that covered a wide range of subject areas including psychology, nursing and psychiatry that were peer reviewed, academically approved and relevant to the research. The databases most relevant to the review were identified as: Medline, CINAHL Ultimate, APA PsycInfo, APA PsycArticles and Academic Search Ultimate. The relevant databases enabled the researcher to explore as many experiences related to mental and physical health, including psychological and medical interventions, that were relevant to the research aims. Firstly, a search was completed to identify psychological and broad healthcare relevant to the review. The ‘date’ limiter was applied from December 2012 to 2023 to ensure that any studies not included in the previous review were included in the current review. The review was published on PROSPERO in December 2023.

Search terms

A scoping exercise of the literature was completed to identify the most frequently used words in the titles of the papers, together with the search terms used in a previous review (Griffith & Hastings, 2014). Following consultation with the second author and an Academic and Library Specialist the search terms agreed were:

"learning disab*" OR "intellectual disabilit*" OR "intellectual developmental disab*" OR "mental* retard*" OR "learning difficult*" OR "special need*" OR "complex need*" OR "additional need*"

AND

“challenging behav*" OR "problem behav*" OR "behav* that concerns" OR "behav* that challenge" OR "behav* disorder*”

AND

Caregiver* OR parent* OR sibling* OR carer* OR mother* OR father* OR famil*

AND

experienc* or perception* or attitude* or view* or feeling* or qualitative or perspective*

Selection

All papers were screened in three stages. Initially, the titles were screened for relevance to the review. The researcher then read the abstracts of papers and if relevance was unclear, the researcher read the full article. Table 1 and 2 contain the inclusion and exclusion criteria.

Table 1.

Inclusion criteria and rationale

Inclusion criteria	**Rationale**
English	Research translation resources not available
Peer reviewed	To approve the quality of the papers
Primary sources	To assess demographic data of the participants
Qualitative and mixed methods literature where it is possible to extract the qualitative literature	To explore rich data of caregiver experiences
Published in academic journals	To approve the quality of the papers
Papers published in December 2012 that are not included in the existing review (Griffith & Hastings, 2014)	To ensure that all studies published after the previous review are included
Family caregivers who support an individual with an intellectual disability who display behaviours of concern	To explore individuals' experiences as a family caregiver
Papers that interview multi-informants and it is possible to extract the data provided by family caregivers	The interest of the review is to explore family caregivers' experiences
Papers that include family caregivers who support individuals without an intellectual disability and it is possible to clearly extract the direct quotes from the family caregivers who support an individual with an intellectual disability	The interest of the review is to explore the experience of family caregivers who support an individual with an intellectual disability
Papers that include family caregivers who support individuals who are living within or outside of the family home	The interest of the review is to explore the experience of family caregivers who support an individual with an intellectual disability. A limited number of papers collected demographic information regarding individual's living circumstances. It was important to include participants with a range of living circumstances to reduce the likelihood of excluding important experiences. This will be considered within the synthesis.
Papers must have an inclusion criterion of supporting an individual with an intellectual disability who display behaviours of concern, a theme of behaviours of concern must be evident or the study must have a focus on a specific setting or service that supports individuals who display behaviours of concern	A limited number of papers included behaviours of concern as an inclusion criterion, particularly international papers. However, many studies identified a theme of behaviours of concern. The papers were included to explore international family caregiver experiences and to reduce the likelihood of excluding important experiences when a theme of behaviours of concern was evident

Papers exploring interventions	To explore caregivers' experiences of psychological and medical interventions

Table 2.

Exclusion criteria and rationale

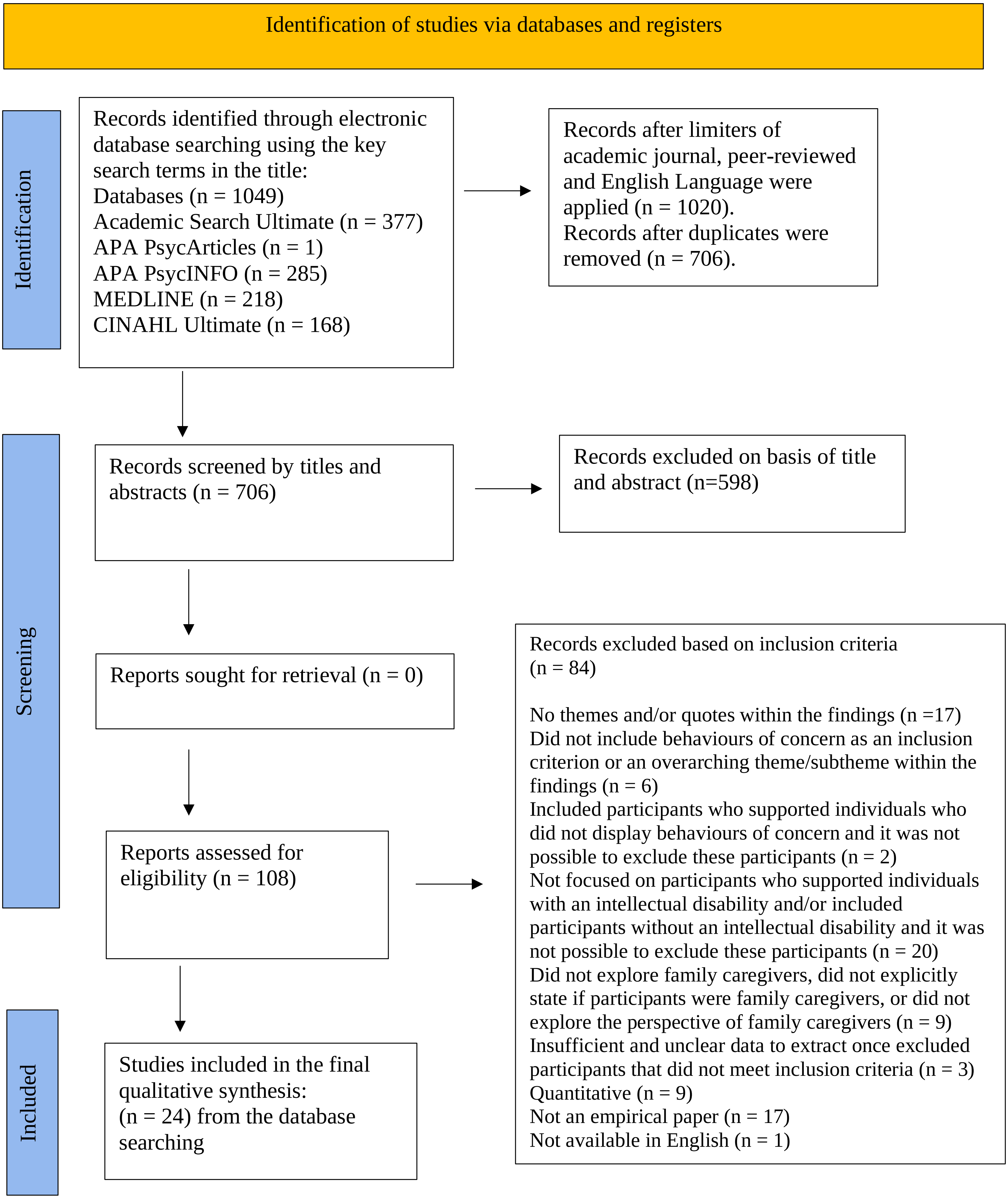
Exclusion criteria	**Rationale**
Studies that do not explore the experience of family caregivers and studies that do not explicitly state that the caregivers are family caregivers	The interest of the review is to explore family caregivers' experiences
Non-qualitative literature	The review aims to explore the qualitative literature of family caregivers' experience. Therefore, quantitative research and mixed methodologies will be excluded where it is not possible to extract qualitative data
Papers published in or before 2012 that were included in the existing review (Griffith & Hastings, 2014)	Review already completed and themes have been synthesised
Papers that interview multi-informants but the authors do not clearly differentiate between the individuals in the findings	The researcher cannot extract the data reported by family caregivers
Studies that include family caregivers who support individuals without an intellectual disability, but the authors do not clearly differentiate between the family caregivers and who they support in the findings	The researcher cannot extract the direct quotes from the family caregivers who support an individual with an intellectual disability
Experiences relating to the COVID-19 pandemic	The events and experiences during this time will be more specifically related to the COVID-19 pandemic. The review aims to explore more general experiences and perceptions of being a family caregiver
Papers that do not have themes or quotes within the findings	Limits the possibility for thematic synthesis of the findings
Papers that include multi-informants that do not meet the inclusion criteria and once these participants have been included there is insufficient data to extract from the perspective of being a family caregiver	Unclear if the findings and themes reflect the perspectives of family caregivers who support an individual with an intellectual disability who displays behaviour of concern

Study selection

The search identified 1049 papers. After the limiters of academic journal, peer-reviewed and English language were applied and duplicates were removed, 706 papers were screened by their title and abstract for relevance to the review. 598 papers did not meet the inclusion criteria (Table 1) and were excluded. 108 articles were assessed for eligibility as it was unclear whether the paper met the inclusion criteria. The researcher did not complete further searches of the literature due to the number of the studies identified through the search. After reading the full text of 108 papers, 24 papers were included in the review. The study selection process was informed by the Preferred Reporting Items for Systematic Reviews and Meta-analyses diagram of search strategy **(**Page et al., 2021) (Figure 1).

Figure 1.

Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) diagram of search strategy **(***Page et al., 2021).*



Records identified through electronic database searching using the key search terms in the title:
Databases (n = 1049)
Academic Search Ultimate (n = 377)
APA PsycArticles (n = 1)
APA PsycINFO (n = 285)
MEDLINE (n = 218)
CINAHL Ultimate (n = 168)

Records after limiters of academic journal, peer-reviewed and English Language were applied (n = 1020).
Records after duplicates were removed (n = 706).

Records screened by titles and abstracts (n = 706)

Records excluded on basis of title and abstract (n=598)

Reports sought for retrieval (n = 0)

Reports assessed for eligibility (n = 108)

Records excluded based on inclusion criteria
(n = 84)

No themes and/or quotes within the findings (n =17)
Did not include behaviours of concern as an inclusion criterion or an overarching theme/subtheme within the findings (n = 6)
Included participants who supported individuals who did not display behaviours of concern and it was not possible to exclude these participants (n = 2)
Not focused on participants who supported individuals with an intellectual disability and/or included participants without an intellectual disability and it was not possible to exclude these participants (n = 20)
Did not explore family caregivers, did not explicitly state if participants were family caregivers, or did not explore the perspective of family caregivers (n = 9)
Insufficient and unclear data to extract once excluded participants that did not meet inclusion criteria (n = 3)
Quantitative (n = 9)
Not an empirical paper (n = 17)
Not available in English (n = 1)

Studies included in the final qualitative synthesis:
(n = 24) from the database searching

Data Extraction

After study selection, key data that was relevant to the review's research aims was extracted based on Wilson's (2009) data extraction form (Appendix E), such as the country in which the research was conducted and further demographic data of participants and the individual that they supported.

Quality Assessment

The quality of each paper was assessed using the National Institute for Health and Care Excellence (NICE) quality assessment appraisal checklist for qualitative research studies (NICE, 2012) (Appendix F). This appraisal checklist was chosen as it is relevant to the review aims, as it considers the context and characteristics of participants. The CASP checklist was considered, however, the NICE checklist aligned better with the research as it included the participant demographics which were central to the research aims. The NICE checklist is based on broadly accepted principles that characterise qualitative research and is widely recognised as a quality assessment tool. Only the qualitative information within studies was assessed. Two research papers were randomly selected and assessed by another researcher and any discrepancies were discussed until the researchers agreed on a single quality rating. The quality assessment ratings were not used as a reason for exclusion but they were considered in the synthesis of the findings.

Data Synthesis

The existing review synthesised the findings using meta-ethnography (Noblit & Hare, 1988). The current review utilised thematic synthesis (Thomas & Harden, 2008) to minimise the researcher influence, give results that stay 'close' to the primary findings and explore family caregiver's experiences (Thomas & Harden, 2008). Thematic synthesis was used in order to analyse the data and identify prominent or recurrent themes (Thomas & Harden, 2008). Thematic synthesis is a method of analysis that was developed to analyse reviews exploring the need, appropriateness and efficiency of intervention and has been found to minimise researcher influence, giving results that stay 'close' to the primary findings. It involves three main stages: 'line by line' coding, generating descriptive themes which do not go 'beyond' the initial dataset and then analytical themes are generated which are interpretations of the initial dataset (Thomas & Harden, 2008). Individuals must be explicit in their understanding and interpretations of meaning of data and it can be completed within pairs or small teams to increase reliability.

Results

Characteristics of studies

The 24 papers included in this review were published between 2014 to 2023. Research took place in a range of countries. Fifteen were from the UK (Botterill et al., 2019; Chase, & McGill, 2019; Chester et al., 2019; Gore et al., 2019; Hassiotis et al., 2018; Inchley-Mort, & Hassiotis, 2014; Jacobs et al., 2016; Kiernan et al., 2019; Kouroupa et al., 2023a; Kouroupa et al., 2023b; McKenzie et al., 2018; Ross & Dodds, 2021; Thompson-Janes et al., 2014; Yacoub et al., 2018; Young-Southward et al., 2017). Two were from Canada (Don & O'Byrne, 2022; Grenier-Martin, & Rivard, 2022). Two were from USA (Muller et al., 2019; Sheldon et al., 2021). One was from Norway (Nag et al., 2019). One was from the Netherlands (Olivier-Pijpers et al., 2020). Three were from Australia (Dew et at., 2019; Dreyfus & Dowse, 2018; Dreyfus et al., 2024).

22 studies used qualitative methodology. Of these, seventeen used semi-structured interviews (Botterill et al., 2019; Chase & McGill, 2019; Chester et al., 2019; Dew et al., 2019; Don &

O'Byrne, 2022; Dreyfus & Dowse, 2018; Dreyfus et al., 2024; Gore et al., 2019; Inchley-Mort & Hassiotis 2014; Jacobs et al., 2016; Kiernan et al., 2019; Kouroupa et al., 2023b; McKenzie et al., 2018; Muller et al., 2019; Ross & Dodds, 2021; Thompson-Janes et al., 2014; Young-Southward et al., 2017). Three used interviews but did not state whether they were semi-structured (Kouroupa et al., 2023a; Olivier-Pijpers et al., 2020; Yacoub et al., 2018). One used a survey (Sheldon et al., 2021). One used both semi-structured interviews and online surveys (Nag et al., 2019). Two used a mixed-methods design. Of these, one used an online survey (Grenier-Martin & Rivard, 2022) and one used semi-structured interviews (Hassiotis et al., 2018) and any quantitative data was carefully excluded.

Characteristics of family caregivers

Overall, there was a total of 509 family caregivers. Sample sizes ranged from 6 to 175 participants. Participants who did not meet the inclusion criteria were carefully excluded (Botterill et al., 2019; Gore et al., 2019; Hassiotis et al., 2018; Inchley-Mort & Hassiotis, 2014; Jacobs et al., 2016; Kiernan et al., 2019; Kouroupa et al., 2023a; Kouroupa et al., 2023b; Nag et al., 2019; Ross & Dodds, 2021; Young-Southward et al., 2017) leaving a total of 492 family caregivers and sample sizes ranged from 4 to 175.

Most caregivers within the studies were mothers. Two studies included siblings only (Chase & McGill, 2019; Yacoub et al., 2018), two included mothers only (Dew et al., 2019; Kiernan et al., 2019; Muller et al., 2019) and one included fathers only (Sheldon et al., 2021). Although aiming to include all genders, two studies only included female participants (Dreyfus et al., 2024; Inchley-Mort & Hassiotis, 2014). Three papers included family caregivers who were grandparents (Dreyfus & Dowse, 2018; Gore et al., 2019; Young-Southward et al., 2017).

Six studies reported the age range of participants (Botterill et al., 2019; Chase & McGill, 2019; Dew et al., 2019, Grenier-Martin & Rivard, 2022; Muller et al., 2019; Sheldon et al., 2021). Overall, ages ranged from 22-82 years. One grouped together the age of family and paid caregivers meaning this data could not be extracted (Kouroupa et al., 2023a).

Five reported the gender of the participants (Botterill et al., 2019; Chase & McGill, 2019; Gore et al., 2019; Kiernan et al., 2019; Kouroupa et al., 2023b). Eleven did not report the gender of participants, however family relations implied gender roles (Dew et al., 2019; Dreyfus & Dowse, 2018; Dreyfus et al., 2024; Grenier-Martin & Rivard, 2022; Inchley-Mort & Hassiotis, 2014; Jacobs et al., 2016; Muller et al., 2019; Nag et al., 2019; Sheldon et al., 2021; Thompson-Janes et al., 2014; Young-Southward et al., 2017). One grouped together the gender of family and paid caregivers, meaning this information could not be extracted (Kouroupa et al., 2023a).

Characteristics of the individual that family caregivers support

Sixteen studies reported the age of individuals (Botterill et al., 2019; Chase & McGill, 2019, Dew et al., 2019; Don & O'Byrne, 2022; Dreyfus & Dowse, 2018; Dreyfus et al., 2024; Gore et al., 2019; Grenier-Martin & Rivard, 2022; Jacobs et al., 2016; Kiernan et al., 2019; McKenzie et al., 2018; Muller et al., 2019; Olivier-Pijpers et al., 2020; Sheldon et al., 2021; Thompson-Janes et al., 2014; Young-Southward et al., 2017). One did not separate the demographic factors of individuals that family and paid caregivers supported, meaning this information could not be extracted (Kouroupa et al., 2023a). One included both surveys and interview methodology but only reported the age range for the interviews (Nag et al., 2019). The age range across the 24 studies was new-born to 62 years.

Eleven reported the gender of individuals (Chase & McGill, 2019; Dreyfus & Dowse, 2018; Dreyfus et al., 2024; Gore et al., 2019; Grenier-Martin & Rivard, 2022; Jacobs et al., 2016; Kiernan et al., 2019; McKenzie et al., 2018; Muller et al., 2019; Sheldon et al., 2021; Young-Southward et al., 2017). One grouped together the gender of individuals that family and paid caregivers supported, meaning this data could not be extracted (Kouroupa et al., 2023a). One reported the gender of individuals for the survey conducted, but not for those who engaged in the interviews (Nag et al., 2019). Individuals were mainly males.

Seventeen studies did not report the living circumstances of the family member and the individual they support (Botterill et al., 2019; Dew et al., 2019; Don & O'Byrne, 2022; Dreyfus & Dowse, 2018; Gore et al., 2019; Grenier-Martin & Rivard, 2022, Hassiotis et al., 2018; Inchley-Mort & Hassiotis, 2014; Jacobs et al., 2016; Kiernan et al., 2019; Kouroupa et al., 2023b; Muller et al., 2019; Nag et al., 2019; Olivier-Pijpers et al., 2020; Ross & Dodds, 2021; Sheldon et al., 2021; Thompson-Janes et al., 2014). Studies that reported the living circumstances of individuals included residential care, supported living, living in the family home, independent living with some support, accommodation in the community and supported living placements (Chase & McGill, 2019; Dreyfus et al., 2024; McKenzie et al., 2018; Young-Southward et al., 2017). One study only included family caregivers if their family member lived within the family home (full time or when not attending term time education) or had left the family home within the last year but spent at least five days or more per month at the family home (Yacoub et al., 2018). One study grouped together the living circumstances of individuals that family and paid caregivers supported, and the data therefore could not be extracted (Kouroupa et al., 2023a).

Twelve studies included behaviours of concern as an inclusion criterion (Chase & McGill, 2019; Dew et al., 2019; Dreyfus & Dowse, 2018; Grenier-Martin & Rivard, 2022; Jacobs et al., 2016; Kiernan et al., 2019; Kouroupa et al., 2023a; Muller et al., 2019; Nag et al., 2019; Olivier-Pijpers et al., 2020; Thompson-Janes et al., 2014; Yacoub et al., 2018). For those that did not, one focused on a forensic setting (Chester et al., 2019), seven focused on behaviour support interventions or services (Botterill, et al. 2019; Dreyfus et al., 2024; Gore et al., 2019; Hassiotis et al., 2018; Inchley-Mort & Hassiotis, 2014; Kouroupa et al., 2023b; McKenzie et al., 2018) and four included themes of behaviour of concern within the findings (Don & O'Byrne, 2022; Ross & Dodds, 2021; Sheldon et al., 2021; Young-Southward et al., 2017). Two studies recruited from the same charity service (Chase & McGill, 2019; Yacoub et al., 2018).

Thirteen studies used thematic analysis (Botterill et al., 2019; Dew et al., 2019; Don & O'Byrne, 2022; Dreyfus & Dowse, 2018; Hassiotis et al., 2018; Jacobs et al., 2016; Kiernan et al., 2019; Kouroupa et al., 2023a; Kouroupa et al., 2023b, McKenzie et al., 2018; Thompson-Janes et al., 2014; Yacoub et al., 2018; Young-Southward et al., 2017). Three used a phenomenological method such as Interpretative Phenomenological Approach (Chase & McGill, 2019; Nag et al., 2019; Ross & Dodds, 2021). Four used Content Analysis (Chester et al., 2019; Grenier-Martin & Rivard, 2022; Inchley-Mort & Hassiotis, 2014; Sheldon et al., 2021). Two used a Grounded Theory Approach (Muller et al., 2019; Olivier-Pijpers et al., 2020). One used a Framework Approach (Gore et al., 2019). One used a codebook methodology (Dreyfus et al., 2024). Table 3 contains further information of the studies included.

Table 3.

Characteristics of studies

Authors, year of publication, location of study	**Research aims**	**Study design and analysis**	**Participant characteristics**	**Characteristics of individuals that participants support**	**Key findings**
Botterill, Cottam, Fowke and Theodore (2019) United Kingdom	To explore the experiences of family caregivers who support young people with intellectual disabilities who have received family-based PBS	Qualitative Semi-structured interviews with individuals Thematic analysis (Braun & Clarke, 2006) Intervention: PBS Inclusion criteria: participants must support someone who has received PBS.	8 parents Family caregivers who supported individuals who did not have an intellectual disability were carefully excluded (n=2) 6 family caregivers met the inclusion criteria for the review Family relation: mother (n=5), father (n=1) Gender: female (n=5), male (n=1) Age range: 43-53 years Ethnicity: British (n=2), Serbian (n=1), Irish (n=1), Asian (n=1), French (n=1) Marital status: not stated Employment: not stated	Age range: 8-17 years Gender: not stated Additional diagnoses: autism (n=3) Behaviours of concern: not stated. Living circumstances: not stated	Positive experiences with services were described when professionals worked closely with families and adopted a person-centred approach, which supported the development of effective strategies to reduce behaviours of concern. Caregivers also valued when professionals were knowledgeable, non-judgmental, honest and patient. Positive outcomes of PBS included increased confidence to support their child, greater understanding of the functions of behaviour and improved wellbeing of the caregiver.
Chase and McGill (2019) United Kingdom	To investigate the perspectives of siblings who support individuals with intellectual	Qualitative Semi-structured interviews with individuals	6 siblings Gender: female (n=6) Age range: 22-53 years	Age range: 19-51 years Gender: female (n=2), male (n=4)	Siblings mostly reported the rewards of being a family caregiver which included the positive impact on their personality (becoming more patient and independent), as well as the challenges they experienced

	disabilities who display behaviours of concern	Interpretative Phenomenological Approach (Smith & Osborn, 2008) Inclusion criterion: participants must support someone who displays behaviours of concern and is known to the community intellectual disability service.	Ethnicity: not stated Marital status: not stated Employment: not stated	Additional diagnoses: cerebral palsy (n=1), autism (n=5), rare chromosome disorder (n=1), attention deficit hyperactivity disorder (n=1), epilepsy (n=1), ‘chromosome abnormality’ (n=1), brain damage at birth (n=1), Down syndrome (n=1), bipolar (n=2), post-traumatic stress disorder (n=1) Behaviours of concern: not stated. Living circumstances: residential care or supported living (n=5), living with their sibling (n=1)	with being a young caregiver (stress and increased responsibilities). Siblings described the impact of caregiving responsibilities on their relationships with others in their family. Some siblings described family relationships becoming stronger, whereas others described increased tension when other family members did not fulfil their responsibilities. Siblings described their responsibilities and often described the desire to increase their sibling’s quality of life. They described wanting to help their parents but also spoke of their worries around the increased responsibilities in the future. Siblings stated that there was inadequate support for family caregivers in general and the importance of peer support from sibling caregivers for wellbeing.
Chester, Greach and Morrissey (2019) United Kingdom	To explore the perspectives of individuals with intellectual disabilities and their family caregivers of a forensic intellectual and developmental disability service	Qualitative Semi-structured interviews within consultation groups Content analysis Intervention: forensic services Inclusion criterion: focus of the paper was around experiences of a forensic service	6 family caregivers Family relation: not stated Age: not stated Gender: not stated Ethnicity: not stated Marital status: not stated Employment: not stated	Age: not stated Gender: not stated Additional diagnoses: not stated Behaviours of concern: not reported. Living circumstances: low or medium secure forensic intellectual disability service (n=5), hospital setting (n=1)	Positive experiences of the service were described when professionals engaged in clear and effective communication, worked collaboratively with families and listened and respected the family’s views and opinions. This helped to reduce family caregivers worries for the future. Caregivers stated the importance of families and services prioritising the quality of life of their family member. Negative experiences of the service were described when caregivers felt professionals did not take a strengths-based approach. Caregivers also highlighted the inadequate support that their family member had access to following discharge and the inadequate support that was available within the community.
Dew, Collings, Dowse, Meltzer, Smith, and James	To explore parents' perspectives of a parent peer support programme	Qualitative	13 mothers Age range: 32-54 years	Age range: 3-26 years Gender: not stated	Positive experiences of the peer support intervention were described in relation to the programme coordinator who facilitated

(2019) Australia		Semi-structured interviews with individuals Thematic analysis (Braun & Clarke, 2006) Intervention: peer support Inclusion criterion: family caregivers who support an individual with intellectual disabilities who display behaviours of concern	Gender: not stated, however sample consisted of mothers. Ethnicity: not stated Marital status: living with partner (n=8), single (n=5) Employment: full time (n=5), part time (n=3), casual/flexible hours (n=2), not in employment (n=3)	Additional diagnoses: mental health difficulties and/or obsessive-compulsive disorder (n=3) Behaviours of concern: authors stated that mothers reported a range of behaviours of concern, with ‘aggression towards oneself and others’ most frequently reported (n=7). No further data was reported. Living circumstances: not stated	activities and engaged in clear and consistent communication. The group format enabled opportunities for social support, connection and belonging. Positive outcomes of the peer support intervention included reduced isolation and increased skills and confidence to support their family member. Some challenges were reported with the peer support intervention which included concerns around boundaries and the challenges associated with maintaining relationships due to the time constraints experienced by some caregivers.
Don and O'Byrne (2022) Canada	To explore family caregivers’ perspectives of how the diagnostic process stratifies children with intellectual disabilities	Qualitative Semi-structured interviews with individuals Thematic analysis (Braun & Clarke, 2006) Intervention: diagnostic process Inclusion criterion: behaviours of concern were found to be a subtheme within the findings.	6 family caregivers Family relation: not stated Age: not stated Gender: not stated Ethnicity: not stated Marital status: not stated Employment: not stated	Age range: 6-14 years Gender: not stated Additional diagnoses: not stated Behaviours of concern: ‘screaming, tantrums, aggression, defiance, incontinence’ Living circumstances: not stated	Caregivers described the difficulties associated with feeling unable to understand the functions of behaviours of concern and feeling unable to meet their needs. Caregivers described negative experiences of services that were inflexible and difficult to access resulting in inadequate support and where there was a power imbalance with professionals. Caregivers described the difficulties associated with attending numerous assessments but the importance of diagnoses to access support. Negative experiences with the public were described, including stigmatisation.
Dreyfus and Dowse (2018) Australia	To examine the experiences of family caregivers who support an individual with intellectual disabilities who displays behaviours of concern, with a focus on self-talk and the demands they experience	Qualitative Semi-structured interviews Thematic analysis (Braun & Clarke, 2006) and tools from a functional linguistic framework (Halliday & Matthiessen, 2014) Intervention: interviews focused on behaviour support services	26 family members were interviewed Family relation: mother (95%), grandparent (5%) Age: not stated Gender: not stated, however sample consisted of 95% mothers	Age range: 4–36 years Gender: female (25%), male (75%) Behaviours of concern: self-harm (54%), harm to others (78%) harm to environment (62%) most frequently reported. No further data was reported.	Caregivers described the rewards of being a family caregiver which included feeling inspired to use their skills to help others. Caregivers also described the challenges which included the high demands and responsibilities they experienced, and the difficulties understanding the functions of behaviours of concern. Caregivers highlighted the changes they had made to their lives to increase the quality of life for their family member which included

		Inclusion criterion: family caregivers who support an individual with intellectual disabilities who displays behaviours of concern	Ethnicity: not stated Marital status: not stated Employment: not stated	Additional diagnoses: not stated Living circumstances: not stated	undertaking training and education to increase their knowledge, moving homes to receive better support and seeking out services and activities to support their family member. Difficulties with services were described in relation to the number of administration tasks caregivers had to complete and negative experiences with professionals which led to caregivers completing formal complaints to services. Some caregivers described supporting their peers to gain more sufficient support and the importance of peer support for wellbeing.
Dreyfus, Nolan and Randle (2024) Published online in December 2023 Australia	To explore the experiences of family caregivers who support individuals with intellectual disabilities with a focus on accessibility to behaviour support services	Qualitative Semi-structured interviews Codebook methodology (Crabtree & Miller, 1992; Roberts et al., 2019) Intervention: interviews focused on accessibility and experiences of behaviour support services Excluded data reported directly linked to the COVID-19 pandemic. Inclusion criterion: focus on behaviour support services	14 mothers Age: not stated Gender: not stated, however sample consisted of mothers Ethnicity: not stated Marital status: not stated Employment: not stated	Age range: 8-55 years Gender: female (n=5), male (n=9) Behaviours of concern: not stated Additional diagnoses: not stated Living circumstances: at home with family (n=6), supported independent living with 24/7 staff support (n=6), independent living with some staff support (n=2). At interview, one lived with family due to the COVID-19 pandemic.	Challenges with support services were described which included significant waiting times, staff shortages, staff turnover, limited staff knowledge and expertise, and the high caseloads. Mothers highlighted the importance of services having a consistent approach in relation to the strategies used to support their family member and the lack of consistency that was often present across services. Mothers reported increased demands due to their role in coordinating services and educating professionals. Mothers described being able to access adequate support if they felt informed and knowledgeable about services and as a result of knowing how to “argue” for them. They described the need for services to make caregivers aware of the support available to increase their confidence to request support.
Gore, McGill and Hastings (2019) United Kingdom	To explore a method to identify family caregiver goal selection and preferences for PBS, to investigate the psychological and emotional processes within the goal selection,	Qualitative Semi-structured interviews with individuals A Framework Approach (Ritchie & Spencer, 1994)	12 family caregivers Family caregivers who did not support an individual with an intellectual disability were carefully excluded (n=4)	Age range: 4-15 years Gender: female (n=2), male (n=5) Additional diagnoses: Down syndrome (n=2), reactive attachment disorder (n=1), hearing impairment (n=2), William’s	Caregivers described the rewards of being a family caregiver which included the strong relationship they had with their family member. Caregivers described the importance of their family member’s quality of life, as well as social connections and inclusion.

	and to explore caregiver needs and experiences	Intervention: goal selection for PBS Inclusion criterion: focus on PBS interventions	8 family caregivers met the inclusion criteria. Family relation: mother (n=5), grandparent (n=2), father (n=1) Two participants were interviewed together and were part of the same family Age: not stated Gender: female (n=6) male (n=2) Ethnicity: not stated Marital status: not stated Employment: not stated	Syndrome (n=1), Autism (n=5), foetal valproate syndrome (n=1), epilepsy (n=1) Behaviours of concern: verbal behaviours (n=6), physical aggression (n=7), 'tantrum' (n=5), self-harm (n=5), property damage (n=1) Living circumstances: not stated	Caregivers described the negative events they had experienced with professionals, members of the public, and their family members. Caregivers stated the importance of professionals adopting a strength-based approach. Caregivers described the difficulties associated with their caregiving role when they felt unable to meet their family member's needs, expressing the challenges they experienced understanding functions of behaviour of concern and the impact of this on their wellbeing.
Grenier-Martin and Rivard (2022) Canada	To explore the experiences of family caregivers who support young children with an intellectual disability who display behaviours of concern, whilst awaiting support from services	Mixed methods Online survey collecting quantitative and qualitative data, utilising open ended questions. Any quantitative data was carefully excluded. Content analysis (L'Écuyer, 1990; Patton, 2002) Inclusion criterion: family caregivers who support an individual with intellectual disabilities who displays behaviours of concern	60 family caregivers Age range: 23-50 years Gender: not stated, however sample consisted of mothers and fathers Family relation: mothers (n = 56), fathers (n=4) Ethnicity: not stated Marital status: married or common-law partner (n=45), separated or divorced (n=10), single (n=4) widowed (n=1) Employment: full-time or part-time (n=48)	Age range: 10 months - 7 years Gender: female (n=29), male (n=31) Diagnoses: 'chromosomal abnormalities' (n=22) genetic syndromes (n=8) Additional diagnoses: communication disorder (n=43), neurological disorder (18), visual impairment (n=17) epilepsy (n=16), reduced mobility (n=15), attention deficit disorder with or without hyperactivity (n=14), hearing impairment (n=11) anxiety (n=6) chronic physical health diagnoses (n=5). Of those, some reported at least one additional diagnosis (n=49), and some	Some parents reported positive experiences with support services, and others reported that services were inadequate. Parents described a need for more support for families, including more information, strategies to help to manage behaviours of concern and availability of peer support. Caregivers described the difficulties in maintaining their wellbeing and the negative impact of challenges associated with understanding the function of behaviour of concern and therefore feeling unable to meet their family member's needs. Parents stated the difficulties they experienced within family relationships, with an emphasis on the difficulties in implementing consistent use of support strategies across family members. Parents described experiencing self-doubt and self-criticism in relation to the strategies they used to support their family.

				reported at least two additional diagnoses (n=40) Behaviours of concern: “not aware of danger/putting self at risk (85%), little collaboration in activities (77%), yelling (67%), crying (63%), refusing to eat or food selectivity (57%), throwing or damaging objects (55%), tantrums (53%), hitting others (52%), refusing to go to bed or difficulties with sleep (50%), biting others (48%) making noises (48%), anxiety (42%), eating too much or often choking (38%), hitting themselves (33%), biting themselves (28%), absconding (25%), complaining often (25%), spitting at others (15%), inappropriate language (5%)” Living circumstances: not stated	
Hassiotis, Poppe, Strydom, Vickerstaff, Hall, Crabtree, Omar, King, Hunter, Bosco, Biswas, Ratti, Blickwedel, Cooper, Howie, & Crawford (2018) United Kingdom	To explore the experiences of PBS from the perspectives of family caregivers, paid caregivers, service managers, therapists and PBS trainers, and the associated outcomes of PBS	Mixed methods Semi-structured interviews with individuals Thematic analysis (Braun & Clarke, 2006) Intervention: PBS Inclusion criterion: family caregiver’s experiences of PBS	11 family caregivers Family relation: not stated Age: not stated Gender: not stated Ethnicity: not stated Marital status: not stated Employment: not stated Participants who were not family caregivers were carefully excluded.	Age: not stated Gender: not stated Additional diagnoses: not stated Behaviours of concern: not stated Living circumstances: not stated	Caregivers described the challenges to their wellbeing and the increase in the challenges when their family member was distressed. Positive relationships with professionals were reported to have a positive impact on wellbeing and increased motivation in their caregiving role. Positive experiences with the service were reported when professionals provided support to both the caregiver and their family member, engaged in clear and consistent communication and when professionals were available for families when they required support. Caregivers described the positive impact that PBS had on the whole family’s wellbeing when professionals provided support to both the caregiver and their

					family member, and when caregivers received a plan to follow at home to support their family member. Challenging experiences with the service included the number professionals involved within their family members care and the number of home visits from professionals. Other difficulties included not being included in the PBS intervention with their family member and limited communication with professionals.
Inchley-Mort and Hassiotis (2014) United Kingdom	To explore the opinions of a PBS model from the perspectives of service users, family caregivers, paid caregivers and professionals	Qualitative Semi-structured interviews with individuals Content analysis (Graneheim & Lundman, 2004) Intervention: PBS model Inclusion criterion: family caregivers' experiences of PBS	8 mothers Age: not stated Gender: not stated, although sample consisted of mothers Ethnicity: not stated Marital status: not stated Employment: not stated Participants who were not family caregivers were carefully excluded.	Age: not stated Gender: not stated Additional diagnoses: not stated Behaviours of concern: "Physical/verbal anger/aggressive behaviour (n=11), self-isolation/withdrawal/refusal to leave house (n=5), personal behaviours e.g., clothes ripping/soaking, smearing, spitting (n=3), difficulties with physical or health wellbeing (n=3), screaming/swearing/shouting (n=3), delusions and paranoia (n=3), incontinence (n=2), sexualised behaviour (n=2), putting self at risk (n=1), difficulties sleeping (n=1), absconding (n=1), vulnerability (n=1)" Living circumstances: not stated	Mothers described the positive experiences that they had with the Complex Behaviour Service. Positive experiences included professionals taking the time to understand their family member and engaging in clear and consistent communication which led to mothers reporting a greater understanding of the functions of behaviour of concern. Mothers reported that they valued the professionals' interpersonal skills and the experience of feeling listened too. Most mothers reported increased skills and knowledge to support their family member, which led to a reduction in the frequency of behaviours of concern and an increase in their family member's quality of life. Mothers also reported the positive impact that the intervention had on their own wellbeing.
Jacobs, Woolfson and Hunter (2016) United Kingdom	To explore how parents experience and understand the behaviours of concern that the individual with	Qualitative Semi-structured interviews with individuals	10 parents participated in the study Family caregivers who supported individuals without	Age range: 8-12 years Gender: female (n=3), male (n=1)	Parents described the strategies that they used to support their family member and they described the different factors that contributed to the functions of behaviour of concern. Parents described wanting to

	intellectual disabilities they support displays	Thematic analysis (Braun & Clarke, 2006) Inclusion criterion: family caregivers who support an individual with intellectual disabilities who displays behaviours of concern	an intellectual disability were carefully excluded. 4 parents met the review's inclusion criteria Family relation: mother (n=3), father (n=1) Age: not stated Gender: not stated, however family relation implied gender roles Ethnicity: White Scottish ethnic background (n=4) Marital status: not stated Employment: not stated	Diagnoses: Cornelia de Lange syndrome (n=1), Down syndrome (n=2) Additional diagnoses: epilepsy (n=1) Behaviours of concern: 'running away, screaming, temper tantrums in public, hiding, and difficulties with sleep' Living circumstances: not stated	provide their family member with the best quality of life and the responsibility that they held to support their child to have the best life. Positive experiences with services were reported when teachers utilised strategies as recommended by family caregivers.
Kiernan, Mitchell, Stansfield & Taylor (2019) United Kingdom	To explore the perspectives of mothers who support a child with intellectual disabilities who displays behaviour of concern	Qualitative Semi-structured interviews with individuals Thematic analysis following the method outlined by Attride-Stirling's (2001) method Inclusion criterion: family caregivers who support an individual with intellectual disabilities who displays behaviours of concern	10 mothers participated in the study. Family caregivers who did not support an individual with an intellectual disability were carefully excluded (n=5) 5 mothers met the review's inclusion criteria Age range: not stated Gender: female (n=5) Ethnicity: not stated Marital status: not stated	Age range: 13-18 years Gender: female (n=1), male (n=4) Additional diagnoses: cerebral palsy (n=1), rare disorder (n=1) Behaviours of concern: not stated. Living circumstances: not stated	Mothers described researching and educating themselves on how to support their family member. Mothers described leaving careers and the difficulties that could arise in relation to family life due to caregiving demands. Mothers described the positive and challenging experiences with support services. Positive experiences were reported when professionals were knowledgeable and engaged person-centred practices. Mothers frequently reported the inadequate support available, with services often being unavailable to families. Mothers also reported high levels of exclusion and negative experiences with members of the public.

			Employment: not stated		
Kouroupa, Hamza, Rafiq, Hassiotis, Rapaport, Jahoda, Taggart, Steed, Cooper, Melville, Marston, Royston, & Ali (2023a) United Kingdom	To examine the experiences of individuals who have received psychosocial interventions to support with behaviours of concern, with a focus on the facilitators and barriers to the interventions	Qualitative Interviews with individuals (does not state if they were semi-structured) Framework method for thematic analysis (Braun & Clarke, 2006; Gale et al., 2013; Ritchie et al., 2013) Intervention: psychosocial interventions Inclusion criterion: family caregivers who support an individual with intellectual disabilities who has a history of displaying behaviours of concern and has received support from services	6 family caregivers Family relation: not stated Age: unclear due to grouping the demographics together with paid caregivers. Gender: unclear due to grouping the demographics together with paid caregivers. Ethnicity: not stated Marital status: not stated Employment: not stated Participants who were not family caregivers were carefully excluded.	Age, gender, additional diagnoses and living circumstances: unclear due to grouping of demographics and the authors not explicitly stating which family caregivers supported each individual Behaviours of concern: not stated	Positive experiences with support services were reported when caregivers felt they were listened to and when professionals were proactive, consistent and engaged in person-centred approaches. Family caregivers highlighted the importance of families supporting their family member during sessions with professionals to be able to advocate, support with communication and help their family member to feel reassured. Challenges with support services included the difficulties associated with shortages of staff, long waiting times, a lack of clarity around services and professional's roles, and inadequate support after their family member had experienced 'crisis'. Family caregivers also highlighted the lack of support available for family caregivers' wellbeing and difficulty accessing support that was available due to the demands on their time and commitments (e.g. employment).
Kouroupa, Hassiotis, Hamza, Courtenay, Hall, Langdon, Taggart, Crossey, Brynmor, & Morant (2023b) United Kingdom	To examine individual's experiences of Intensive Support Teams	Qualitative Semi-structured interviews (individual interviews and focus groups) Thematic analysis (Braun & Clarke, 2006) Intervention: intensive support teams Inclusion criterion: family caregivers who support an individual with intellectual disabilities and are receiving	9 family carers Family relation: parent (n=7), siblings (n=1), aunt (n=1) Age: not stated Gender: female (n=3), male (n=6) Ethnicity: White British (n=7), Black African (n=1), Asian Indian (n=1) Marital status: not stated Employment: not stated	Age: not stated Gender: not stated Additional diagnoses: not stated Behaviours of concern: not stated. Living circumstances: not stated	Caregivers highlighted the positive experiences with intensive support teams when families were actively included within interventions, and when professionals provided individualised and personalised care and communicated with other service providers to ensure strategies were consistent. Challenges were reported when professionals provided family caregivers with limited communication. Caregivers described the challenges associated with professionals not having shared experiences of supporting a family member with intellectual disabilities who displays behaviour of concern. Caregivers described

		support from an Intensive Support Team	Participants who were not family caregivers were carefully excluded.		how they often had to repeat their stories to a number of different professionals and that they would value having a care coordinator to reduce this.
McKenzie et al., (2018) United Kingdom	To explore family caregivers' experiences of PBS interventions	Qualitative Semi-structured interviews with individuals (n=3) and with one focus group (n=5) Thematic analysis (Braun & Clarke, 2006) Intervention: PBS approaches Inclusion criterion: family caregivers who support individuals with intellectual disabilities who have received PBS	8 parents Age: not stated Gender: not stated Ethnicity: not stated Marital status: not stated Employment: not stated	Age range: 25-37 years (4 not reported, 1 reported late 30s) Gender: female (n=2), male (n=8) One caregiver support three individuals with intellectual disabilities who displayed behaviours of concern. Additional diagnoses: autism (n=4), epilepsy (n=1), Down syndrome (n=2), rare syndrome not specified (n=1) Behaviours of concern: not stated. Living circumstances: residential care (n=3), accommodation within the community (n=2), 'specialist' provider (n=1), not specified (n=3), and one reported their family member had experienced living in hospital settings and supported living placements (n=1)	Caregivers described the love they had for their family member, as well as the challenges they experienced, with a focus on the emotional impact of being a family caregiver. Positive experiences were described with services when professionals provided person-centred support and were knowledgeable, and when caregivers were included in interventions and felt listened to. PBS and positive behaviour approaches were reported to be effective when the plans incorporated individualised strategies and care plans. Consistency in staff and approach was important to caregivers and increased therapeutic relationships with professionals. Positive outcomes of positive behaviour approaches included a reduction in the frequency of behaviours of concern and a positive impact on caregivers' wellbeing. Negative experiences with services were described when staff did not adopt a person-centred or consistent approach and when family caregivers did not feel listened to. Caregivers also described the challenges associated with having to 'fight' for support, resulting in them feeling disempowered.
Muller, Brady, Warren and Fleming (2019)	To examine the impact of behaviours of concern on families who support children with Fragile X Syndrome	Qualitative Semi-structured interviews with individuals	53 mothers Age range: 25-47 years	Age range: 8-10 years Gender: female (n=11), male (n=42)	Mothers described the emotional impact of the caregiving role highlighting emotions of frustration and stress. They reported the behaviours of elopement and self-harm as particularly distressing. Mothers described the strategies they used to help support their

United States of America		Grounded theory approach (Gibbs, 2008) Inclusion criterion: family caregivers who support an individual with intellectual disabilities who has a history of displaying behaviours of concern	Gender: not reported, however sample consisted of mothers Ethnicity: Caucasian (n=50), African American (n=2), Latino (n=1) Marital status: married (72%) Employment: part-time or full-time (61%)	Additional diagnoses: autism (n=18) Behaviours of concern: “Defiance (n=47), hyperactivity or inattention (n=47), tantrums (n=41), stereotypy (n=32), verbal stereotypy (n=18), social inappropriateness (n=31), verbal aggression (n=30), physical aggression (n=29), anxiety (n=25), lack of personal safety (n=19), incontinence (n=16), sleep difficulties (n=16), elopement (n=15), clingy (n=13), self-harm (n=13), property destruction (n=12), overeating (n=6), stealing (n=5), vomiting (n=3), undressing (n=3).” Living circumstances: not stated	family members during times of distress including avoidance of public events or places. Mothers reported the negative events they had experienced with people in public. Some mothers reported worries around their family member growing older and stronger and if they would be able to support them in the future.
Nag, Hoxmark and Nærland (2019) Norway	To explore parents’ experiences of supporting their child with Smith-Magenis syndrome (SMS) who display behaviours of concern, with a focus on views of competency and experiences of support services for support with behaviours of concern	Qualitative Online survey using open ended questions (n=32) and semi-structured interviews (n=4) Phenomenological method (Creswell, 2013) Inclusion criterion: family caregivers who support an individual with SMS who displays behaviours of concern	For the surveys (n=32): Gender: not stated, however family relation implied gender roles Family relation: mother only (n=15), father only (n=1), mother and father completed survey collaboratively (n=16) Age: not stated For the interviews: Family relation: mothers (n=4) Age: not stated Gender: not stated, however sample consisted of mothers Ethnicity: not stated	For the surveys (n=32): Age range: not reported Gender: female (n=18), male (n=14) Additional diagnoses: not reported Living circumstances: not stated For the interviews (n=4): Age range: 10-22 years Gender: not stated Additional diagnoses: not reported Living circumstances: not stated Incorporating both the interview, and the survey data:	Parents described the difficulties they experienced in relation to their wellbeing, with a focus on the emotional impact of behaviours of concern and parents’ lack of confidence and knowledge about SMS. Parents reported that services were often inadequate and professionals did not have sufficient knowledge about SMS to be able to support their family member. Parents described the difficulties associated with professionals with no shared experiences resulting in limited insight and understanding of their wellbeing and experiences. Positive experiences were described with professionals who demonstrated understanding, which was described to have

			Marital status: not stated Employment: not stated	Behaviours of concern: “self-harm behaviours, aggressive behaviours, inappropriate behaviours and controlling behaviours” were reported in a theme within the findings.	a positive impact on parents’ and family member wellbeing.
Olivier-Pijpers, Cramm, and Nieboer (2020) Netherlands	To explore experiences of the residential services specialised in providing services for individuals with intellectual disabilities who display behaviours of concern, with a focus on the environment	Qualitative Interviews (does not state if they were semi-structured) Grounded theory approach Intervention: residential service organisations Inclusion criterion: family caregivers who support an individual who displays behaviours of concern	8 family caregivers Two pairs of parents participated in the interviews together Family relation: parents (n=4), sibling (n=1), guardian (n=1), father (n=2) Age: not stated Gender: not stated Ethnicity: not stated Marital status: not stated Employment: not stated	Age: 21–62 years Gender: not stated Additional diagnoses: autism, addiction, borderline disorder, and depression. Behaviours of concern: not stated. Living circumstances: not stated	Positive experiences with the service were reported when caregivers felt understood and when professionals engaged in clear communication and adapted interventions to meet the family member’s needs. Negative experiences with the service were reported when staff used restrictive interventions. High staff turnover and financial constraints was reported to have an impact on both caregivers and their family members. Caregivers highlighted the importance of organisational values such as respect and safety.
Ross & Dodds (2021) United Kingdom	To identify risk factors to admission to inpatient services for children with intellectual disabilities	Qualitative Semi-structured interviews with individuals Interpretative Phenomenological Analysis (Knight et al., 2003) Intervention: inpatient admission services Inclusion criterion: behaviours of concern were found to be a central theme	5 family caregivers Family relation: parents and relatives (specific roles not stated) Age: not stated Gender: not stated Ethnicity: not stated Marital status: not stated Employment: not stated	Age: not stated Gender: not stated Additional diagnoses: not stated, however brain damage and mental health difficulties, were reported within a subtheme. Behaviours of concern: ‘physical aggression to others, self-harm, disruptive behaviour and verbal aggression’ Living circumstances: not stated	Caregivers described the challenges of their role and impact on the family member when they were struggling to maintain their own wellbeing. Caregivers described inadequate support from services. Positive experiences with services were described when family caregivers felt understood and listened to and when staff were proactive and provided practical support. Challenging experiences with services were reported when services did not work together and when services experienced high

			Participants who were not family caregivers were carefully excluded.		staff turnover. Staff turnover impacted on the therapeutic relationship between families and staff and increased the number of times families had to repeat their story.
Sheldon, Oliver, and Yashar (2021) United States of America	To explore the experiences of fathers who support their child with Down syndrome	Qualitative Online survey: open ended questions Content analysis (Boyatzis, 1998; Patton, 1990) Inclusion criterion: behaviours of concern were found to be a subtheme within the findings	175 fathers Age range: 29-82 years Gender: not stated, however sample of fathers Ethnicity: Black (n=5), Asian (n=4), White (n=152), Chicano (n=9), Native Hawaiian (n=1), Multi-ethnic (4) Marital status: married (n=165), partner, living together (n=4), divorced (n=5), single (n=1) Employment: not stated	Age range: new-born - 36 years Gender: female (n=79), male (n=96) Diagnoses: Down syndrome Additional diagnoses: not stated Behaviours of concern: ‘stubbornness, aggression/temper tantrums, lack of motivation, lack of focus/concentration’ were stated in a subtheme within the findings Living circumstances: not stated	Caregivers described how their love for their family and the inspiration they got from them had resulting in changes to their personality and life. Caregivers also described the challenges they experienced which included worries about the future, negative experiences with people in public, self-doubt and self-criticism, fatigue and inadequate support. Some caregivers reported further difficulties with their emotional wellbeing, such as feelings of sadness and isolation, and described their concerns regarding financial difficulties.
Thompson-Janes, Brice, McElroy, Abbott, and Ball (2014) United Kingdom	To explore parents’ experiences of a therapeutic group and the outcomes of the group	Qualitative Semi-structured interviews with focus groups Thematic analysis (Braun & Clarke, 2006) Intervention: therapeutic group Inclusion criterion: family caregivers who support an individual who displays behaviours of concern.	11 family caregivers Family relation: mothers (n=5) fathers (n=6) Gender: not stated, however family relation implies gender role Age: not stated Ethnicity: not stated Marital status: not stated Employment: not stated	Age range: 5-15 years Gender: not stated Additional diagnoses: not stated Behaviours of concern: not stated. Living circumstances: not stated	Parents identified a number of positive outcomes of the Confident Parenting group including more effective communication with their family member, a greater understanding of the function of behaviour of concern and more effective strategies to support their family member. As a result they described increased confidence, wellbeing and a more positive relationship with their family member. Prior to the group, parents reported worries and concerns about the group format, including being judged and feeling isolated within their caregiving role. On completing the group parents reported positive

					outcomes including feeling supported and safe and not feeling judged as a result of the shared experiences.
Yacoub, Dowd, McCann and Burke (2018) United Kingdom	To explore the perspectives of siblings who support autistic individuals with intellectual disabilities, with a focus on behaviours of concern	Qualitative Interviews with individuals (does not state if these were semi-structured) Thematic analysis (Braun & Clarke, 2006) Inclusion criterion: family caregivers who support an individual who displays behaviours of concern	11 siblings Age: not stated Gender: not stated Ethnicity: not stated Marital status: not stated Employment: not stated	Age: not stated Gender: not stated Additional diagnoses: Autism (n=11) Behaviours of concern: not stated. Living circumstances: family members lived within the family home (full time or when not attending term time education) or had left home within the last year but spent at least five days or more per month at the family home.	Siblings described both rewards and challenges that they experienced and how the experience of being a sibling caregiver can both positively and negatively impact on childhood experiences and the sibling relationship. Rewards included feeling inspired by their sibling. Siblings described the emotional impact on their wellbeing which included experiences of anxiety and guilt, for example when they were not helping their parents to support their sibling. Siblings reported worries concerning their increasing responsibilities in the future, particularly in relation to parents becoming unable to support their sibling. Negative experiences were reported with support services and members of the public. Siblings reported a lack of support from services which increased the pressure on the family system and increased worries for the future.
Young-Southward, Cooper and Philo (2017) United Kingdom	To explore individuals' experiences of transition to adulthood, with a focus on health or wellbeing	Qualitative Semi-structured interviews Thematic analysis (Braun & Clarke, 2006) Inclusion criterion: behaviours of concern were found to be a subtheme	23 family caregivers Family relation: mother (n=19) grandparent (n=3) father (n=1) Two sets of caregivers participated in the interviews together. Age: not stated	Age range: 16-25 years Gender: female (n=7), male (n=16) Additional diagnoses: not stated Behaviours of concern: 'self-harm or aggressive behaviours' were reported in a subtheme within the findings	Caregivers described the difficulties the family experienced during the transition to adulthood, which included the increased distress their family member experienced and resulted in an increased frequency of behaviours of concern. Caregivers described difficulties with their wellbeing and some discussed the emotional impact of the adjustment to a potential long term caregiving role. Caregivers reported

			Gender: not stated, however family relation reported implies gender roles Ethnicity: not stated Marital status: not stated Employment: not stated Participants who were not family caregivers were carefully excluded.	Living circumstances: home (n=21), residential care (n=1), individual flat with 24-hour care (n=1)	worries around the future health and wellbeing of their family member and limited opportunities to develop independence. Caregivers described their frustration at the inadequate support from services including long waiting times and lack of funding and individualised care.

Quality Assessment

All studies in the review were rated as high quality (++) (n= 19) or lower quality (+) (n= 5) using the NICE (2012) quality assessment. High quality studies fulfilled all or most of the quality assessment criteria, meaning their conclusions were highly unlikely to alter. Lower quality studies fulfilled some of the quality assessment criteria, meaning their conclusions were unlikely to alter.

The most frequent reasons for a lower quality score was limited reporting on the researcher's role or limited demographic data, with other reasons including unclear methods of analysis or authors not reporting the number of authors who had analysed the data. Overall, theoretical approaches were appropriate, study aims were clear, designs were defensible and the findings of the studies were relevant and clearly presented (See Appendix G for the quality assessment scores).

Data Synthesis and Analysis

The researcher read the papers twice to familiarise themselves with the findings and then completed 'line-by-line' coding of themes and of participant quotes to identify descriptive themes within and across each study. Initially each line was coded according to meaning and content of the dataset, and as new studies were analysed, several new codes were developed which were added to the 'bank' of codes. The initial codes that were developed were combined into a list of codes and themes were developed which described family caregivers' experiences. The researcher considered how the themes and quotes from each paper related to each other, and then the analytic themes that emerged from these were considered within research supervision. Through discussions in supervision, additional analytical themes emerged ensuring that these themes went beyond the descriptive themes. Table 4 contains a summary of the themes identified. Appendix H and I contain an example of the data analysis and the number of studies that contributed to each theme. The researcher is not a family caregiver of an individual (outsider position). The researcher engaged in processes to increase reflexivity and reduce bias which included reflecting on data analysis within supervision and with peers, and the researcher kept a journal of these reflections.

Table 4. Superordinate and subordinate themes identified

Superordinate theme (Analytical themes)	Emotional responses and mental health difficulties: Adjustment to a new life	Preferences for support for my family member	Caregiver needs
Subordinate themes (descriptive themes)	“Love and affection” Changes in identity and relationships “I cannot understand what my family member is trying to tell me” “This is what I deal with every single day” Worries, anxiety and isolation	Staff skills Personalised and considered care Support and opportunities	Who is supporting family caregivers? Feeling informed and involved

Theme: Emotional responses and mental health difficulties: Adjustment to a new life

This theme describes the process of adapting to the role as a family caregiver and its emotional impact. Family caregivers described the rewards and the challenges.

Subtheme: “Love and affection”

Family caregivers described their love for their family member, describing pride in their personality, development and achievements and their positive impact on people around them (Gore et al., 2019; Sheldon et al., 2021). Caregivers also described the strong relationship they had with their family member (Gore et al., 2019; Sheldon et al., 2021).

> *“The affection, care and love our child brings to this dance of life."*
> *(Sheldon et al., 2021; Subtheme: Enjoyable personality characteristics)*

Caregivers emphasised their family member’s strengths and positive characteristics, and therefore stressed the importance of professionals taking a strengths-based approach. Receiving positive feedback from professionals about their family member’s strengths and characteristics increased the hope and confidence of family caregivers and engagement in interventions (Chester et al., 2019; Dew et al., 2019; Gore et al., 2019).

Subtheme: Changes to identity and relationships

Caregivers stated the positive impact that their family members had on their understanding and awareness of others (Chase & McGill, 2019; Kiernan et al., 2019; Sheldon et al., 2021).

> *“I think he has made me more empathetic and sort of more patient with people, to try to understand what they are going through.”*
> *(Chase & McGill, 2019, Subtheme: personal characteristics, p9)*

Parents described themselves as ‘parenting professionals’ having engaged in research to identify strategies and ideas to support their family member (Dreyfus & Dowse, 2018; Kiernan et al., 2019). They spoke of feeling inspired to use these new skills and knowledge to help others (Kiernan et al., 2019; Yacoub et al., 2018).

> *“I think that I have good patience because of the experience of being his brother. I am now studying social care as a result.”*
>
> *(Yacoub et al., 2018, Subtheme: Differences – gains and losses, p149)*

Caregivers described different impacts on their lifestyle and aspirations for the future. These included leaving careers (Dreyfus & Dowse, 2018; Kiernan et al., 2019), being unable to retire due to financial difficulties (Sheldon et al., 2021), moving homes to receive better support (Dreyfus & Dowse, 2018) and the emotional impact of adjustment to becoming a long-term caregiver (Young-Southward et al., 2017). Caregivers described the impact on family life and relationships, often as a result of caregiver wellbeing, demands and differences in opinions and support strategies (Kiernan et al., 2019; Ross & Dodds, 2021; Sheldon et al., 2021). Limited offers of support from family members or failing to fulfil caregiving expectations resulted in tension between family members whilst appropriate offers of support improved family relationships (Chase & McGill, 2019; Sheldon et al., 2021).

> *‘...your whole life revolved around his behaviour, what you could and couldn’t do. How you could function as a family revolved around his needs.’*
>
> *(Kiernan et al., 2019; Subtheme: Behaviour touches everything*)

Subtheme: “I cannot understand what my family member is trying to tell me”

Caregivers described the frustration they felt when they were unable to understand the individual’s communication and were unable to meet their needs (Don & O’Byrne, 2022; Gore et al., 2019; Grenier-Martin & Rivard, 2022; Sheldon et al., 2021; Yacoub et al., 2018). Being unable to meet the individual’s needs led to guilt, self-criticism and reduced confidence (Gore et al., 2019; Grenier-Martin & Rivard, 2022; Nag et al., 2019; Sheldon et al., 2021; Thompson-Janes et al., 2014; Yacoub et al., 2018). If professionals were unable to provide caregivers with adequate support or effective strategies, this further increased caregivers’ feelings of hopelessness, and if professionals were critical this increased caregivers’ self-doubt (Don & O’Byrne, 2022; Nag et al., 2019).

“We have tried everything, begged her to stop, cried in despair, hold her, not hold her…”

(Nag et al., 2019; Theme: Parents’ strategies for meeting the challenging behaviours of their children with SMS, p364)

Subtheme: “This is what I deal with every single day”

Many caregivers reported high levels of stress, the most prevalent causes being the difficulties associated with managing the demands from support services including administration tasks, time spent trying to contact professionals, waiting times and having to ‘fight’ for support (Dreyfus & Dowse, 2018; Ross & Dodds 2021; Sheldon et al., 2021; Young-Southward et al., 2017). Other causes of stress included financial difficulties, inadequate support, behaviours of concern and other everyday demands (Chase & McGill, 2019; Dreyfus & Dowse, 2018; Ross & Dodds 2021; Yacoub et al., 2018).

> *"...in the days when we were dealing with all that service provision, you know, that roundabout that you are on. I used to show them my calendar. I used to hold it up to them and go, "Look. Look. This is what I deal with every single day. This is how many phone calls I have made today. This is who I spoke to today." And I once drew a map: doctor, specialist, psychologist, psychiatrist, day program, blah blah. I said, "This is the number of people I am dealing with every day as well as trying to get the meal on the table." It is so overwhelming."*
>
> *(Dreyfus & Dowse, 2018; Theme: "I manage…")*

Caregivers described the positive impact that professionals could have on their wellbeing when they were becoming stressed and overwhelmed (Hassiotis et al., 2018).

> *"You know, it gets just a bit you feel worn out when he gets a bit fed up. So if you have got somebody coming in to encourage you, it cheers you up again."*
>
> *(Hassiotis et al., 2018; Theme: Carer burden, p47)*

Subtheme: Worries, anxiety, and isolation

Many caregivers reported loneliness and isolation. Worries about behaviours of concern and negative experiences with members of the public resulted in them avoiding places (Grenier-Martin & Rivard, 2022; Gore et al., 2019; Kiernan et al., 2019; Muller et al., 2019; Nag et al., 2019). Family caregivers described how being criticised by people in the community (e.g., tutting, head shaking, inappropriate comments) impacted on their wellbeing and confidence to attend public events (Dew et al., 2019; Gore et al., 2019; Muller et al., 2019; Thompson-Janes et al., 2014) and therefore some caregivers described the need to educate the public

(Yacoub et al., 2018). Some caregivers also described isolation from their friends (Botterill et al., 2019).

> *"He was loud, and someone asked us to leave, and I thought it was the rudest thing ever the way they did it, and I've never stepped foot in the church with him again. We just don't go because that stuck with me. I know not every place is going to be like that, but I think I just get like the anxiety and the nerves and the defensiveness just even thinking of walking into a church with him. I just can't do it."*
>
> *(Muller et al., 2019; Subtheme: Verbal stereotypy)*

> *"Sometimes I'm in tears when we're at home and I'm thinking I wish we had of gone but my husband's saying you know what you'd have been like – would have been on edge."*
>
> *(Gore et al., 2019; Subtheme: Just naughty children, p1707)*

Many caregivers reported experiencing worries for the future (Chase & McGill, 2019; Chester et al., 2019; Sheldon et al., 2021; Yacoub et al., 2018; Young-Southward et al., 2017). The most frequently expressed worry was that individuals would not be adequately supported by services when family members became too old, physically unwell or had passed away (Chester et al., 2019; Sheldon et al., 2021; Yacoub et al., 2018).

> *"I just don't have much faith in if I wasn't around I don't think he's be very well looked after."*
>
> *(Chester et al., 2019; subtheme: Ongoing support in the community)*

Theme: Preferences for support for my family member

Family caregivers described the positive experiences they had with services and staff teams, and the aspects of the support that had a significant impact on their family member's wellbeing.

Subtheme: Staff skills

Caregivers reported positive experiences with services when staff were proactive, non-judgmental and understanding, and knowledgeable about behaviours of concern, comorbid diagnoses and the services available (Botterill et al., 2019; Kouroupa et al., 2023b; McKenzie et al., 2018). Regarding support for caregivers, involvement of a paid facilitator, who was skilled in communicating with families and organising events, to coordinate a peer support group, was valued by caregivers (Dew et al., 2019).

> *"The staff there have excellent knowledge of autism so they're very calm [laughs]"*
>
> *(McKenzie et al., 2018; Subtheme: The technicalities, p9)*

Professionals however were reported to largely lack expertise and knowledge about behaviours of concern (Nag et al., 2019; Olivier-Pijpers et al., 2020; Sheldon et al., 2021), often resulting in caregivers educating the professionals (Dreyfus et al., 2024). Caregivers described professionals without lived experience as lacking insight into their difficulties and experiences at home (Nag et al., 2019).

Subtheme: Personalised and considered care

Caregivers highlighted the importance of person-centred care for their family member. Professionals who spent time to understand the context of the family and their family member and adapted strategies and interventions to meet the needs of the whole system were highly regarded (Kiernan et al., 2019; Kouroupa et al., 2023a; Olivier-Pijpers et al., 2020). Caregivers reported the importance of professionals taking time to understand their family member and the functions of behaviours, acknowledging their strengths to increase quality of life and develop effective care plans (Gore et al., 2019; Inchley-Mort & Hassiotis, 2014; McKenzie et al., 2018). Caregivers valued professionals who engaged in communication with all of the services supporting their family member to ensure effective and consistent strategies were utilised across different contexts (Kouroupa et al., 2023a).

> "*The behaviour nurse was the best thing that ever happened. Hugely intensive I have to say but the advice and time and support that he spent with us as a family, trying to understand the triggers, trying to find the right kind of methods to work with him, was phenomenally beneficial.*"
>
> *(Kiernan et al., 2019; Theme: Square services, round needs)*

Caregivers reported that the experience of personalised care for families was reduced by difficulties in services including the complexity of systems, inflexibility, funding and eligibility criteria (Don & O'Byrne, 2022; Youth-Southward et al., 2017). The importance of consistency in staff teams to provide personalised care was highlighted (Kouroupa et al., 2023a; Kouroupa et al., 2023b; McKenzie et al., 2018), but caregivers reported a high turnover of staff (McKenzie et al., 2018; Olivier-Pijpers et al., 2020; Ross & Dodds, 2021) limiting the development of trust, rapport and understanding between families and staff.

> *"Sometimes we did see the same person and sometimes we didn't. I used to think "well how are they supposed to know what's going on if it's a different person?" it felt like they didn't know the full history of our family."*
>
> *(Ross & Dodds, 2021, subtheme: Staff turnover, p7)*

Subtheme: Support and opportunities

The lack of support for individual's mental and physical health from services and within the community was highlighted. Caregivers reported that services were experiencing difficulties in funding and staffing, resulting in long waiting times and inadequate support (Kouroupa et al., 2023a; McKenzie et al., 2018; Olivier-Pijpers et al., 2020; Ross & Dodds, 2021; Yacoub et al., 2018). Overall, they felt individuals received limited support and there was a lack of co-ordination between services (Chester et al., 2019; Dreyfus et al., 2024; Kiernan et al., 2019; Kouroupa et al., 2023b; Nag et al., 2019; Ross & Dodds, 2021; Yacoub et al., 2018). Some caregivers described the added responsibilities of coordinating services, increasing exhaustion (Dreyfus et al., 2024). The caregivers who reported that services were able to meet their family member's needs felt this resulted from their knowledge of available services and how to "argue" for support (Dreyfus et al., 2024).

> *"I did turn it [respite] down at first I have to admit that, but it was because he only got offered 18 hours per year. What's the point in that?... I couldn't believe what I was hearing. There's me thinking "18 hours a month" and then I realise what I heard and that it was 18 hours per year."*
>
> *(Ross & Dodds, 2021; Subtheme: 'Lack of suitable respite opportunities', p7)*

Caregivers reported a desire for individuals to have more opportunities to develop meaningful relationships and independence (Gore et al., 2019; Young-Southward et al., 2017). They described a lack of opportunities (Ross & Dodds, 2021; Sheldon et al., 2021) and this was particularly evident as individuals left school and transitioned to adult services which led to difficulties establishing routines, friendships and developing independence (Young-Southward et al., 2017) impacting on the wellbeing of family caregivers (Sheldon et al., 2021).

> "*There's nothing for him to do in the community, so he's kind of on his own.*"
>
> *(Young-Southward et al., 2017; Theme: Relationships, p12)*

Theme: Caregiver needs

Although most described the lack of support that was available for family caregivers, some had engaged in interventions aimed at supporting their wellbeing. Caregivers highlighted the elements of support that had an impact on their wellbeing and caregiving skills.

Subtheme: Who is supporting family caregivers?

Caregivers stated that there is a lack of support available to help them feel equipped to support their family member and that they had to seek out guidance independently (Nag et al., 2019; Sheldon et al., 2021). Many specifically described the lack of support available for family caregivers' wellbeing (Chase & McGill, 2019; Chester et al., 2019; Grenier-Martin & Rivard, 2022; Kouroupa et al., 2023a; Sheldon et al., 2021; Yacoub et al., 2018). The importance of their own wellbeing was highlighted by caregivers who described difficulties implementing behavioural strategies when they were experiencing difficulties with their mental and/or physical health (Mckenzie et al., 2018). Those who had been offered support for their wellbeing found this difficult to access due to the demands of their caregiving role (Kouroupa et al., 2023a).

"No one's suggested anything, or offered me anything…any support for myself, mental health."

(Kouroupa et al., 2023a, Subtheme: Access to NHS and social care resources, p10)

Support for caregivers was most frequently offered as a group intervention. Some caregivers initially expressed concerns about being in a group, particularly about being criticised by others (Thompson-Janes et al., 2014). Following the group, however, they reported a number of positive outcomes, including the benefits of peer support (Thompson-Janes et al., 2014). The group format gave them the opportunity to work collaboratively and gain practical advice from others with shared experience. Caregivers reported having increased confidence, knowledge and strategies to support their family member, and an increased awareness of the importance of their own wellbeing (Dew et al., 2019; Dreyfus & Dowse, 2018; Thompson-Janes et al., 2014). The benefits of peer support were frequently mentioned throughout the papers (Chase & McGill, 2019; Dreyfus & Dowse, 2018).

"I think the peer support group that I belong to… I can say that for me it's been almost liberating being able to speak openly and honestly or asking for advice or sharing ideas, that's been really beneficial."

(Dreyfus & Dowse, 2018, Theme: I assist…)

Subtheme: Feeling informed and involved

Caregivers stressed the importance of support services involving them in interventions recognising their knowledge, skills and understanding of the individual and described positive experiences when this had happened (Botterill et al., 2019; Chester et al., 2019; Kouroupa et al., 2023a; Kouroupa et al., 2023b; Olivier-Pijpers et al., 2020). They highlighted the importance of the whole system working together to adapt strategies to meet the needs of the family with consideration of the family context and environment (Chester et al., 2019; Jacobs et al., 2016; Kiernan et al., 2019; McKenzie et al., 2018). Support services that included caregivers as part of their team were described as having a positive impact on the whole family's wellbeing (Botterill et al., 2019; Hassiotis et al., 2018) and increased their confidence and knowledge of strategies to support the individual, consequently reducing behaviours of concern (Botterill et al., 2019; Chester et al., 2019; Inchley-Mort & Hassiotis, 2014; McKenzie et al., 2018).

> *"It was about supporting the family and um, you know my health is just as important as [young person]'s because if I'm not in the right frame of mind, um, and in the right head space and have the confidence to tackle some of the things that [service] were asking me to try it would have failed."*
>
> *(Botterill et al., 2019; Subtheme: Emotional Support, p58)*

Positive experiences with services were reported when professionals engaged in clear and consistent communication with family caregivers and were responsive when they required support (Chester et al., 2019; Dew et al., 2019; Hassiotis et al., 2018; Inchley-Mort & Hassiotis, 2014; Kouroupa et al., 2023a; Kouroupa et al., 2023b; Olivier-Pijpers et al., 2020). Trust and rapport with professionals and engagement in interventions was facilitated when caregivers felt they were listened to and their knowledge and expertise was valued (Kouroupa et al., 2023a; Botterill et al., 2019; Chester et al., 2019), and when caregivers felt supported by professionals in relation to their own wellbeing (Botterill et al., 2019; Hassiotis et al., 2018).

> *"… they've all really taken onboard what the difficulties are for [1100011], and for us as well. I really genuinely feel that just being listened to has made a huge difference."*
>
> *(Kouroupa et al., 2023a; Subtheme: Rapport and Relationship Building)*

However, caregivers described the power imbalances that could be present with professionals and that they that often felt that their skills or expertise were not valued and their opinions and suggestions were dismissed (McKenzie et al., 2018). Some caregivers felt judged by professionals and overwhelmed by the number of home visits (Hassiotis et al., 2018).

> *"They knew better than we did. That was their attitude. They were trained professionals and we were just the parents."*
>
> *(McKenzie et al., 2018, Subtheme: On different sides, p11)*

Discussion

This review aimed to explore the experiences of family caregivers who support an individual with an intellectual disability who displays behaviours of concern. Thematic synthesis indicated three themes across 24 papers, highlighting the caregivers' emotional responses and experiences with support services. It is suggested that relationships appeared to exist between the themes, for example, barriers to accessing personalised care from services were often linked to emotional responses.

The review aimed to provide an update to the existing review (Griffith & Hastings, 2014), accounting for the changes within National Policy and the increased implementation of PBS within services. Consistent with the existing review (Griffith & Hastings, 2014), caregivers reported the love they felt for their family member, as well as the challenges they experienced. Caregivers continued to report positive (e.g., high expertise, professionals who are proactive, collaborative and provide consistent support) and challenging experiences with support services (unavailable, difficult to obtain, provided inadequate support due to issues such as funding, lack of expertise and staff turnover). Additional challenges were also identified in the current review, in the UK and internationally, including eligibility criteria reducing access to services and significant waiting times and a shortage of staff impacting on the quality of care.

A significant difference between the reviews was that caregivers reported a need for support for their own wellbeing in the current review. There are differing findings on the impact of support services to caregiver's wellbeing with some findings suggesting there is no association (White & Hastings, 2004), whilst others more recently suggested that higher satisfaction with care is positively associated with caregiver's quality of life (Cramm et al., 2012; Faust & Scior, 2008). Caregivers' identification of the need for support may reflect the increase in challenges to inadequate support impacting negatively on their wellbeing, the implementation of the Care Act in 2014 highlighting caregivers' needs and recent societal changes encouraging openness about mental health and the need for support (British Association for Counselling and Psychotherapy, 2021).

The review highlighted difficulties in inclusion and access to public services for individuals and the impact on caregivers' wellbeing despite the UK National Policy commitment to provide opportunities for people with intellectual disabilities to engage in meaningful activities in their own community (Department of Health, 2001). This supports previous findings that there are limited opportunities for social inclusion for individuals with intellectual disabilities (Grung et al., 2020), and that a lack of inclusion can have a negative impact on caregivers' wellbeing (Mitter et al., 2019).

Assessment of the strength of the review

The quality assessment indicated that most of the studies were of high quality and therefore did not impact upon the review or interpretation of the findings. Where some studies did not fulfil all the quality assessment criteria, this was mainly due to the authors not reporting the researcher's role or the limited demographic information reported regarding the context of participants and/or the person they support.

The sample consisted of caregivers from the UK, Canada, USA, Norway, Netherlands and Australia. It should be noted that although all these countries are thought to have policies in place to support individuals with intellectual disabilities, these may offer different levels of support for caregivers which may affect the findings. Nine studies from outside the UK were included limiting the international conclusions that can be drawn. However, common themes were found across the studies associated with emotional wellbeing and experiences of support services, suggesting that the experiences and desires of family caregivers in different countries may be similar. This supports the findings of previous studies that difficulties with support services are experienced by caregivers' internationally (Kishore, 2017).

One of the main findings of the review, not previously highlighted, was the importance and benefits of peer support. Further research is needed however to increase the generalisibity of the findings in consideration of gender and family roles as most participants who stated the benefits of peer support identified as female and mothers. Two studies that included fathers found fathers expressed the benefits of peer support (Thompson-Janes et al., 2014) and sought out social support and provided support to others (Sheldon et al., 2021), challenging previous findings that female caregivers are more likely to seek social support. As the participants of the second study were recruited from support groups however the results may be biased (Sheldon et al., 2021) and further research is required. The limited number of studies outside the UK also limits the generalisability to other countries. Given the reported service constraints and the more recent finding of the importance of social support for caregiver wellbeing (Foster, 2021), future research should explore group and peer support interventions as these may provide an effective and efficient approach to meet the needs of family caregivers.

Limitations

Relevant literature may have been missed as manual searches were not completed. Some papers that reported mostly positive experiences conducted evaluations of their own service's support interventions, or recruited through support services (Botterill et al., 2019; Dew et al., 2019; Hassiotis et al., 2018; Inchley-Mort & Hassiotis, 2014) potentially affecting caregivers' willingness to report negative experiences, particularly if caregivers felt dependent on services (Mckenzie et al., 2018). Alternatively, the services with the capacity to complete service evaluations may have been those with higher staffing and funding, and therefore provided more high-quality support. Although some papers provided explanations of how they increased validity (Botterill et al., 2019; Dew et al., 2019; Inchley-Mort & Hassiotis, 2014), the papers did not report the researcher role or position making it unclear how involved the authors were in the interventions. For those who did report their position, some lead researchers had a dual role of interviewer and facilitator of support groups (Thompson-Janes et al., 2014), which may have impacted on caregiver's responses. More balanced experiences were reported by one study that interviewed participants within focus groups which may suggest that the group format supported caregivers to report the challenges as well as the strengths of services (Chester et al., 2019). The results may also reflect a sample bias with those caregivers who had positive experiences or were most engaged with the interventions volunteering to take part in the research. Nonetheless, common themes were found regarding the positive experiences of services across the 24 papers, suggesting similar views of high-quality support.

The review mostly reflects the experiences of mothers, reducing generalisability and future research should explore the experiences of fathers, siblings and grandparents. Findings may differ dependent on demographic factors for example mothers who support individuals have been found to report reduced wellbeing (Kumar et al., 2013; Norlin & Broberg, 2013). Demographic data including participant characteristics of both caregivers and their family member including gender, age, family relation and ethnicity should be collected as this may have unique effects on support needs and inform intervention.

Clinical Implications and Further Research Implications

Most of the studies in this review focused on caregivers' experiences of interventions and support services provided for the individual they supported. The review suggested that family caregivers need support for their wellbeing and that by doing this, services may increase the quality of care to individuals (Reinhard et al., 2008). Future research needs to explore the current support available for caregiver wellbeing and the potential use of peer support and group interventions from individuals with lived experience, which have already been found to have positive outcomes with caregivers of older adults (Khiewchaum & Chase, 2021). Services need to work with caregivers to improve access to support groups (Kouroupa et al., 2023a, Thompson-Janes et al., 2014) and think creatively about the opportunities offered through technology (Dew et al., 2019).

To support caregiver wellbeing and improve the outcomes for individuals services need to deliver person-centred care (Watchman et al., 2020) recognising the skills and knowledge of the caregivers in developing interventions and support plans. Staff need to communicate consistently with caregivers (Wodehouse & McGill, 2009), and to be knowledgeable and skilled in person-centred care and in supporting individuals who display behaviours of concern.

The review aimed to explore the demographic factors of family caregivers to consider differences in support needs dependent on life circumstances however a lack of demographic data reported in the studies prevented this. Previous studies have found that increased additional diagnoses and severity of behaviours of concern may be associated with higher stress levels in caregivers (White & Hastings, 2004) and result in the need for a greater level of support (Douma et al., 2006) but the lack of data meant the current review could not add to this. Data on whether the individual was living within or outside the family home was rarely collected so conclusions on the impact of this could not be drawn. Future research should collect this demographic data to explore the impact on the level of support need and inform the development of support services.

The review found a lack of accessibility and inclusion for engagement within individual’s community. As inclusion within the community can increase wellbeing, social support and physical health outcomes (NICE, 2016), opportunities for meaningful activities, education, employment and social relationships need to be developed in the community for individuals. The provision of opportunities within the community may work towards promoting inclusion and reduce the reported negative experiences of stigmatisation and increase family wellbeing (NICE, 2016).

Conclusion

This study demonstrates an updated review of literature, including a quality assessment of the studies and identifies the need for further research into the demographic factors that might impact on the unique experiences of being a family caregiver. There is a clear need for services to provide more support for family caregivers wellbeing, potentially through peer support group interventions. There is also a need to improve the support that services provide to the individual through person-centred approaches which have a positive impact on the whole family. Services must address the difficulties which impact on access to support and deliver training to professionals at all levels within services, ensuring that person-centred values are incorporated within organisational values. Overall, the review did not find significant differences between family caregivers' experiences internationally, and support from services and professionals should be made widely available and accessible internationally, to increase caregiver wellbeing, and the quality of support caregivers can provide their family member.

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Part Two

The Experiences of Compassion for Family Caregivers who Support Individuals with Learning Disabilities who Display Behaviours of Concern

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This paper is written in the format ready for submission to the Journal of British Journal of Learning Disabilities

Please see Appendix D for the Guideline for Authors

Word count: 8337 (excluding abstract, accessible summary, keywords, tables, figures and references)

Abstract

Background

Literature has shown that behaviours of concern are more prevalent in individuals with a learning disability and can be a way of communicating personal needs and/or distress. Behaviours of concern can increase the likelihood of caregivers experiencing physical harm and psychological distress. Compassion has been found to be beneficial for wellbeing however previous research has suggested that family caregivers may experience difficulties in engaging in self-compassion and it is unclear whether giving or receiving compassion increases their wellbeing. The current study explored the meaning and experience of compassion for family caregivers who support individuals with learning disabilities who display behaviours of concern.

Methods

The study utilised a qualitative design. Seven semi-structured interviews were completed with family caregivers. Reflexive thematic analysis was used to analyse the data.

Findings

The analysis generated three themes: ‘compassion is not one thing’, ‘identity: me as a caregiver’, and ‘it’s a whole range of hats you have to wear as a carer’.

Conclusions

Family caregivers reported experiencing difficulties with self-compassion. Self-compassion interventions may be beneficial to support family caregivers and by increasing their wellbeing this may increase the quality of support they provide to individuals.

Accessible Summary

- Compassion has been found to be important for wellbeing. It is possible to increase people’s ability to engage in compassion. The current study explored the meaning and experience of compassion for family caregivers of individuals with learning disabilities who display behaviours of concern.
- Seven interviews were completed with family caregivers.
- Family caregivers described that compassion could mean different things to them depending on the situation and described experiencing difficulties with self-compassion.
- The research is important to understand how services and others can better support family caregivers’ wellbeing which may increase the quality of care they can provide to individuals.

Keywords

Family caregivers; behaviours of concern; learning disability; compassion; experiences

Introduction

In the UK, a learning disability has been defined as a significant impairment in both intellectual functioning and adaptive behaviour, which is apparent before adulthood (British Psychological Society [BPS] 2015). Adaptive behaviours include skills that have been learned over time and are performed daily, including conceptual (language, reading, writing, money, time, number), social (interpersonal skills, social responsibility, self-esteem, social problem solving, following rules, avoiding exploitation) and practical skills (BPS, 2015). Using the data collected by the Office for National Statistics (2020) and Public Health England (2016), Mencap (n.d.) estimates that there are 1.5 million people with a learning disability in England.

The term 'profound and multiple learning disability' has been used to describe individuals who often require support with significant learning, communication and physical needs, and who may have more than one disability (BPS, 2015; Doukas et al., 2017). The terminology 'severe, profound and multiple learning disability' which is sometimes used by services is a description of an individual's needs, rather than a clinical diagnosis (Bellamy et al., 2010; Doukas et al., 2017) and is used in the current study to reflect that the caregivers are supporting individuals who have profound and multiple needs.

Behaviours of concern

Individuals with a learning disability sometimes engage in behaviour that has previously been termed 'challenging'. 'Challenging behaviour' has been defined as "culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in, the person being denied access to their community facilities"

(Emerson, 1995, pp.233). Historically, behaviour has been described using terminology that has negative connotations (Chan et al., 2012). With recognition that behaviours are adaptive, functional and displayed within the context of the individual's environment, labels such as "challenging" (Emerson & Einfield, 2011) have been replaced with terms that reflect this. Therefore, the preferred term of 'behaviours of concern' (Chan et al., 2012) is used throughout the paper.

It is estimated that between 10-15% of individuals with a learning disability display behaviours of concern (Emerson et al., 2001; Jones et al., 2008), with the increased prevalence reflecting the functions of behaviours to communicate personal needs and/or distress (Bowring et al., 2017). Behaviours of concern can lead to exclusion from services and social isolation, resulting in a decreased quality of life (Cooper et al., 2009; Emerson et al., 2001; Holden & Gitlesen, 2006). For caregivers, behaviours of concern can increase the likelihood of experiencing physical harm and psychological distress (Cooper et al., 2009; Hastings, 2002).

Caregivers

A Census in 2021 estimated that there were five million people in England and Wales who identified as unpaid caregivers but research by Carers UK (2023) has suggested this figure could be closer to 10.6 million. It is currently estimated that there are 1.5 million people with a learning disability in England (Parkin, 2023) and that this figure will rise as the general population rises (Emerson & Hatton, 2008). As many of these individuals live within the family home (Foundation for People with Learning Disabilities, 2022), there will potentially be an increase in the number of family caregivers (Emerson & Hatton, 2008). Literature to date has mainly focused on paid caregivers and may not reflect the differing needs, demands and wellbeing of family caregivers.

Family caregivers

Supporting an individual who has profound and multiple needs may present family members with increased challenges in relation to their caregiving roles and personal lives. 70% of family caregivers have reported reaching or nearly reaching their ‘breaking point’ (Mencap, 2006) and report stress, frustration, anger, guilt, shame, loneliness and feelings of not being understood, resulting in them experiencing anxiety and/or low mood (Challenging Behaviour Foundation, 2022). The increased prevalence of mental health difficulties in people with learning disabilities (Emerson & Hatton, 2008) may increase the likelihood of caregivers experiencing stress, anxiety and low mood (Shah, Wadoo & Latoo, 2010; Carers UK, 2015).

Caregiving and Compassion

There are two main theories of compassion. Neff (2003a) defines compassion as a non-judgemental understanding towards oneself, particularly during times of pain and failure. Neff (2003a) suggests that self-compassion involves self-kindness (showing understanding towards oneself about difficult experiences), common humanity (observing experiences as part of being human), and mindfulness (observing thoughts in awareness rather than over-identifying with them). Research exploring the use of the self-compassion scale (Neff, 2003b) highlighted the importance of self-compassion, with strong correlations between self-compassion and psychological wellbeing (Zessin, Dickhäuser, & Garbade, 2015).

Gilbert et al., (2017) define compassion as a sensitivity to suffering, with a commitment to try and alleviate and prevent it. Compassion Focused Therapy (CFT) is a third-wave therapeutic approach of which the primary aim is to reduce shame and self-criticism, by increasing compassion (Gilbert et al., 2009). Gilbert et al., (2009) identified three flows of compassion: "self to self" (showing compassion to the self), "self to others" (showing compassion to others) and "others to self" (receiving compassion from others), particularly during times of difficulty. CFT is increasingly being considered an effective intervention for individuals who experience high self-criticism and/or shame (Leaviss & Uttley, 2014; Cuppage et al., 2017) and has been found to increase wellbeing across different client groups, including parents and caregivers (Guillen, 2022) and individuals with learning disabilities (Clapton et al., 2018). CFT describes three systems: threat, soothe and drive, each of which serve different functions. The threat system perceives and responds to threats, the drive system motivates and excites, and the soothing system manages distress (Gilbert, 2005). Engaging in self-compassion requires individuals to show sensitivity, sympathy, distress tolerance, empathy, non-judgement and care for one's wellbeing, receiving compassion from others requires individuals to allow others to notice their distress and to be open to empathy from others, and compassion for others requires individuals to be aware of others' suffering, and wanting and taking steps to alleviate it (Gilbert et al., 2017). This study will draw upon Gilbert et al's., (2017) theory of compassion.

Within CFT, barriers to compassion are defined as fears, blocks, and resistances (FBRs). Individuals may fear compassion if they believe that receiving it from others is a "weakness" or that they may be rejected if they show others compassion. Blocks to compassion may be a result of the environment, for example limited time or resources, or the impact of reduced psychological wellbeing. Resistances to compassion occur when individuals have an opportunity to engage in the flows of compassion, but choose not to, potentially because of beliefs that there is no point to compassion, self-advantage or shame. FBRs have been found to be associated with self-criticism and mental health difficulties (Gilbert & Choden, 2014; Gilbert et al., 2014).

Self-compassion is important for wellbeing (Barnard & Curry, 2011) and may be particularly important for caregivers who experience challenges in their caregiving role. Caregivers of individuals with a learning disability who display behaviours of concern may experience increased self-criticism and guilt (Davenport & Zolnikov, 2021; Lathren, 2023) resulting in increased difficulties in exercising compassion (Berardini, Chalmers & Ramey, 2021). Family caregivers may experience threats in relation to self-compassion, such as a lack of time, and/or fears around self-compassion such as feeling they should prioritise other's needs before their own (Berardini et al., 2021; Diggory & Reeves, 2022).

Caregivers have largely reported experiences of feeling unsupported by services and/or professionals, which may impact on their wellbeing. Family caregivers of individuals with learning disabilities who display behaviours of concern have reported difficulties with services including little collaboration between professionals, having to seek out support to understand the services/support available and having to repeatedly contact services to elicit a response (Griffith & Hastings, 2014). Services were described as complex, overwhelming and stressful, and caregivers reported frustration and a lack of trust in professionals, particularly if they felt their opinions were treated as insignificant or ignored (Griffith & Hastings, 2014). Negative experiences with professionals may increase fears to self-compassion and compassion to others (Merritt, & Purdon, 2021) and potentially decrease caregiver's wellbeing. Whereas positive interactions and experiences with professionals may facilitate the experience of compassion, for example professionals who were proactive, caring, honest and communicated clearly (Griffith & Hastings, 2014).

A good support network has been found to enhance people's wellbeing and family caregivers have reported the positive impacts of peer support. Positive impacts included reduced feelings of isolation and increased connectedness with others with shared experiences (Chase & McGill, 2019) resulting in an increased ability to prioritise their wellbeing (Gore et al., 2022). Positive experiences may facilitate family caregivers' openness to receiving compassion and their ability to engage in self-compassion.

Showing compassion to others is associated with psychological wellbeing (Sheldon & Cooper, 2008) and may be an integral part of being a family caregiver. Given the frequency with which they may need to offer compassion, family caregivers may be more skilled and find it easier to show compassion to others as opposed to receiving compassion or engaging in self-compassion. Alternatively, caregivers may experience compassion fatigue or exhaustion and find it difficult to show compassion to others (Lynch, Shuster, & Lobo, 2017).

The literature reports different findings for how helpful compassion is for caregiver's wellbeing. A study of family caregivers of older adults did not find a significant relationship between showing compassion to others or receiving compassion from others and distress but found that self-compassion had a positive impact on family caregiver's wellbeing (Murfield et al., 2021). A possible explanation for this insignificant result is how compassion from others is measured by the Compassionate Engagement and Action Scale (CEAS; Gilbert et al., 2017) (Murfield et al., 2021). The CEAS explores compassion from others, particularly in terms of fears, which may be associated with shame, self-criticism and depression (Kirby, Day & Sagar, 2019). When utilising the Self-Compassion and Compassion from Others Scales (Gilbert et al., 2017), self-compassion was found to act as a protective factor to wellbeing, reducing the impact of caregiving stress on depressive symptoms (Hsieh et al., 2021) and when utilising the Fears of Compassion Scales (Gilbert et al., 2011), showing compassion to others and receiving compassion from others was found to increase wellbeing (Hermanto et al., 2016; Mongrain, Chin, & Shapira, 2011). However, limited research with family caregivers has explored all three flows of compassion.

Clinical relevance & aims of study

Engaging in compassion has been shown to be an effective coping strategy and as it can be developed, it is a potential target for intervention. If family caregivers experience difficulties engaging in compassion this may negatively affect their wellbeing, impacting on their ability to show compassion to others and the wellbeing of the individual they care for.

It is unclear whether compassion is helpful or improves family caregivers' wellbeing. This study used qualitative methods to explore family caregivers understanding and experience of compassion and the facilitators and barriers to engaging in compassion, with potential to inform the development of interventions to support the increasing number of family caregivers. Qualitative methods were used as contradictory results have been found around the benefits of compassion for caregiver wellbeing. The study focused on family caregivers who support individuals with severe, profound and multiple learning disabilities who display behaviours of concern. For the purpose of the study the word "individual" is used to refer to a person with severe, profound and multiple learning disabilities who displays behaviours of concern and is supported by a family caregiver. The research aimed to explore the meaning and experience of compassion, including the facilitators and FBRs to each flow of compassion for family caregivers of an individual. The research questions were: what is the meaning of compassion, and what are the facilitators and FBRs to compassion for family caregivers of an individual?

Method

Design

This study explored the meaning and experience of compassion to family caregivers who support individuals through semi-structured interviews. Previous literature has found contradictory results regarding how helpful compassion may be for family caregivers' wellbeing with one potential reason for this being the use of the CEAS (Gilbert et al., 2017). To better understand the experience of compassion, the current study utilised a qualitative design. Qualitative methodology was chosen to provide rich detailed descriptions of the meaning, facilitators and FBRs to each flow of compassion. Demographic data was collected to gather information about the context of participants.

Ethical approval was granted from the University of Hull Faculty of Health Sciences Ethics Committee (Appendix J).

Recruitment and Participants

Recruitment took place through social media platforms (Facebook, Twitter, online forums), and the Challenging Behaviour Foundation (Appendix K). Participants were individuals who identified as a family caregiver of an individual. Table 1 contains the inclusion criteria. Family caregivers interested in taking part in the study contacted the researcher, and the researcher provided participants with an information sheet, consent form, and demographic questionnaire (Appendix L, M, N). On completion the participant and researcher agreed how the interview would take place (Microsoft Teams, telephone or face-to-face) and a time and date for the interview.

Table 1.

Inclusion criteria

Inclusion criteria	Rationale
Identify as a family caregiver of an individual with a severe, profound, or multiple learning disability who displays behaviours of concern	Aim of the research is to explore the experiences of family caregivers of an individual with a severe, profound, or multiple learning disability who displays behaviours of concern
Able to give informed consent	Participants must be able to understand the information about the study to make an informed decision about whether to participate
Can speak English	Individual's first language did not have to be English. The researcher was open to different levels of English but a level of fluency was required to enable the researcher to manually transcribe the interviews as the research budget was unable to fund translation costs.
To complete the interview face-to-face, participants must live in the Humber and North Yorkshire area	Research budget is unable to fund transport costs outside of the Humber and North Yorkshire area

Recruitment took place from October 2023 to April 2024. Sixteen family caregivers expressed interest in participating in the research. Eight participants completed the consent form and demographic questionnaire. One participant requested to withdraw from the research due to personal reasons. Eight participants who initially expressed an interest in the study did not make further contact.

Seven family caregivers participated. All were from the United Kingdom (UK) and identified as female. Participants were mothers (n=5) and siblings (n=2) and identified as White (n=6) and Jewish (n=1). Age range included 40-49 (n=3), 50-59 (n=2) and 60 or above (n-=2). Employment included part-time employment (n=3) and full-time caregiver (n=4). Marital status included married (n=3), single (n=2), other (n=1) and widowed (n=1). Extra caregiving responsibilities included caring for parents (n=5). The most frequent behaviours of concern were distressed behaviours (crying and shouting) (n=4), aggressive behaviours (biting, grabbing, or punching) (n=3), self-harm (n=3) and vulnerability and reduced awareness of danger (n=3). Further concerns included refusing to eat or drink or eating non-food items (n=2), refusing to walk (n=1) and experiences of psychosis (n=1). Table 2 and 3 contain a summary of participant and individual characteristics. Participants were encouraged to choose a pseudonym. In Table 3, the individuals' pseudonyms are in bold.

Table 2.

Participant characteristics

Pseudonym	Ethnicity	Age of participant	Gender of participant	Employment status	Marital status	Relation to family member	Extra caregiving responsibilities
Hope	White	50-59	Female	Part time employment	Married	Parent	Parent and parent-in-law
Mia	White	40-49	Female	Part time employment	Single	Sibling	Parent
Donna	White	60 or above	Female	Full time caregiver	Other	Parent	N/A
Rita	Jewish	60 or above	Female	Full time caregiver	Single	Parent	Parent
Luna	White	40-49	Female	Full time caregiver	Married	Parent	Parent
Paula	White	40-49	Female	Full time employment	Married	Sibling	N/A
Jack Sprat	White	50-59	Female	Full time caregiver	Widow	Parent	Parent

Table 3.

Characteristics of the individual that participants support, with pseudonym

Pseudonym and pseudonym for family member	Age	Gender	Living circumstances	Support that the individual receives	Amount of support from others
Hope, **Lenny**	19 or younger	Male	Lives with Hope	Respite care, 1:1 support	40 hours, 24 hours x 24 hours Direct payments of 5 hours 3.5 hours every Saturday
Mia, **Lilly**	40-49	Female	Supported living accommodation	Day service	1 hour 15 minutes per week
Donna, **April**	20-29	Female	Lives with Donna	Self-directed support via council, social work	45 hours per week
Rita, **Marcus**	20-29	Male	Lives with Rita	No support from others	No support from others
Luna, **Jackson and Reggie**	20-29	Male (twins)	Supported living accommodation	2:1 support for 24 hours	24 hours for 7 days
Paula, **Melvin**	30-39	Male	Residential care	1:1 support	Constant supervision within residential care 8 hours of 1:1 support
Jack Sprat, **Tara**	20-29	Female	Lives with Jack Sprat	Respite care, attends day centre	Day centre for 5 days each week, 5 hours 35 minutes Respite 4 nights every 6 weeks

Procedure

The initial proposal was informed by discussions with professionals with experience of working with people with learning disabilities and their families and then shaped through discussions with experts by experience. Family caregivers highlighted the importance of spending time to discuss the meaning of compassion as the meaning and experience may change daily and that experiences with professionals may have impacted on how caregivers view and engage with compassion. The semi-structured interview schedule (Appendix O) was informed by previous compassion research (Cackett, 2022; Durant, 2016) and the feedback from family caregivers. The schedule was evaluated through a pilot interview with someone with no psychological knowledge of compassion. The feedback from the interview was that although the researcher explained Gilbert et al's., (2017) definition of 'compassion', 'compassion' remained an abstract concept. The researcher revised the interview schedule to include a question asking participants if they would like the researcher to use a different word, of their choice, for 'compassion'.

Interviews took place in a private space, to ensure confidentiality and to reduce the potential for the interview to negatively impact on participants or the individuals. Six interviews took place via video call (Microsoft Teams) and one via telephone call. The researcher firstly gave participants an overview of the study, opportunities to ask questions and gained consent for audio recording. The researcher ensured that all participants knew that they could ask the researcher to stop the interview and delete the recording at any point and that they could request to withdraw and delete the recording within two weeks of completing the interview. The anonymisation of participant data after two weeks was explained as the rationale for being unable to withdraw after this period. At the end of the interview, the researcher provided participants with the opportunity to ask questions and to provide feedback about the study. Interviews lasted between 54–98 minutes (average 78 minutes). After each interview, participants were provided with a support sheet (Appendix P). Interviews were transcribed and data was anonymised.

Analysis

Reflexive Thematic Analysis (TA) was selected to analyse the findings as it highlights the importance of understanding the meaning and experience of participants, facilitating a broader understanding of compassion and their lives (Braun & Clarke, 2019, 2022).

Reflexive TA facilitates the collection of words that caregivers use and analysis that provides an insight into their thoughts, feelings and beliefs. Reflexive TA was aligned to the researcher's ontology and epistemology (Braun & Clarke, 2019) (Appendix B). An explorative and inductive approach to TA was used to analyse the meaning of compassion and the facilitators to compassion. A deductive approach to TA was used to analyse the FBRs to each flow of compassion as the definition of FBRs (Gilbert et al., 2011, 2017) was utilised to code the data.

The researcher considered utilising Interpretative Phenomenological Analysis, however, as the research questions were focused on analysing the definition of compassion and the barriers and facilitators to the experience of compassion, rather than analysing the characteristics of the participant sample, reflexive TA was thought to be more appropriate. TA facilitated reflection on the researchers' lens and position and any power dynamics that might be present ensuring that respect and sensitivity was shown towards participants and their contexts. Given the evidence that family caregivers of individuals with learning disabilities have reported difficult and disempowering events and experiences with professionals which may impact on the interviews and the findings, this was felt to be important for the current study.

Reflexive TA was completed utilising Braun and Clarke's (2006, 2022) approach:

1. *Familiarisation:* the researcher listened to the audio recordings twice, read and re-read transcripts, whilst making notes on initial observations about any ideas and insights about the data, and to ensure the researcher was familiar with each dataset.
2. *Generating Initial Codes*: the researcher coded ideas within the data that appeared to be relevant and meaningful to the research questions, considering patterns beginning to arise. This coding aimed to capture the meanings of the data including my own

analytical observations and interpretations of the data. Initial codes and relevant data were grouped together to identify potential themes. This was completed by clustering the codes and data that appeared to share a similar meaning or concept which provided meaningful interpretations in relation to the research questions.

3. *'Searching' for themes*: initial codes and relevant data were grouped together to identify potential themes. This was completed by grouping together the codes and data that appeared to share a similar meaning or concept, which provided meaningful interpretations in relation to the research questions.
4. *Reviewing themes:* themes were considered to ensure that they were relevant in relation to the codes, data and research aims. The researcher assessed the fit of the initial themes by rereading the transcripts to ensure that they reflected the initial data and to consider whether they were the most relevant themes for the research questions. This was completed in collaboration with the researcher's supervisor who discussed the relevance of the themes and as a result some themes were collapsed together.
5. *Defining and naming themes:* the researcher gave each theme a clear definition and a name. Here the researcher fine-tuned the analysis to ensure that all the overarching themes and subthemes were clear, separate and accurately reflected the overall meaning and concept of each theme. At this stage, the researcher completed a summary of each overarching theme which supported the researcher to fine-tune the analysis.
6. *Write up:* the researcher began to write the findings, and selected relevant quotes for each subtheme in relation to the research aims. The researcher weaved together the narrative of each subtheme with the relevant quotations ensuring that the quotes were meaningful and accurately portrayed the narrative.

To establish inter-reliability, the researcher’s supervisor checked the data analysis of two transcripts and reflected on initial codes and emerging themes within research supervision. Appendix Q and R contain an example of the data analysis and a summary of the number of participants who contributed to each subtheme.

Researcher influence

The primary researcher is a 25-year-old, White-British, female trainee clinical psychologist and is not a family caregiver of an individual. The researcher became interested in family caregivers’ emotional wellbeing whilst working within an adult community learning disability service with family caregivers. TA acknowledges the importance of the researcher’s understanding and interpretation of the data and the need for the researcher to reflect on this throughout the research process. To minimise bias and increase reflexivity, the researcher kept a reflective journal and engaged in research supervision with a Clinical Psychologist experienced in learning disability services and research. Appendix A contains the researcher’s reflective statement.

Results

When analysing the data, three overarching themes and nine subthemes were generated (Table 4).

Table 4.

Summary of overarching themes and subthemes

Overarching Themes	**Compassion "is not one thing"**	**Identity: me as a caregiver**	**"It's a whole range of hats you have to wear as a carer"**
Subthemes	Self-compassion: "letting myself off the hook"	The "perfect" caregiver	"I am doing this on top of everything else"
	Shared experiences: "in the same boat"	Showing others compassion: a way of life	Importance of compassion: "Passing compassion down the line"
	Professionals: Translated into support	A journey to self-compassion	
	Others: Does not have to be anything big or fancy		

1. Compassion: "it is not one thing"

This theme describes the meaning of compassion to family caregivers.

Overall, all caregivers described that the meaning of compassion encompassed kindness, understanding, awareness and thoughtfulness, as well as doing something to help or that felt useful to caregivers and/or their family member.

> "It's kindness, people being kind… Being kind, kind to you, kindness and thoughtful, thoughtful about [Lenny] you know, or how difficult it might be with him [Lenny]."
>
> Hope

> "It is about seeing people's troubles and doing something about them."
>
> Rita

Jack Sprat’s immediate associations with the word compassion were feelings of grief and sadness and she felt the word “understanding” most related to her meaning of compassion.

> “I sort of feel like compassion is around sadness… It is like someone is suffering or approaching death.”
>
> Jack Sprat

Each flow of compassion appeared to encompass a different meaning depending on the flow of compassion and the people involved.

1.1 Self-compassion: “letting myself off the hook”

Caregivers reported that self-compassion involved recognising the pressure and the emotional stress caregivers often experienced. Caregivers described feeling absorbed by concerns regarding the individual’s health and emotional wellbeing, and self-criticism and self-doubt in their abilities as caregivers. These thoughts were increased by their expectations of themselves and the pressure that they felt to provide individuals with the best life. They described showing self-compassion through acknowledging their skills and that they were doing their best.

> “It is very difficult to care for somebody with such special needs and to be kind to yourself essentially, to remind yourself you're not, you're not, always, you know, calm and patient and it is, yeah, to forgive yourself.”
>
> Mia

Rita suggested an alternative view that “self-love” was intrinsic to human beings, and caregivers could focus on creating a positive life for themselves and their families by caring for their physical and emotional wellbeing and engaging in meaningful activities.

> “You can just break it down into those components that do people good, you know, the sleep and the diet and the exercise and then you build up to ultimately… Having a meaning in life, having a purpose.”
>
> Rita

1.2 Shared experiences: “in the same boat”

Caregivers reported that shared experiences provided a deeper understanding and was a facilitator to both accepting compassion from others, and to showing others compassion.

> “I've got friends and, you know, they are friends who've got children who've, you know, maybe like fall into PMLD categories… Kindness flows naturally in that situation.”
>
> Luna

Others having a deeper understanding led to caregivers feeling accepted within their community, experiencing reduced fears regarding criticism and rejection, and increased confidence and drive in relation to their caregiving roles.

“Everyone’s there with their children trying to sort of, you know, feel normal probably… Needing some help to to do that, needing a playground… Just a little bit of understanding that everybody’s in a slightly harder than normal situation… If your child started getting in a state and banging their head or something, you know, they weren’t going to like tell you to leave.”

Donna

“That you are not on your own… Other people out there that are going through the similar situations and that… It gives ya like a kick… I can carry on, I can!”

Jack Sprat

A deeper understanding appeared to allow caregivers to spend time with others in a safe space and not feel guilty in relation to events.

“The son of this family who was the person with the very profound disabilities of all kinds died recently, he died… He'd been coming to the art… And his mum now comes to the art… She said she was a bit worried about coming because she didn’t want people to get upset on her behalf… But somehow, people don’t, because everybody understands her situation.”

Donna

1.3 Professionals: Translated into support

Caregivers described that receiving compassion from professionals was facilitated by professionals showing awareness and understanding towards the family. When professionals took the time to listen and support caregivers and their family, caregivers were able to accept compassion from them as they felt that their concerns had been acknowledged and actioned.

> “Like the epilepsy nurse she's sort of said that's not normal [Lenny] is it? (.) And I was like no… Once they understand your child… They understand and then action… Understanding, and sort of a personal touch towards [Lenny].”
>
> Hope

Caregivers described positive experiences when professionals showed compassion to both them and the individual by including caregivers within the interventions.

> “She was learning, he was learning, I was learning, we were all learning together.”
>
> Rita

1.4 Others: Does not have to be anything big or fancy

For individuals who did not have shared experiences, caregivers described how limited insight and understanding could act as a block to showing caregivers’ compassion.

> “They just go the other way and then they don't help you (.) and when is all they really need to do is say “oh is there anything I could do right now that could help”… It might be easier if we were some kind of stereotypical people, I don't know who they are, but like someone might write a story about someone sitting in a wheelchair who just smiles, and doesn’t, you know [display behaviours of concern].”
>
> Donna

Caregivers described resisting compassion if they felt it was being offered as a result of sympathy or pity without recognition of the joy that the individual brought to their lives.

> “People don’t quite know what to say… They feel for you but also, you know, everything’s not bad… You’re raised in your family, and you love your kids and you’re doing happy stuff and nice stuff as well… There can be this whole oh “poor you” and I like, I can't take that at all.”
>
> Luna

Caregivers emphasised the importance of people without shared experiences showing compassion. Compassion was described as small acts, that can make a huge difference to caregiver’s wellbeing, reducing isolation.

> “So I took [my child] out the restaurant just to to just to get him out… And the bus driver must have been on his break… He opened the door from the where he he was seated, he said “oh would you like to come and sit in the bus and have a go at pretending to drive?... I cried because I was so happy.”
>
> Hope

Across the three subthemes it was evident that caregiver’s experience of receiving compassion was impacted by individual differences, and the need for communication to facilitate compassion.

> “Somebody giving you the space to be yourself and let them know what you need at that time… I wouldn't want somebody to just come and give me a hug if I was upset because it would probably make me worse.”
>
> Paula

2. Identity: me as a caregiver

This theme describes the FBRs and facilitators to compassion in relation to family caregiver's role and identity.

2.1 The "perfect" caregiver

Caregivers described many barriers to self-compassion. Fears included self-criticism and high expectations of oneself, which were often increased by expectations from others', an expectation to be 'strong', and caregivers' motivation to provide the best quality of life for the individual.

> "I find myself… beat myself up a little bit too much and cause you got this, expectation that you're going to be perfect, and you should be… Should help this vulnerable person and behave in a certain way."
>
> Mia

A focus on their family members quality of life resulted in resistances to self-compassion.

> "It always feels a little bit selfish, that, you shouldn't be spending time right about yourself."
>
> Jack Sprat

Fears including self-criticism were further increased by negative experiences with professionals.

> “We’re always thinking we weren’t doing it well enough… You’re always thinking you you’re not doing enough, and if we did more, she would, by now, she’d be… Because I think that is often the attitude of the people who are working with you.”
>
> Donna

2.2 Showing others compassion: a way of life

Caregivers described a limited number of FBRs in relation to showing others compassion which was linked to the importance they placed on showing compassion to others as part of their identity.

> “Just second nature, you know, so if if I’ve got the capacity to do it, it’s it’s not even a question. It’s just who I am.”
>
> Mia

Caregivers described a facilitator to showing others compassion was their ability to recognise others’ distress and show compassion, resulting from their experience as a caregiver.

> “She's not like there like crying her eyes out to me (.) she's quite wound up about it, but I totally recognise that that is how mums of children with autism are, actually are and end up because you do have to keep going and staying strong.”
>
> Luna

As a result of their experiences, caregivers described offering compassion in a way that they would find helpful.

“If a child’s having a meltdown or something, saying, you know, you’re doing a good job, rather than somebody tutting because they think that the child should not be screaming.”

Hope

The most frequent block to showing others compassion was feeling overwhelmed. During these times, Luna described how this felt unsettling to her, due to the intrinsic nature of compassion.

“That was a really weird situation for me to be in ‘cause, you know, up until those times like I would have regarded myself as a really kind compassionate person.”

Luna

2.3 A journey to self-compassion

Caregivers described an increased number of FBRs to self-compassion. They described fears such as selfishness and being undeserving, as well as resistances including prioritising other’s needs.

“What would you call it when you’ve got feelings of grandeur to be compassionate to yourself?... I get it very rarely where I’m like I deserve this!... It’s just not part of my default setting.”

Mia

“It’s just not a natural thing for me, I’m more concerned about others.”

Jack Sprat

Some caregivers described being aware of their emotions at times and the strategies they used to manage these feelings.

> "I erm never think that I've done enough, erm, and I overthink everything… And I always think I've got it wrong… But sometimes I think, you know, I'm <u>only one person</u> and this is a lot for one person, erm, so sometimes I give myself a pat on the back."
>
> Jack Sprat

Caregivers described that experiencing difficulties with their wellbeing resulted in learning and placing greater importance on self-compassion.

> "It's very easy to be really critical of your parenting where stuff like that's [behaviours of concern] going on, and I think it just got to a point where it's like, you know, we're just in this horrible situation, but I I do feel like I had to get into a quite difficult situation before that kicked in for me."
>
> Luna

After difficult times, caregivers described implementing resistances to showing others compassion to increase their wellbeing and facilitate self-compassion.

> "Ultimately, I burnt myself out a few times in my more adult life and I have to take care of myself better… I have to still be strong enough for myself, for my sister, and for my kids."
>
> Mia

Caregivers' motivation for self-compassion mostly related to ensuring that they were mentally and physically healthy to give high quality care to their family member.

“I think if if we'd have done this five, six years ago, it would have been totally different, but yeah, I think as a person, I’ve I’ve kind of grown to understand, that if, like I say, if I don’t do that with myself, I’m not the best person I can be for other people.”

Paula

Caregivers stated the value and importance of self-compassion but described the difficulties they experienced with engaging in it.

“I think it's a great idea, don’t know if I do it.”

Jack Sprat

3. “It’s a whole range of hats you have to wear as a carer”

This theme describes the number of demands on family caregivers that can impact on their ability to engage in compassion and highlights the importance of receiving compassion from others.

3.1 “I am doing this on top of everything else”

Most caregivers described the additional time and demands that services placed on them and how this increased blocks to self-compassion, increased their stress and reduced the time available to focus on themselves. The breakdown of support from services, the travel and administration tasks were highlighted as particularly frustrating.

“So much admin, so much chasing up, so much frustration… It’s a lot of hours spent chasing up.”

Jack Sprat

Caregivers reported that inadequate support from services resulted in them acting in ways that did not align with their intrinsic nature of showing others compassion (e.g., resistances) and increased self-criticism.

> “I have treated people within social services and education not as I would normally treat people because I would just literally be like ‘I don't care I just need to get this sorted for my kid’.”
>
> Luna

In addition, caregivers reported that managing personal life stressors such as unexpected events, deaths, illnesses and relationship breakdowns, whilst maintaining their caregiving role, acted as blocks to self-compassion.

> “I think the thing as well as being carers or whatever, we have all the normal things happening and we’ve had, you know, grandparents who die and people in hospital.”
>
> Donna

Rita described fears associated with showing self-compassion during difficult times but described facilitators as noticing feelings of distress and returning the focus back to basic needs.

> “I felt very much ‘can I come first?’ and there was just so much going on… Hence the making myself have lentil soup, it was symbolic as much as it was lentil soup, it was to do something for myself.”

Rita

Caregivers described the blocks they experienced as a result of prioritising other's needs and being unaware of their emotional stress. Hope described how being unable to express her needs to others acted as a block to receiving compassion.

"Nobody knew… They said I didn't realise it got that bad so erm, so yeah, it's tricky, if you don't tell people, or if you don't realise yourself, then it is really hard for someone to show you compassion."

Hope

Professionals were able to facilitate caregivers' ability to consider their wellbeing by acknowledging the high emotional stress they were experiencing during times of difficulty.

"She just gave me this big hug and she said, you know, you have to, like, try and look after yourselves as well… And I thought, yeah, so she can just she can see… the effect that this is having… It sort of validates the situation you're in."

Donna

Physical distance from the caregiving role was described as a facilitator to receiving compassion from others, giving caregivers permission to focus on themselves. Paula reported that physical distance increased her ability to engage in self-compassion, reducing fears such as selfishness.

"He took me outside and I was allowed to break down and crumble and he just, you know, held space for me in that moment."

Mia

"It's taken the kids to move out and other people to not be here for for me to focus my energy on me."

Paula

3.2 Importance of compassion: Passing compassion down the line

All caregivers recognised the positive impact of receiving compassion on their wellbeing. Caregivers described that receiving compassion from others acted as a facilitator to engaging in self-compassion and showing others compassion.

"It's a lifeline… How do you maintain patience and caring and understanding when you your own personal life is being trampled all over?... I'm not giving the best care to my sister, am I? So her [a friend's] kindness has allowed me to remain sane and remain, you know, remain the capacity to be caring to my sister."

Mia

Caregivers described that the main facilitator to self-compassion was their drive to provide the best quality of life to their family member and the acknowledgement that they could not do this if they were feeling significantly unwell or overwhelmed.

"If you're not looking after yourself, you can't be the person looking after everybody else."

Paula

> "If I know what I'm doing for myself is also gonna be a benefit to my clients or my kids, then, you know, that's much more motivating."
>
> Luna

Caregivers described the significance of self-compassion and compassion from others for their wellbeing and caregiving role as this enhanced and maintained their ability to show others compassion.

Discussion

Overview of findings

The research aimed to explore the meaning of compassion and the facilitators and FBRs to compassion experienced by family caregivers of individuals, based on Gilbert et al's., (2017) theory of compassion. Thematic synthesis indicated three overarching themes which explored the meaning and experience of compassion for family caregivers.

In describing the meaning of compassion, caregivers felt this was dependent on who the compassionate act involved. Shared experiences were found to facilitate each flow of compassion, supporting previous research that found that connection with others facilitated self-compassion (Wiita, Weinstein, & Ho, 2024). Receiving compassion from others appeared to be largely facilitated by others recognising that caregivers had a role outside that of caregiver. Caregivers defined compassion differently for professionals stating the importance of engaging in person-centred practices, understanding the family and their difficulties, and offering support to meet their needs.

The overarching finding of the current study was that family caregivers reported an increased number of FBRs in relation to self-compassion. Caregivers described feelings of guilt and selfishness if they prioritised time for self-compassion over the needs of others. They described feeling more able to recognise their emotions if others considered the importance of their wellbeing and that physical distance from their caregiving role was a facilitator to self-compassion. The demands they experienced reduced the time available and acted as a resistance to engaging in self-compassion. The study supports previous findings with family caregivers of older adults who described the importance of self-kindness but found it difficult to engage in (Wiita et al., 2024) and young family caregivers who reported increased barriers to self-compassion (Berardini et al., 2021). It also supports previous findings that physical distance from the family caregiving role facilitates self-compassion (Wiita et al., 2024).

In line with previous findings, caregivers described the ease with which they engaged in showing others compassion, potentially reflecting this being an integral aspect of their caregiving role (Beradini et al., 2021). Within the current study, caregivers also described the potential for this to result in 'burnout' and the strategies they used to protect their wellbeing including exercising resistances to showing others compassion during times of emotional stress. This is consistent with research findings that family caregivers can experience compassion fatigue as a result of significant and prolonged stress (Blair, 2017), particularly when caregivers feel unable to relieve others suffering or withdraw from their caregiving role (Day & Anderson, 2011). Caregivers are more at risk of this at times of significant life demands and social isolation (Day & Anderson, 2011), resulting in a reduced ability to show others compassion (Figley, 2002). Caregivers in the study mostly referred to experiencing compassion fatigue with people other than the individual they supported, but it is important for future research to explore the experience of compassion fatigue with the individual to inform how services can support caregivers more effectively.

In consideration of demographic factors, it is important to note that caregivers mostly had extra caring responsibilities which increased demands on caregivers and the FBRs to self-compassion. Living circumstances did not appear to impact on the experience of compassion, however, one caregiver described the time required to travel to an individual living outside the family home as an increased block.

Links between the themes

The theme ‘the “perfect” caregiver’ had links to many of the themes and contributed to several FBRs. A theme map was created to show how the themes were linked to one another, with ‘the “perfect” caregiver’ at the centre of the map, to illustrate how this theme contributed to FBRs (Figure 1). Caregivers described increased FBRs to self-compassion due to high expectations of themselves within their caregiving role, and a desire to meet these demands and provide the best quality of life for the individual. As a result, caregivers described self-criticism, guilt and selfishness in relation to self-compassion throughout the themes ‘the “perfect” caregiver’, ‘a journey to self-compassion’ and ‘letting myself off the hook’. Caregivers also described self-criticism in the theme ‘showing others compassion: a way of life’ when they experienced blocks and resistances to showing others compassion. Self-doubt in their caregiving skills was heightened by criticism from professionals and may have reinforced the need to focus on the health and development of the individual. Caregivers described that their focus on others meant they were sometimes unaware of their own emotional stress which reduced their ability to seek support from others, acting as a block to receiving compassion from others.

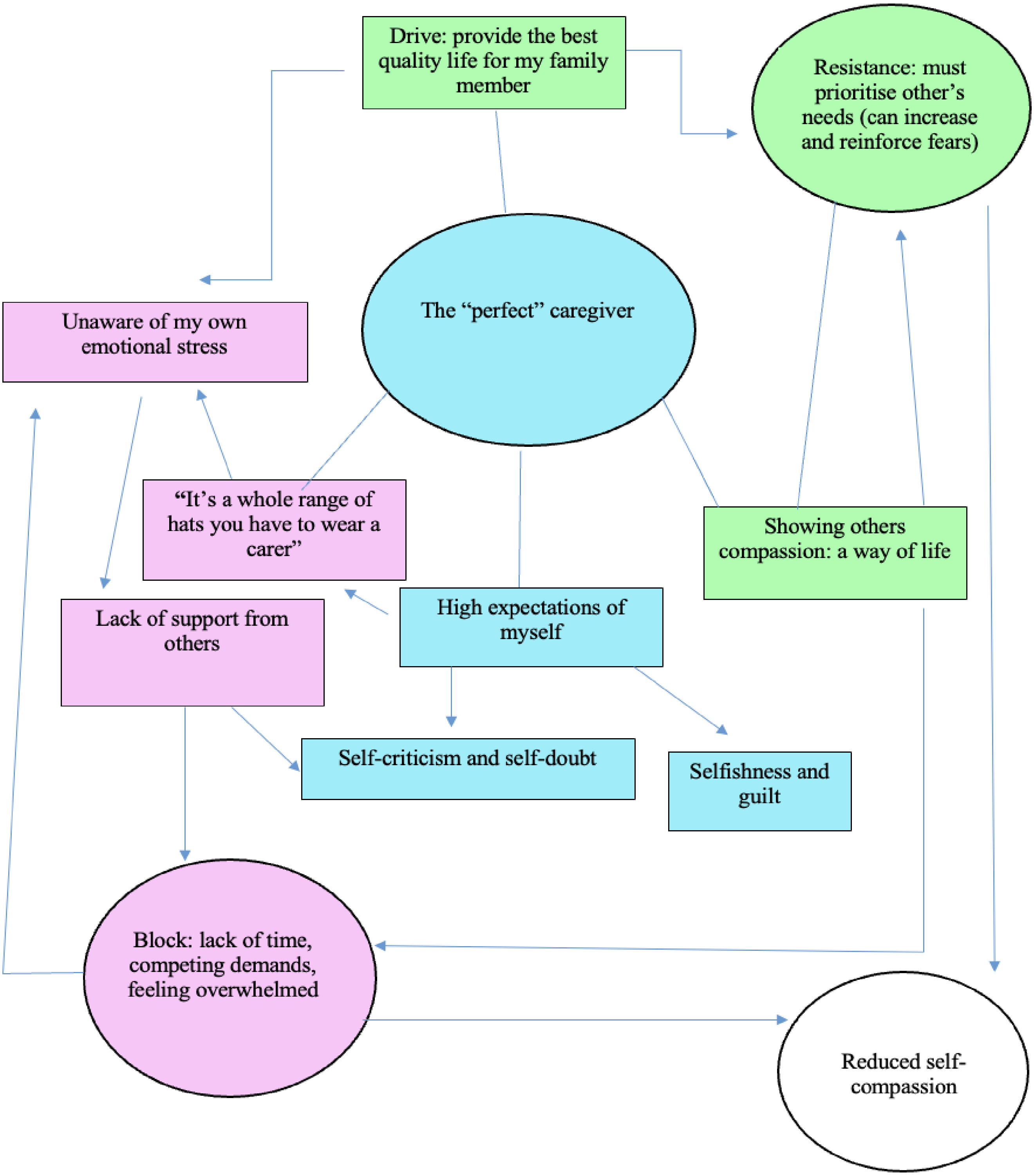

Figure 1.

Links between FBRs and themes

Colour coding:
Blue: Fears to compassion
Pink: Blocks to compassion
Green: Resistances to compassion

A theme map was created to portray the facilitators of compassion that caregivers experienced (Figure 2). The theme ‘The “perfect” caregiver’ appeared to be at the centre of the theme map given caregivers drive to provide the best quality of life for the individual.

Caregivers described the significance of receiving compassion as an individual, outside of being a caregiver and the acknowledgement of their wellbeing from others appeared to enable caregivers to consider the importance of their wellbeing. Caregivers described their motivation for self-compassion as to stay well to be able to support their family member. Receiving compassion from others increased their ability to engage in self-compassion and enabled them to provide the best quality of life for their family member fulfilling the expectations of the ‘the “perfect” caregiver’.

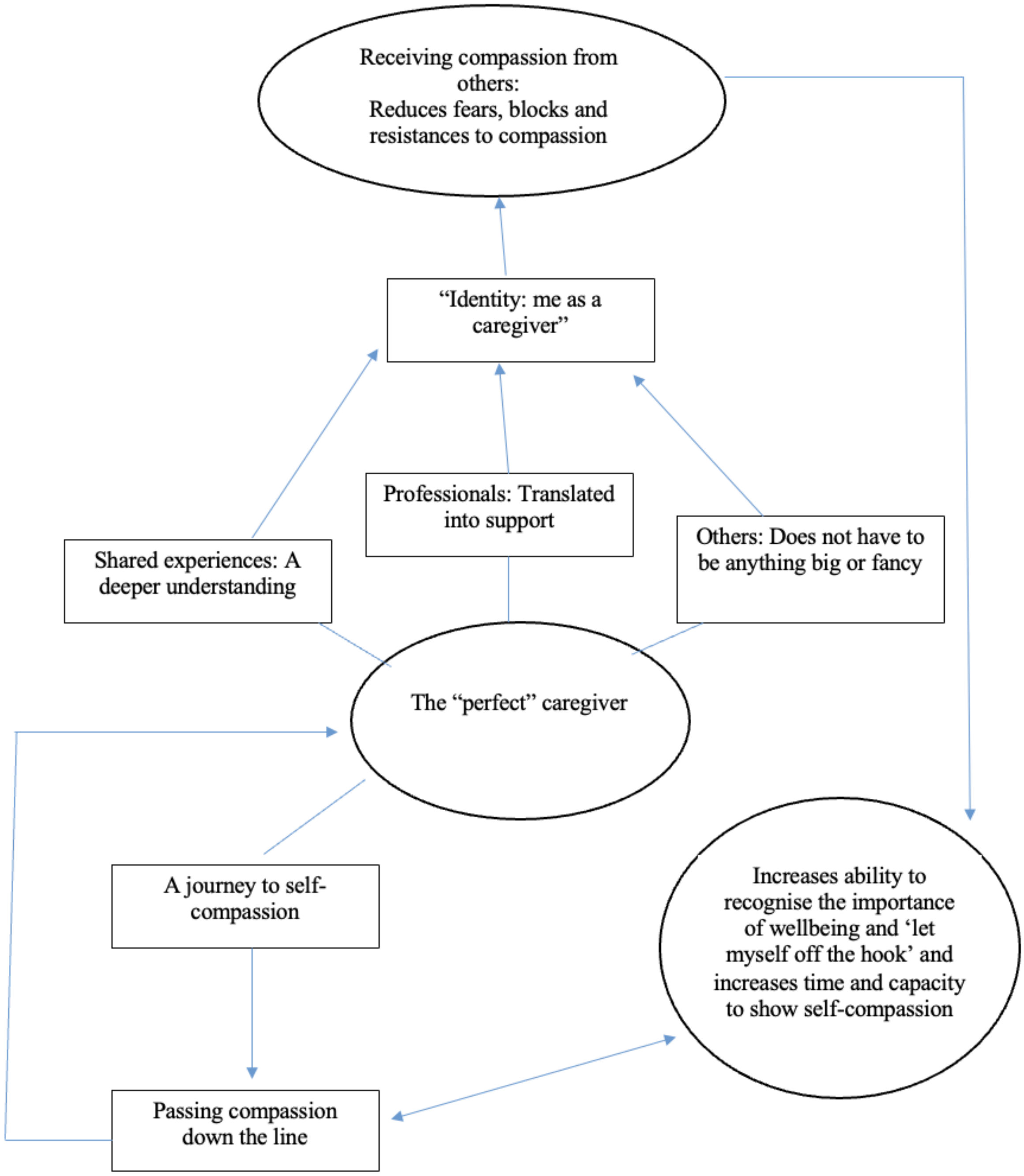

Figure 2.

Links between facilitators and themes

In the current study caregivers described a dominant drive and threat system and increased FBRs to self-compassion (Figure 3). An overactive drive system can lead to high self-criticism, resulting in an overactive threat system which can result in a smaller soothing system and lead to difficulties with wellbeing (Gilbert, 2005, 2009).

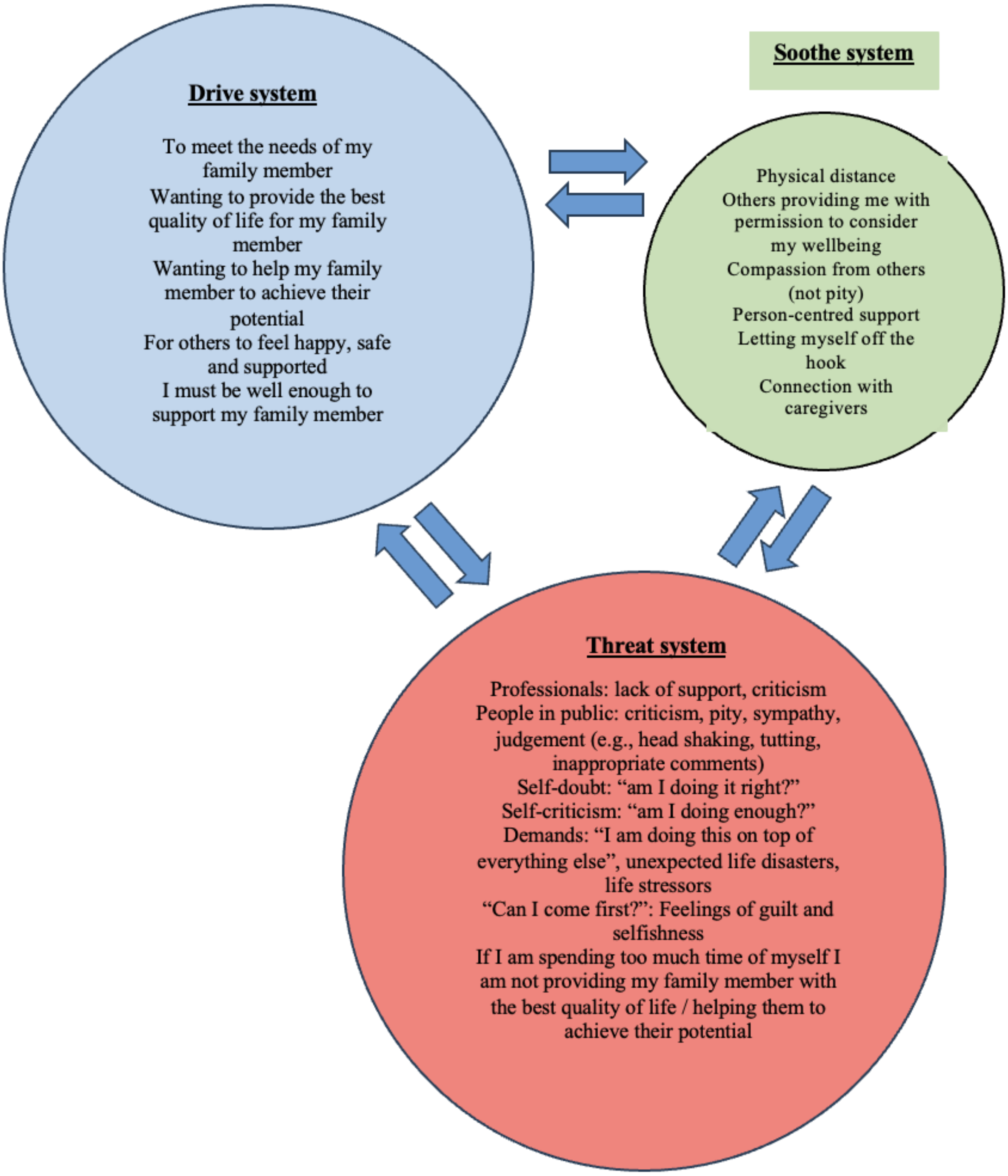

Figure 3.

Three systems formulation model (Gilbert, 2005) in consideration of participant responses

Strengths and limitations

Previous literature has mostly reported the experiences of family caregivers who are mothers. The current study adds to previous findings by the inclusion of sibling caregivers as well as mothers. Siblings and mothers described similar definitions and experiences of compassion. One difference that was apparent was that siblings reported the blocks they experienced to compassion when parents became unwell or died, and the increase in responsibility for the individual at an emotionally difficult time. However the experience of compassion for mothers and siblings was largely dependent on the time and resources available and their need for increased compassion from others during difficult times.

Twelve participants was recognised as a sufficient sample size for a doctoral thesis project utilising Reflexive TA (Braun & Clarke, 2013). Sixteen caregivers expressed an interest in the study initially, and eight agreed to participate, with one caregiver having to withdraw for personal reasons. Many participants described the difficulties in finding time for the interview because of the demands as a caregiver. The qualitative design and the time required to participate may have limited the sample size. However, in the seven interviews conducted, strong dialogue and rich data were generated, and common themes emerged. The research aims were narrow and the research exploring FBRs was focused on Gilbert et al's., (2011, 2017) theory of compassion, which suggested that the seven interviews were sufficient (Malterud, Siersma, & Guassora, 2016).

The research reflects the experiences of caregivers identifying as female, residing in the UK, who mostly identified as white. The meaning and experience of compassion and the importance of each flow of compassion may differ depending on cultural and societal views and future research should explore international experiences to understand if any patterns emerge. As policies that identify the needs of individuals with learning disabilities may differ internationally, the findings may not be generalisable to caregivers living outside the UK.

The study mainly included mothers and as male and female roles may be different within family systems (Thackeray & Eatough, 2018), and societal expectations of being compassionate may differ, further research on male caregivers' experiences of compassion and coping strategies (Pelchat, Levert, & Bourgeois-Guérin, 2009) is required to better understand how to support them.

A limitation is that individuals lived both inside and outside of the family home which may have impacted on the homogeneity of the participant sample. The different living arrangements will have affected the number of hours of support family caregivers provided which may have had an impact on the experience of compassion (increased barriers). However, the study did not find any significant differences related to the definition or the experience of compassion by caregivers who either supported individuals within or outside of the family home. Although differences will have been present in relation to their experiences specific to their living arrangements, the participants overarching definition and experiences of compassion appeared to be similar, which may have been a result of all individuals being family caregivers of individuals with learning disabilities who display behaviours of concern, regardless of their living circumstances.

A further limitation is that as a result of my lens as a Trainee Clinical Psychologist, there may have been a small number of experiences that were significant and important but were not included within the findings. On reflection, I noticed one story that I had not included within my analysis in which a participant described the mistrust that they had with professionals as a family member had experienced abuse from professionals. I found the experience of abuse difficult to listen to and was very aware of my position as a professional within the interviews. Although this was experienced by a minority of the participants, this is still an important story to portray within the study and in the findings.

Clinical Implications

The results of the current study have indicated the need for self-compassion interventions and the potential use of peer support groups to support caregiver's wellbeing. Studies have found support groups increase caregivers' wellbeing, knowledge and resilience (Chakraborti et al., 2021) and enhance self-compassion (Hlabangana & Heath, 2019). They can create non-judgemental spaces and encourage individuals to discuss difficult events, challenges and thoughts and feelings increasing wellbeing and reducing isolation (Boss, 2010). As the ability to exercise self-compassion can be increased (Ahmed, & Raj, 2022), future research should explore the potential of peer support groups as an intervention to increase caregivers' ability to engage in self-compassion. Increased self-compassion has been found to decrease depression and stress (Diggory, 2020) and may reduce the number of caregivers who reach 'crisis point' helping caregivers to maintain the quality of care they can provide (Northouse et al., 2012), benefitting caregivers, services and individuals. Given the current demands on the National Health Service and reported inadequate support from services, peer support groups may provide an effective and efficient intervention. However, further support is firstly needed to support caregivers to be able to attend interventions.

Caregivers may require further support from services to feel fully able to embed self-compassion within their daily lives. Therefore, services need to consider the blocks caregivers experience and ensure caregivers have time to engage and embed self-compassion into their lives (Fernández-Ávalos et al., 2020). Support services also need to embed values that align with person-centred care (Harden et al., 2017), ensuring that professionals have the knowledge and skills to deliver a strength-based approaches considering the needs of the whole family system.

Work needs to continue across all services to develop supportive and compassionate attitudes to families within communities to promote inclusivity and reduce isolation. Future research should explore caregivers’ needs and experience of the education system and the potential of inclusive education to foster positive and inclusive attitudes.

Research implications

Caregivers reports of increased FBRs to self-compassion within this study suggests it is important for future research to explore self-compassion interventions for family caregivers. Previous research has found that it is possible to increase individual’s ability to engage in self-compassion and the benefits of this for wellbeing. It is important to understand whether self-compassion interventions are beneficial to reduce fears and resistances to self-compassion for family caregivers, and if the interventions are beneficial for wellbeing.

Conclusion

Overall, the present study outlines how the sample of female family caregivers residing in the UK define and experience each flow of compassion. Caregivers described showing compassion to others to be an integral part of their identity, although this was not without its difficulties. Participants reflected upon the increased number of FBRs that they experienced in relation to self-compassion. Engaging in self-compassion appeared to be difficult due to the high drive to provide their family member with the best quality support and the high demands and lack of time they experienced in their role. This research supports the need for further support from services for family caregivers which will inevitably benefit the individual that they support.

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Part Three: Appendices

Appendix A: Reflective statement

Listening to caregivers and writing my thesis has been a journey of learning and reflection. Whilst feeling stressed and overwhelmed, and experiencing my own feelings of self-criticism and self-doubt, I felt guilty when trying to take time to engage in self-compassion as opposed to working. As I am now at the end of my thesis journey, although I still experience self-doubt and self-criticism, I am also able to reflect on my strengths and feel empowered by what I have achieved.

Selecting the research

At first, choosing an area of research to study for three years at Doctorate level felt very overwhelming. I was keen to find something I felt passionate about and I started to look at the field of intellectual disability as I had enjoyed working with children and adults and their families whilst training. I had been introduced to the concept of compassion and Compassion Focused Therapy at the beginning of the course and I had reflected on my own willingness to show others compassion whilst struggling to engage in self-compassion. Bringing the two areas together led to me looking at how family caregivers of individuals with an intellectual disability understand and engage in compassion.

Designing the Study

I had no previous experience of qualitative research but after a workshop on the concept of “constructivism” and the idea that meaning is based on experiences had interested me. As I started to explore the potential study with professionals working in intellectual disability services, they talked about the “journey” of becoming a caregiver and the highly emotive events they experience. Following this, I spoke to a family caregiver who told me that that the meaning of compassion can change on a daily basis for caregivers and compassion from others can feel “intrusive” and "offensive". This highlighted the individual experience of compassion and made me want to explore it further.

Ethical Approval

I debated between NHS and University ethical approval and made my final decision of University approval for a number of reasons. A number of charities and organisations had agreed to post an advertisement, some family caregivers had offered support to shape the study and a PHD student offered feedback on their difficulties in recruiting from NHS organisations but success through social media and online forums. Initially, it felt quite daunting not to go through NHS ethics approval and I was really relieved when the Challenging Behaviour Foundation agreed to advertise my research, creating an opportunity for me to recruit caregivers from many different walks of life.

Although I had been told about the long process of ethical approval, I still found the length of time and the number of corrections requested disheartening and it was difficult to hear about peers starting to complete their interviews whilst I was still waiting for ethical approval. However, the process gave me suggestions and feedback from researchers with extensive knowledge in completing research with people with intellectual disabilities and family caregivers increasing my confidence in my research.

Recruitment

The support from the Challenging Behaviour Foundation who posted the advert for the research helped in my recruitment of caregivers.

Initially I felt guilty about placing further demands on caregivers' time when negotiating dates and times for interviews. I was also worried as there was a delay between caregivers expressing an interest in the research and agreeing to an interview, but I became more hopeful as participants started to contact me and I began the interview process.

Interviews

The interview process was very rewarding and I felt privileged that family caregivers had given up their time to participate in my research. Following each interview, I reflected on my own thoughts and feelings, to reduce researcher bias, but I also reflected on the parallels with my own difficulties in engaging with self-compassion.

I was nervous as I had never completed research interviews before and I felt pressured to ensure that the participants felt it had been worthwhile to give up their time to meet me. My confidence increased after the first interview with some positive feedback from the participant and I was able to start to use the interview schedule more flexibly. On reflection, the feedback from one participant on the importance of exploring caregivers experience from a compassionate perspective as opposed to focusing on the “fighters” perspective and “battling” with services was a pivotal moment for me. The potential value and importance of the research for caregivers made me proud of the research and what had started as a stressful “hoop to be jumped through” became meaningful and valuable. I started to feel less guilty about the time the interviews were taking, as caregivers reflected on the importance of the research with me. Hearing the positive feedback about the content and the process of the interviews further increased my confidence.

Whilst designing the research caregivers offered feedback on the difficult and sometimes traumatising events they experienced with professionals. I was nervous therefore of the impact of my role as a professional and spent time to build a rapport and trust with participants emphasising that I was there to listen and to learn from them about their experiences and views of compassion. In the interviews participants shared both their positive and negative experiences with professionals and I wondered whether my transparency about my role as a “trainee” clinical psychologist had enabled me to reduce any power imbalance that might have been present. Throughout the interviewing process I was appreciative and honoured by the participants honesty and openness.

Data analysis

I had initially intended to recruit eight to twelve participants but after the first seven interviews I reflected with my supervisor on the large amount of data and themes that had already been generated. I had hoped to continue to recruit participants to ensure that the themes were also reflected in further interviews however a number of weeks had passed without any caregivers contacting me to participate in my research. I was very aware of the time constraints for caregivers and started to consider information power with my supervisor. I began reflecting on the aim of qualitative research as to develop themes specific and relevant to the research aims and not to create generisable results (Malterud et al., 2016). I reflected upon my confidence regarding the interviews, and how after the first interview, I had become less nervous and had not followed the interview schedule as rigidly and was able to explore the experience of compassion more openly and freely with the knowledge that I was not biasing the findings. I reflected on the rapport that was established during each interview, and the interviews that I had completed had generated a strong quality of dialogue, increasing information power (Malterud et al., 2016). As a result, I decided not to conduct further interviews.

Through hours of mind mapping, collating my thoughts and reading and rereading transcripts, I felt as though the process was finally starting to come together. One of the most difficult aspects was selecting the quotes to include in the paper as so many were powerful, but I was restricted by the word count.

Write-up

I found the prospect of writing up the research the most overwhelming part of the process and I was filled again with self-doubt. The words of the research team who recommended “just start writing” helped me to start putting my thoughts down onto paper and I tried to use some of my learning and engage in self-compassion.

Systematic literature review

I found the systematic literature review (SLR) particularly difficult. I found it harder to motivate myself to complete it as I didn’t have the inspiration that I got from the participants in the interviews, to motivate me when I was feeling tired, stressed or overwhelmed. I was disappointed initially when I read Griffith and Hastings (2014) review and even more disappointed when I saw another review was planned to update it as it seemed as though this had already completed the review I intended to do. Through supervision I was able to identify the limitations of the Griffith and Hastings (2014) review and identify a SLR that was “different enough”, taking an international focus and a broader research question looking at both caregiver’s general experiences and experiences of support services. The international and broader research aims resulted in my SLR including 24 studies which I found difficult to manage and could often find myself engaging in avoidance due to feeling overwhelmed. Initially I found it frustrating and felt as though I had to reread all 24 studies every time I returned to it. As I started to develop the initial codes and create themes, I started to hear the voices of the participants in my empirical research and started to consider the potential importance of the wider implications of the SLR.

Choice of Journals

I chose to write my literature review for the Journal of Applied Research in Intellectual Disability as this has an international, multidisciplinary audience, which is aligned with my research aims, and published the Griffith and Hastings (2014) review.

For my empirical project, I chose to write for the British Journal of Learning Disabilities because it publishes papers that explore debates and developments in research, policy and practice that are relevant to the field of my research in learning disabilities.

Final reflections

Overall, I have felt honoured to have been able to write about the experiences of family caregivers. Throughout this journey, I have reflected on my own difficulties with self-compassion, particularly regarding feelings of self-criticism and self-doubt as well as guilt when I was not prioritising my research. I was able to link this back to wanting to do justice to the stories of those who participated in my research. As I am writing this and approaching the end of my thesis journey, I can also reflect on the rewards I have experienced as a result of completing my research. I feel proud of myself, for all that I have achieved in relation to my research skills and my resilience. My research has made me more passionate about the support that is available for family caregivers and the individuals they support and I hope that my research can provide an insight into the experiences of family caregivers, and most of all, make a difference.

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Appendix B: Epistemological statement

The researcher’s views align with a critical realism perspective, and a constructivist epistemology, which guided the design and the process of the research. Critical realism aims to discover a ‘truth’ whilst acknowledging the lens through which the truth is discovered (Fletcher, 2017). Constructivism states that meaning is created through individual subjective experiences (Raskin, 2002) and research data and findings do not offer a generalisable ‘truth’, but instead reflect individual’s perception of meaning, created and shaped by their experiences and cultural context.

It is important to acknowledge that the concept ‘intellectual disability’ can be viewed as socially constructed by people who place meaning on behaviour, interaction and intelligence (Klotz, 2004). The concept ‘behaviours of concern’ can also be viewed as a social construct, as they are a product of the interaction between the individual and their environment and can often be dependent upon contextual factors (Nunkoosing, 2000; Banks et al., 2007). The researcher acknowledges the position of exploring the meaning and experiences of intellectual disabilities and behaviours of concern in a world that has created these constructs, whilst also acknowledging that the acquisition of knowledge and of social constructs around health and social care has led to clinical implications for people with intellectual disabilities and their caregivers (Nunkoosing, 2000).

A critical realism ontology approach to this research was appropriate as the researcher utilised both an inductive and deductive approach to reflexive thematic analysis to explore experiences of the meaning and experiences of compassion (Braun & Clarke, 2021, 2022). The meaning and facilitators of compassion is a new area of research and therefore required an inductive approach to thematic analysis, whereas Gilbert et al’s., (2011, 2017) definitions of the fears, blocks and resistances experienced in relation to compassion is an established concept however and deductive thematic analysis was therefore utilised to analyse and code the data regarding barriers to compassion (Braun & Clarke, 2006).

Epistemology is the study of knowledge, and how individuals acquire knowledge (Willig, 2019). The researcher aligns with a constructivist position and does not exclusively subscribe to either social constructionism or interpretivism. A broad constructivist position enabled the researcher to consider the importance of interactions and experience, and how these impact on the development of meaning, in consideration of context and established theory. The researcher believes that language is important, and each person's language may describe their reality and create a shared meaning (Berger & Luckman; cited in Speed, 1991, p. 400), which reflects each person's truth. The researcher believes that all 'truths' are equally valid and that no single 'truth' or interpretation exists (Dickerson & Zimmerman, 1996; cited in Rapmund, 2000). The researcher explored the meaning of compassion for each participant before asking about their experiences of compassion. This enabled the researcher to better understand how participants define compassion before exploring their experiences of what has shaped their meaning and experience of compassion. The researcher believes that it is important to remain flexible and open regarding the emotional experiences of others.

A constructivist approach to this research was appropriate as both the systematic literature review and the empirical paper aimed to further understand the lived experiences of family caregivers of individuals with a learning disability who display behaviours of concern. It is important to acknowledge how the meaning and experience of compassion may differ dependent on the contextual factors and experiences of the family caregiver. The systematic literature review explored the international experiences of family caregivers, which may differ dependent on contextual factors including culture, support services, expectations and social norms.

Reflexive processes

The researcher kept a reflective journal throughout the research enabling them to reflect and acknowledge their thoughts, feelings, experiences and biases, which might influence the findings. The journal was used to continually acknowledge the researchers position and lens through which the researcher was conducting the project (an outsider position) in order to minimise the potential for researcher bias to affect the findings.

The structure of the interview schedule was considered through a social constructionist and postmodern lens as it aimed to gather data about the experiences of compassion for family caregivers and what facilitated or increased difficulties in engaging with compassion. This informed the researchers understanding of the interactions that had shaped the meaning of compassion for the participants. Further context for the interview was gathered in the form of the demographic questionnaire and the first 10-20 minutes when participants described their journey of becoming a caregiver. This was important to help the researcher to gain a better understanding of any demographic factors that may have impacted upon participants meaning and experience of compassion.

The aim of keeping the reflective journal and engaging in the reflexive processes within research supervision was to minimise the bias and influence of the researcher on the process and findings within the research. Although these steps were taken to minimise researcher bias, it is important to note that the position, lens, experience and beliefs of the researcher may have had an impact on the findings of the research. These experiences and beliefs may include the researcher's own meaning and experience of compassion (including increased difficulties with self-compassion) and the knowledge that the researcher acquired whilst working with family caregivers who support individuals with intellectual disabilities including the difficulties experienced with support services.

In conclusion, the critical realism and constructivist position was considered throughout the research. Although the researcher hoped to reduce researcher bias in engaging with reflexive discussions and in keeping a reflexive journal, the findings of the research are thought to have been influenced by both the participants and the researcher.

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Appendix C: Author Guideline for the systematic literature review

Journal of Applied Research in Intellectual Disabilities

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, new submissions should be made via the Research Exchange submission portal: https://wiley.atyponrex.com/journal/JAR. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at anytime by logging in to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our FAQs or contact submissionhelp@wiley.com.

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2. AIMS AND SCOPE

JARID is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

In order for a paper to be considered for publication, it must be about people with intellectual disabilities. Manuscripts which focus upon autism will be considered only when the focus is also upon intellectual disabilities. Papers which focus upon autism and exclude people with intellectual disabilities will not be considered.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision.

Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Original Articles, including Clinical Trials (see guidance within section 5), ***Review Articles*** and ***Brief Reports*** are accepted by the Journal. ***Theoretical Papers*** are also considered, provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Authors who are submitting original articles where qualitative methods have been used must ensure that their choice of method is well justified and issues relating to methodological rigor are effectively addressed.

Articles and ***Theoretical Papers*** should not exceed 6000 words;

Review Articles should not exceed 7000 words;

Brief Reports should not exceed 2000 words.

All word limits are inclusive of the abstract. References, Words in Tables, Captions/Legends, Figure and Figure captions/legends are excluded from the word limits.

Please note that papers submitted for Special Issues should also not exceed 6000 words.

4. PREPARING THE SUBMISSION

Use of Language

The language used to describe disability differs across countries, cultures and disciplinary fields, and continues to evolve. All manuscripts submitted to JARID must use language that promotes the value of all people as full members of our shared society. Pejorative language inclusive of euphemisms must not be used. For JARID this includes the use of older language that has been used to describe people with intellectual disabilities such as “retarded”, "special needs", "disease", “handicapped”, or “mentally handicapped”. Using any terms which are offensive, or patronising may lead to rejection of your submitted manuscript.

JARID recommends using person-first and/or identity-first language thoughtfully and appropriately. For example, the language used to describe both people with intellectual disabilities and autistic people has evolved based on recent advocacy efforts. When referring to people with autism, it is acceptable to use either identity-first language (e.g., “autistic people”) or person-first language (e.g., people with autism”), while identity-first language is not used to describe people with intellectual disabilities, where person-first language is preferred. Thus, people with intellectual disabilities should be referred to as people with intellectual disabilities.

We have consulted with over 40 self-advocates through Learning Disability England which included the North West Self-Advocacy Group, as well as Self-Advocacy Together and asked them what language we should use when writing about people with intellectual disabilities.

People with intellectual disabilities said that they do not like to be referred to by acronyms or abbreviations. Authors must therefore not use an abbreviation to describe intellectual disabilities such as "ID" or "LD". Instead, use person-first language such as children, teenagers, adults, or people with intellectual disabilities, avoiding acronyms or abbreviations.

The terms "learning disabilities" and "learning difficulties", though used in some countries to refer to people with intellectual disabilities, can cause confusion among readers. These terms are not used by the journal to refer to people with intellectual disabilities. Authors must only use the term "learning disabilities or difficulties" where this refers to a specific learning disability/disorder– such as a specific learning difficulty in reading, written expression or mathematics. **If "learning disabilities" or "learning difficulties" are used, authors must not use an abbreviation.**

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- Figures and tables should have legends. Figures should be uploaded in the highest resolution possible.
- References may be submitted in any style or format, as long as it is consistent throughout the manuscript.
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- Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper
- An ORCID ID, freely available at https://orcid.org (Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)
- The title page of the manuscript, including:
    - Your co-author details, including affiliation and email address. (Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)
    - Statements relating to our ethics and integrity policies, which may include any of the following (Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication):
        - data availability statement
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JARID has a double-anonymized peer review process so please ensure that all identifying information such as author names and affiliations, acknowledgements or explicit mentions of author institution in the text are on a separate page.

Abstract

All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. We kindly request that authors place the abstract and title at the beginning of the main manuscript document.

Lay Summary

Please provide 3 or 4 bullet points summarizing the main finding of your work, the impact of it for people with intellectual disabilities and for the research community.

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Author Guidelines Updated September 2019

Appendix E. Data Extraction Form

Data extraction based on Wilson's (2009) data extraction form, adapted for the purpose of the review aims

Author, title, year of publication	Country	Research aims	Sample size	Characteristics of participants (age, gender, ethnicity, marital status, employment status, relation to family member)	Characteristics of person caregivers support (age, gender, additional diagnoses, behaviours of concern, living circumstances)	Intervention	Methodology	Analysis	Key findings (themes, quotes, conclusions)	Quality

Appendix F: The National Institute for Health and Care Excellence Checklist for Qualitative Studies

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
Study design		
3. How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach?	Defensible Indefensible Not sure	Comments:

- Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? - Is the selection of cases/sampling strategy theoretically justified?		
Data collection		
4. How well was the data collection carried out? For example: - Are the data collection methods clearly described? - Were the appropriate data collected to address the research question? - Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:
Trustworthiness		
5. Is the role of the researcher clearly described? For example: - Has the relationship between the researcher and the participants been adequately considered? - Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:
6. Is the context clearly described? For example: - Are the characteristics of the participants and settings clearly defined? - Were observations made in a sufficient variety of circumstances - Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable? For example: - Was data collected by more than 1 method?	Reliable Unreliable Not sure	Comments:

- Is there justification for triangulation, or for not triangulating? - Do the methods investigate what they claim to?		
Analysis		
8. Is the data analysis sufficiently rigorous? For example: - Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? - How systematic is the analysis, is the procedure reliable/dependable? - Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:
9. Is the data 'rich'? For example: - How well are the contexts of the data described? - Has the diversity of perspective and content been explored? - How well has the detail and depth been demonstrated? - Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:
10. Is the analysis reliable? For example: - Did more than 1 researcher theme and code transcripts/data? - If so, how were differences resolved? - Did participants feed back on the transcripts/data if possible and relevant? - Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
11. Are the findings convincing? For example:	Convincing Not convincing	Comments:

• Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Not sure	
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
13. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		
14. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported	Comments:
Overall assessment		

As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comments:

Appendix G: NICE (2012) Quality Checklist Assessment Ratings

Study	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Botterill et al., (2019)	Appropriate	Clear	Defensible	Appropriately	Not described	Not sure	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Chase and McGill (2019)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Chester, Greach, & Morrissey (2019)	Appropriate	Clear	Defensible	Appropriately	Unclear	Unclear	Reliable	Not rigorous	Rich	Not sure / Not Reported	Convincing	Relevant	Adequate	Appropriate	+
Dew et al., (2019)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Don and O'Byrne, (2022)	Appropriate	Clear	Not sure	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Dreyfus & Dowse (2018)	Appropriate	Clear	Defensible	Appropriately	Not described	Not sure	Reliable	Not sure/not reported	Rich	Not sure/not reported	Convincing	Relevant	Adequate	Appropriate	+

Dreyfus, Nolan, and Randle (2024)	Appropriate	Clear	Defensible	Appropriately	Not described	Not sure	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Gore, McGill, & Hastings (2019)	Appropriate	Clear	Defensible	Not sure/ Inadequately reported	Not described	Not sure	Reliable	Rigorous	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	+
Grenier-Martin, and Rivard (2022)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Hassiotis et al., (2018)	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Inchley-Mort, & Hassiotis (2014)	Appropriate	Clear	Defensible	Appropriately	Unclear	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Jacobs, Woolfson, and Hunter (2016)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Not sure/not reported	Convincing	Relevant	Adequate	Appropriate	++
Kiernan, Mitchell, Stansfield & Taylor (2019)	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Not reported	Convincing	Relevant	Adequate	Appropriate	++
Kouroupa et al., (2023a)	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear (for this review)	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++

Kouroupa et al., (2023b)	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
McKenzie et al., (2018)	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Muller et al., (2019)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not reported	++
Nag, Hoxmark, & Nærland (2019)	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Ross & Dodds, (2021)	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Not sure/not reported	Convincing	Relevant	Adequate	Appropriate	++
Olivier-Pijpers, Cramm, & Nieboer (2019)	Appropriate	Clear	Defensible	Appropriately	Unclear	Unclear	Reliable	Rigorous	Rich	Not sure/ not reported	Convincing	Relevant	Adequate	Not sure	+
Sheldon, Oliver, & Yashar (2021)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++

Thompson-Janes, Brice, McElroy, Abbott, & Ball (2016)	Appropriate	Clear	Defensible	Appropriately	Clearly described	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not stated	++
Yacoub, Dowd, McCann, & Burke (2018)	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Not sure/ not reported	Convincing	Relevant	Inadequate	Appropriate	+
Young-Southward, Cooper & Philo (2017)	Appropriate	Clear	Defensible	Appropriately	Not described	Not sure	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++

Appendix H. Example line by line coding for a study that met the inclusion criteria for the review (Chase & McGill, 2019).

Study themes and quotes (Chase & McGill, 2019)	Line by line coding	Emerging analytical themes
Taking on added responsibility Though participants described various degrees of responsibility, they all expressed a feeling of impending additional responsibilities for their brother or sister. Most participants' brother or sister are likely to remain in a residential setting rather than living directly with them - however all participants saw themselves as the next-in-line carer:	Worries for the future Increasing responsibilities Changes to caregiver role in the future	Worries for the future
'I think there will always be that nagging feeling in the back of my head that I know that I have a lot of responsibility now but one day, that responsibility will be even bigger.' (Alice)	Worries for future although wanting to support and help parents within their caregiving role	
A few participants emphasized a desire to relieve their parents of anxiety about the future. Carol had assured her parents at an early age that she would take on the primary care responsibility. She described the challenge of the sudden shift of roles and her initial reaction to the unexpected added responsibility:		
'When my mother suddenly took ill, it was still unexpected. I wasn't ready at that point. I didn't expect to take on that full role at that point but that's how it happened.' (Carol)	Changes in role and readiness, unexpected increasing responsibilities	Worries for the future
Support		
Ongoing need for support Participants noted that support surrounding people with disabilities is typically directed to the individual with the disability and their parents and even this may be perceived as inadequate. Where support for siblings is provided, it is likely to be focused on young siblings. Participants expressed a need for ongoing support:	Inadequate support for family caregiver wellbeing and in particular sibling wellbeing Need for a focus on caregiver wellbeing	Caregiver needs Who is supporting family caregivers?
'If there is still not enough support for parents, but there is still more support than		

there is for siblings; that in itself is saying a lot.' (Alice) *'I have to go through a lot… it can have a big impact on siblings* and *they need to be accounted for, as well.'* (Kate) Mutual support between siblings Participants commonly mentioned the importance of mutual support between siblings. Friendships built on a mutual understanding that eliminates the 'elephant in the room' (Christine) were reported as providing the most useful type of support: *'(…) You equally feel supported at the same time. It doesn't just feel like you are being counselled by someone or being listened to by someone who doesn't understand… you are able to offer support to them in the way that they are able to offer support to you... It doesn't matter how old they are or how different your lives are or anything when you're talking to a sibling, you're talking to a sibling and that can make such a huge difference.'* (Alice)	Inadequate support for family caregiver wellbeing Caregiver needs Need for family caregiver support Recognition of family caregiver role within family system, differing experiences based on family role Similar experiences enhances understanding Social support Feeling listened too and heard by someone with experiences of being a family caregiver, and specifically a sibling Sharing knowledge and strategies, balanced support	Caregiver needs Who is supporting family caregivers? Who is supporting family caregivers? Peer support Importance of support from others with shared experiences

Appendix I: Studies that contributed to each subtheme, within each overarching theme

Overarching Theme	Subtheme	Studies that contributed to each subtheme
Emotional responses and mental health difficulties: Adjustment to a new life	"Love and affection"	Chester et al., (2019) Dew et al., (2019) Gore et al., (2019) Sheldon et al., (2021)
	Changes in identity and relationships	Chase & McGill (2019) Dreyfus & Dowse (2018) Kiernan et al., (2019) Ross & Dodds (2021) Sheldon et al., (2021) Yacoub et al., (2018) Young-Southward et al., (2017)
	Frustration and self-doubt	Don & O'Byrne (2022) Gore, McGill & Hastings (2019) Grenier-Martin & Rivard (2022) Nag, Hoxman, & Nærland (2019) Sheldon et al., (2021) Thompson-Janes et al., (2014) Yacoub et al., (2018)
	Stressed and overwhelmed	Dreyfus & Dowse (2018) Chase, & McGill (2019) Hassiotis et al., (2018) Ross & Dodds (2021) Sheldon et al., (2021) Yacoub et al., (2018) Young-Southward et al., (2017)
	Worries, anxiety, and isolation	Botterill et al., (2019) Chase & McGill (2019) Chester, Geach, & Morrissey (2019) Dew et al., (2019) Gore, McGill, & Hastings (2019) Grenier-Martin & Rivard (2022) Kiernan et al., (2019) Muller et al., (2019) Nag, Hoxman, & Nærland (2019) Sheldon, Oliver, & Yashar (2021) Thompson-Janes et al., (2014) Yacoub et al., (2018) Young-Southward, Cooper & Philo (2017)
Preferences for support for my family member	Staff skills	Botterill et al., (2019) Dew et al., (2019) Dreyfus, Nolan, & Randle (2024) Kouroupa et al., (2023b) McKenzie et al., (2018) Nag, Hoxman & Nærland (2019) Olivier-Pijpers, Cramm, & Nieboer (2020) Sheldon, Oliver, & Yashar (2021)
	Personalised and considered care	Don & O'Byrne (2022) Gore, McGill, & Hastings (2019) Inchley-Mort & Hassiotis (2014) Kiernan et al., (2019) Kouroupa et al., (2023a) Kouroupa et al., (2023b)

		McKenzie et al., (2018) Olivier-Pijpers, Cramm, & Nieboer (2020) Ross & Dodds (2021) Youth-Southward, Philo, & Cooper (2017)
	Support and opportunities	Chester, Greach, & Morrissey (2019) Dreyfus, Nolan, & Randle (2024) Gore et al., 2019 Kiernan et al., (2019) Kouroupa et al., (2023a) Kouroupa et al., (2023b) Mckenzie et al., (2018) Nag, Hoxman, & Nærland (2019) Olivier-Pijpers, Cramm, & Nieboer (2020) Ross & Dodds (2021) Sheldon, Oliver, & Yashar (2021) Yacoub et al., (2018) Young-Southward, Cooper & Philo (2017)
Caregiver needs	Who is supporting family caregivers?	Chase & McGill (2019) Chester, Geach, & Morrissey (2019) Dew et al., 2019 Dreyfus & Dowse (2018) Grenier-Martin & Rivard (2022) Kouroupa et al., (2023a) Mckenzie et al., (2018) Nag, Hoxman, & Nærland (2019) Sheldon, Oliver, & Yashar (2021) Thompson-Janes et al., (2014) Yacoub et al., (2018)
	Feeling informed and involved	Botterill et al., (2019) Chester, Greach, & Morrissey (2019) Dew et al., (2019) Hassiotis et al., (2018) Inchley-Mort & Hassiotis (2014) Jacobs, Woolfson, & Hunter (2016) Kiernan et al., (2019) Kouroupa et al., (2023a) Kouroupa et al., (2023b) McKenzie et al., (2018) Olivier-Pijpers, Cramm, & Nieboer (2020)

Appendix J: Ethical and Health Research Authority approval

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Maureen.Twiddy@hyms.ac.uk
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PRIVATE AND CONFIDENTIAL
Charlotte Barber
Faculty of Health Sciences
University of Hull
Via email

Thursday 19th October 2023

Dear Charlotte,

FHS 22-23.99 - Compassion in caregivers of family members with severe, profound, or multiple LD who display behaviours of concern

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

The approval is valid until 31st September 2024. If you require an extension to this end date or you need to report any further amendments to your study please complete Form C which can be found at Research Ethics (sharepoint.com) for staff and Student Research Ethics (sharepoint.com) for students.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

CWhitfield

Dr Clare Whitfield
Deputy Chair, FHS Research Ethics Committee

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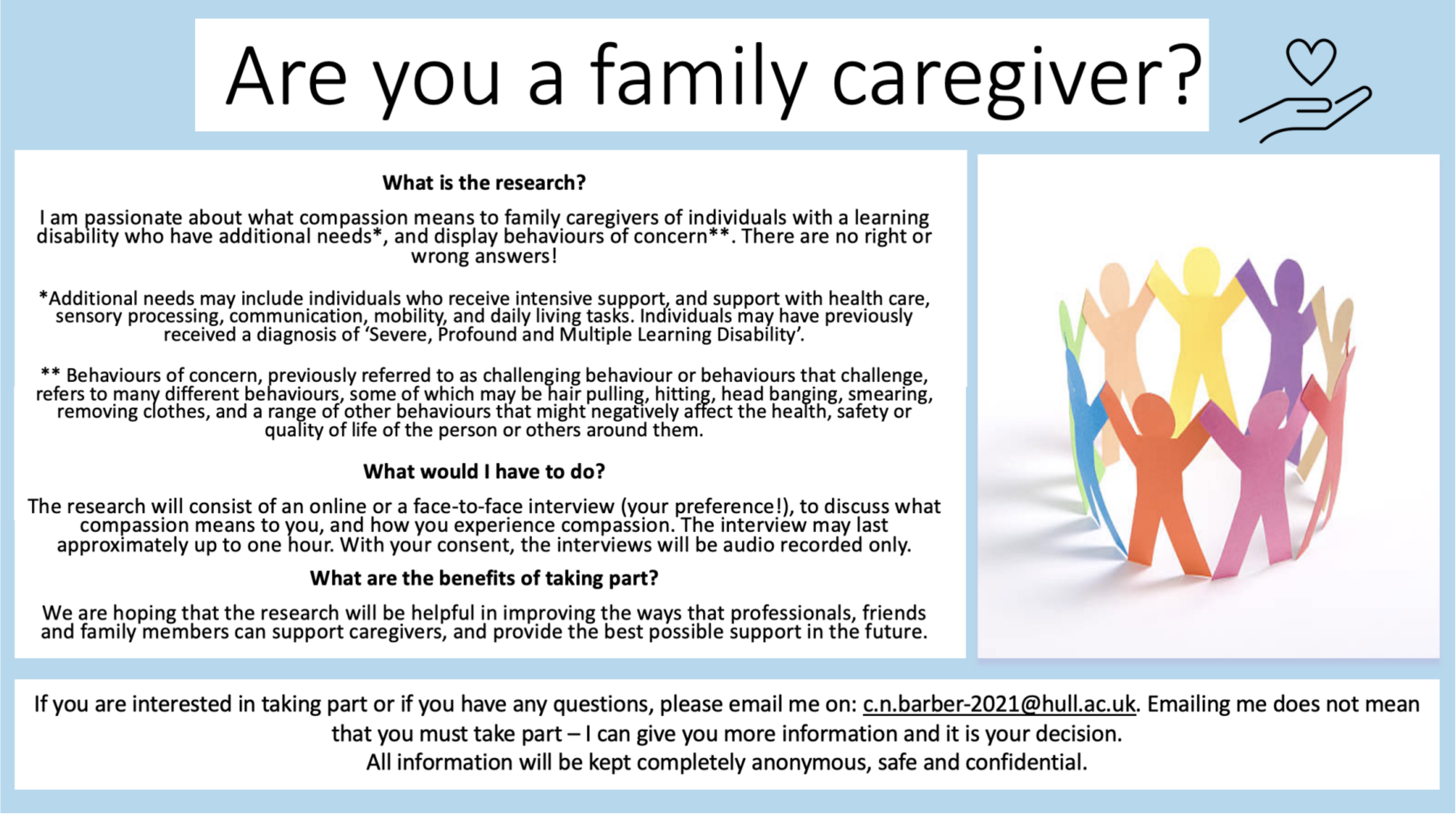
Appendix K: Recruitment poster



Are you a family caregiver?

What is the research?

I am passionate about what compassion means to family caregivers of individuals with a learning disability who have additional needs*, and display behaviours of concern**. There are no right or wrong answers!

*Additional needs may include individuals who receive intensive support, and support with health care, sensory processing, communication, mobility, and daily living tasks. Individuals may have previously received a diagnosis of 'Severe, Profound and Multiple Learning Disability'.

** Behaviours of concern, previously referred to as challenging behaviour or behaviours that challenge, refers to many different behaviours, some of which may be hair pulling, hitting, head banging, smearing, removing clothes, and a range of other behaviours that might negatively affect the health, safety or quality of life of the person or others around them.

What would I have to do?

The research will consist of an online or a face-to-face interview (your preference!), to discuss what compassion means to you, and how you experience compassion. The interview may last approximately up to one hour. With your consent, the interviews will be audio recorded only.

What are the benefits of taking part?

We are hoping that the research will be helpful in improving the ways that professionals, friends and family members can support caregivers, and provide the best possible support in the future.

If you are interested in taking part or if you have any questions, please email me on: c.n.barber-2021@hull.ac.uk. Emailing me does not mean that you must take part – I can give you more information and it is your decision.
All information will be kept completely anonymous, safe and confidential.

Appendix L: Participant Information Sheet

UNIVERSITY OF HULL | FACULTY OF HEALTH SCIENCES

Participant Information Sheet

Thank you for showing an interest in my research project.

I would like to invite you to take part in my research project which is part of my Doctorate in Clinical Psychology. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what will be involved if you do take part. Please read the following information carefully and discuss it with other people if you wish. Please ask me if there is anything that is not clear or if you could like more information.

Title of study: Compassion in family caregivers, who care for individuals with a learning disability who have additional needs*, and display behaviours of concern**.
*Additional needs may include individuals who receive intensive support, and support with health care, sensory processing, communication, mobility, and daily living tasks. Individuals may have previously received a diagnosis of 'Severe, Profound and Multiple Learning Disability'.
** Behaviours of concern, previously referred to as challenging behaviour or behaviours that challenge, refers to many different behaviours, some of which may be hair pulling, hitting, head banging, smearing, removing clothes, and a range of other behaviours that might negatively affect the health, safety, or quality of life of the person or others around them.
Being a caregiver can be both a rewarding, and a challenging experience. Compassion has been found to be important for wellbeing, however compassion can raise difficult and complex feelings for many people. Compassion can be defined as being kind to yourself, offering kindness to others, and accepting kindness from others. This research aims to explore what compassion means to caregivers, and how caregivers experience compassion. There is no right or wrong answers, we want to learn more about how caregivers think about compassion and what compassion means to you.

What is the purpose of the study?

The study aims to understand more about what caregivers of family members think about compassion, and what compassion means to caregivers. We hope to find out more information about what makes it easier and what makes it more difficult for caregivers to show themselves compassion, receive compassion from others, or show others compassion. We hope to find out more information about compassion to help others, including professionals, to know how we can better support caregivers.

Why have I been invited to take part?

You are being invited to take part in this study because you are a caregiver of a family member with additional needs who displays behaviours of concern, and you speak English.

What will happen if I take part?

Before the interview, you will be asked to provide an email address/telephone number for the researcher to contact you on to agree for a date, time, place for the interview to take place. You will have the option of the interview taking place via telephone, video call (e.g., Zoom or MS Teams), or face to face if you live within the Humber and North Yorkshire area. If you decide to take part in the study using video call, the researcher will contact you to provide you with the 'Zoom' or 'MS Teams' link. If you decide to take part in the study face to face and you live in the Humber and North Yorkshire area, the researcher will contact you to agree on a location for the interview to take place. You will be asked to take part in an interview that may last approximately 60-90 minutes.

You will have to read and sign a consent form. Please send the consent form back to the researcher before the interview takes place, and let the researcher know when you have sent the consent form. The researcher will contact you, to give you a gentle reminder to return the consent form, if the researcher has not already received it, two weeks and one week before the interview takes place. The researcher will also contact you to remind you to read through the information sheet before the interview takes place, two weeks before the interview takes place. If the researcher has not received the consent form before the interview takes place, it is possible for us to audio record verbal consent instead to make sure that you still have the chance to take part.

During the interview, the researcher will ask you to take her through your experience of being a caregiver, and what the meaning of compassion is to you, and your experiences of compassion. An example of a question that the researcher will ask is "please could you tell me about a time where you have shown yourself compassion?". The interview will be audio recorded, transcribed (everything that we have said will be typed up into a document), so the researcher can analyse all the interviews to find the themes in the data. Only the researcher and the researcher's supervisor will be able to listen to the audio recordings and read the transcribed interview data. The interviews will only be audio recorded with your consent. Quotes that you said during the interview may be used in the write up of the research, and in conference presentations. You will not be identifable by the quotes, I will replace your real name with a false name.

Do I have to take part?

You should only take part if you want too. Once you have read the information sheet, please contact the researcher or the researcher's supervisor if you have any questions. If you decide to take part, we will ask you to sign a consent form. You will be given a copy of this consent form to keep.

What are the possible risks of taking part?

No deception or significant risk will be involved when taking part in the study.

Although the researcher’s aim is not to cause any distress to you or the person that you care for, there is the possibility that during the interview you may feel or become distressed whilst discussing difficult events or feelings. The person that you care for may also be at risk of becoming distressed if they hear difficult, or sensitive conversations. It is important that you have a private place to complete the interview in order to respect both you and the person that you care for. We do not want to upset anyone. If the researcher is concerned about the caregiver or the person who they care for, the researcher will discuss any concerns with you, and my supervisor.

If you were to tell me that you or another person is being hurt or harmed or is at risk of these things, I would have to tell my supervisor, and where appropriate, other professionals, including the safeguarding team, to keep you and the person that you care for safe. We do not want you to feel anxious or under surveillance about this, instead we wanted to be upfront and honest about what I would have to do if I was concerned about you or the person that you care for.

The researcher will provide all participants with telephone numbers and email addresses for support services around the local area, for participants to get in contact with if you feel you may want some further support. You can also contact the University of Hull research team.

What are the possible benefits of taking part?

There are no immediate benefits for the participants to take part in the research. However, the aim of the research is to add to what we know about what compassion means to caregivers, and how caregivers think about compassion. The findings hope to generate recommendations and interventions for how people, professionals and support services can support caregivers as best as possible. By taking part in this research, you will add to the knowledge and understanding in this area. Beyond this, there are no benefits to taking part in the research.

How will we use information about you?

We will keep all information about you safe and secure.

All data collected will be kept completely confidential.

We will need to use information from you for this research project, including:

Your contact details for the researcher to contact you to organise the interview, such as a date, time and location for the interview to take place. You can sign up to receive a summary of the results once the study is completed, and the researcher will keep your contact details safe and secure until the link to the results have been sent to you. Your contact details will be immediately deleted once the interview process is complete, or the summary link has been sent.

The interview will be audio recorded. The audio recording and the interview transcript will be stored on the researcher's secure NHS laptop during the interview and destroyed after being immediately uploaded onto the University of Hull's secure data base. Any paper information will be locked in the researcher's secure bag, and shredded immediately after the paper copy is scanned into the University of Hull secure data base. Any personal data collected from you (your name, contact details) will be destroyed at the point at which the interview process has been completed. You will have the option to sign up to receive a summary link of the research findings once the write up process is complete. Your contact details will be immediately deleted after the link has been sent.

Your data will be processed in accordance with the UK-GDPR and the Data Protection Act 2018, which will mean:
We will keep all data secure, confidential and anonymous. No-one will know that you took part in the study. Your name will be replaced with a number which will be attached to your consent form and interview data. In the write up of the study, your name will be replaced with a false name.
The interview will be audio recorded. Quotes that you said during the interview may be used in write up of the research study and in conference presentations. Your name will be replaced with a false name, so you cannot be identifed by the quotes used.
All data will be kept on the University of Hull's secure data base for 10 years after the study is completed. After 10 years, the data will be destroyed.
Only the researcher, the researcher's supervisor and the research team will have access to the data.
Data will only be shared within the research team, and this will only be done with your consent.

Data collected in this research may be used to support future research and may be shared anonymously with other researchers. You will not be identifiable.

What are your choices about how your information is used?

You are free to withdraw at any point during the study, without having to tell me a reason. If you choose to withdraw from the study during the interview, the information that you have told me will be destroyed. You have the right to ask me to remove any information that you told me up to 2 weeks after the interview has taken place. It is impossible to destroy the information that you have told me, once I have replaced your name with a number and false name, as I will no longer be able to identify which information you told me.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

At www.hra.nhs.uk/information-about-patients/ and https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/
By asking one of the research team

By contacting the University of Hull Data Protection Officer by emailing dataprotection@hull.ac.uk or by calling 01482 466594 or by writing to the Data Protection Officer at University of Hull, Cottingham Road, Hull, HU6 7RX
By reviewing the University of Hull Research Participant privacy notice: https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/docs/quality/research-participant-privacy-notice.pdf

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a ‘task in the public interest’

If you are not happy with the sponsor’s response or believe the sponsor processing your data in a way that is not right or lawful, you can complain to the Information Commissioner’s Office (ICO) (www.ico.org.uk or 0303 123 1113).

How is the project being funded?

This study is being funded by the University of Hull, Cottingham Rd, Hull HU6 7RX.

What will happen to the results of the study?

The results of the study will be summarised in the researcher’s thesis for the award of Doctorate in Clinical Psychology. The research may be published in a relevant scientific journal. Only the write up of the study may be published. The transcripts of the interviews will not be published.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by **the Faculty of Health Sciences Ethics Committee, University of Hull.**

Who should I contact for further information?

If you have any questions or require further information about this study, please contact on the email address c.n.barber-2021@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

Dr Nick Hutchinson: n.hutchinson@hull.ac.uk

Alternatively, please contact university-secretary@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix M: Consent form

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CONSENT FORM

Title of study: Compassion in family caregivers, who care for individuals with a learning disability who have additional needs*, and display behaviours of concern**.

*Additional needs may include individuals who receive intensive support, and support with health care, sensory processing, communication, mobility, and daily living tasks. Individuals may have previously received a diagnosis of 'Severe, Profound and Multiple Learning Disability'.

**Behaviours of concern, previously referred to as challenging behaviour or behaviours that challenge, refers to many different behaviours, some of which may be hair pulling, hitting, head banging, smearing, removing clothes, and a range of other behaviours that might negatively affect the health, safety or quality of life of the person or others around them.

Name of Researcher: Charlotte Barber

Please tick box

1. I confirm that I have read the information sheet dated 19/10/2023 version 3 for the above study. I have had the opportunity to consider the information, ask questions and have had any questions answered satisfactorily. ☐

2. I understand that my participation is voluntary. I understand that I am free to withdraw at any time during the interview, without giving any reason. I understand that if I withdraw during the interview, the data I have provided will be destroyed. ☐

3. I understand that if I decide to withdraw after the interview has taken place, the information can only be destroyed if I decide to withdraw up to 2 weeks after the interview is completed. I understand that I cannot withdraw once my data has been anonymised, as you will not be identifiable.

4. I understand that the research interview will be audio recorded and that quotes that I said during the interview, may be used in the write up of the research study, and in conference presentations. I understand that my name will be replaced with a false name, so nobody will be named or identifiable in the write up of the study. ☐

5. I understand that the research data, which will be anonymised (not linked to me), will be retained by the researchers and may be shared with others and publicly disseminated to support other research in the future. ☐

6. I understand that my personal data will be kept securely in accordance with data protection guidelines and will only be available to the immediate research team. ☐

7. After the research study is complete, and the findings have been written up, I would like to receive a summary of the results. ☐

If yes, please leave your email address below for the researcher to contact you with a summary of the results in the future:

8. I agree to take part in the above study.

Name of Participant	Date	Signature
Name of Person	Date	Signature

Appendix N: Demographic questionnaire

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Demographic questionnaire

The geographical area that I live in is (e.g., local authority) ☐

My ethnicity is:

Asian or Asian British ☐

Black, Black British, Caribbean or African ☐

Mixed or multiple ethnic groups ☐

White ☐

Other, please describe ☐

My age is:

19 or younger ☐

20 – 29 ☐

30 – 39 ☐

40 – 49 ☐

50 – 59 ☐

60 or above ☐

The age of the person I care for is:

19 or younger ☐

20 – 29 ☐

30 – 39 ☐

40 – 49 ☐

50 – 59 ☐

60 or above ☐

The gender that I identify with is:

Female ☐

Male ☐

Other ☐

The gender that the person I care for identifies with is:

Female ☐

Male ☐

Other ☐

My marital status is

Single ☐

Married ☐

Other ☐

What is your employment status

I am a full-time caregiver for my family member ☐

Full time work ☐

Part time work ☐

Other (please describe below) ☐

What relation are you to your family member that you provide support for

Parent ☐

Sibling ☐

Grandchild ☐

Grandparent ☐

Niece / Nephew ☐

Other (Please state) ☐

Do you live in the same house as the person that you care for

Yes ☐

No ☐

If no, please describe where the person that you care for lives (for example, residential living accommodation)

Does the person that you support receive any type of support currently:

Respite care ☐

1:1 support ☐

Day service ☐

Other (Please describe below) ☐

How many hours of support does the person that you care for receive from others

Do you have any other caregiving responsibilities

Yes (please state the responsibilities) ☐

No ☐

Appendix O: Semi-structured interview schedule

Opening/Introduction

1. Introduce the interview by explaining what is involved in the interview, timing of the interview
2. Check understanding of information sheet
3. Check consent again and that participants are happy to continue

"I would like to ask you if we can spend the first 10-20 minutes of the interview talking about your experience and journey of becoming a caregiver? I know 10-20 minutes might sound like a really short time, but we will be able to talk about some of the experiences you have had as we work through the questions. Are you happy to tell me about your experiences?"

Background questions

1. How many hours of support do you provide for your family member, and please could you briefly describe what your average caregiving day involves?
2. Please could you briefly tell me about and describe the behaviours of concern that the person that you care for engages with?

Definition of compassion

"I would like to ask you some questions about 'compassion' about what the word 'compassion' means to you as a caregiver, if compassion is or can feel helpful or unhelpful, and what might make it easy or difficult to engage in. Being a caregiver can be both a rewarding, and a challenging experience. Compassion has been found to be important for wellbeing, however compassion can raise difficult and complex feelings for many people. I would like to hear about your experiences of compassion since becoming a caregiver. I am using a specific meaning of compassion, would you like me to read out this definition?

- Optional if yes: compassion can be defined as being kind to yourself, offering kindness to others, and accepting kindness from others. It is also about being sensitive to and noticing when you or someone else is distressed, and then taking helpful steps to help reduce or prevent the distress. Would you like me to share my screen with this definition on or do you want to write it down as a visual cue?

This is my definition of compassion but I want to hear about yours. This is just one idea. There are no right or wrong answers. I am open to hear absolutely anything, so please do not worry about any examples of how big or small they might feel to you in regards to compassion and your experiences."

Compassion

These first few questions are about what compassion means to you.

- Can you tell me what showing compassion to yourself means to you?
- Can you tell me what showing compassion to other people means to you?
- Can you tell me what receiving compassion from others means to you?
  - Optional if participants answer don't know: what comes to mind when you think of compassion to yourself/ compassion to others/ receiving compassion to others?
- Is there a word you would like me to use for the word compassion throughout the interview that feels meaningful or more relevant for you?

Self-compassion:

In this section I am going to ask you about when you have shown yourself compassion. Many people can find it difficult to show yourself compassion, whereas for others it might come more naturally.

- Could you tell me about a time you have shown yourself compassion?

In relation to your example you have just told me about, could you tell me:

- What did you notice about how you felt when you were showing yourself compassion?
    - Optional: How did you know or recognise those feelings in yourself?
    - Optional: Did anything make it difficult to notice your feelings?
    - Optional: How did you try to help yourself in relation to those feelings?
- Did anything make it difficult for you to show yourself compassion?
- Did anything make it easier for you to show yourself compassion?
- What do you think about the idea of being and showing yourself compassion?
- Do you have many opportunities to show yourself compassion?
    - Optional: What and when are these opportunities?
- In general, is there anything that helps you or makes it to feel easier to show yourself compassion?
- In general, is there anything that makes it more difficult, or makes it feel more difficult to show yourself compassion?

Receiving compassion from others:

In this section I am going to ask you about when other people have showed you compassion, and how this felt when other people showed you compassion. Many people can find it difficult to receive compassion from others, whereas for others it might come more naturally.

Can you tell me about either a situation that was difficult for you as a caregiver which may have increased feelings of distress for you, and someone has offered kindness and compassion to you, or when someone, or when you have told someone about a situation that was difficult and/or distressing for you as a caregiver?

- Did the person(s) notice your distress? What did they notice?
- Did anything make it more difficult for the person(s) noticing your feelings of distress?
- Did the person(s) try to help you manage your feelings of distress?
    - Optional: How did they try to help you manage these feelings of distress?
- How did you feel when the person showed you compassion?
- Did it feel difficult for you to allow the person(s) to respond to your distress by helping, and showing you compassion?
- Did anything make it easier for you to allow the person(s) to respond to your distress by helping, and showing you compassion?
- How often are others in a situation where they could show you compassion?
    - Optional: what do these opportunities look like?
    - Optional: Did others showing you compassion feel helpful or unhelpful to how you were feeling?

Showing others compassion:

In this section I am going to ask you about when you have shown other people compassion. Sometimes it can be difficult to show other people compassion. Many people can find it difficult to show others compassion, whereas for others it might come more naturally.

- Can you tell me about a time that you noticed another person struggling or experiencing distress, so this could be noticing someone in distress in general, or someone experiencing distress in relation to their caregiver role?
- How did you notice that they were feeling distressed?
- Was there anything that made it harder for you to notice their distress?
- Was there anything that made it easier for you to notice their distress?
- Did you try to help them with their distress?
    - Optional: If yes, how did you try to help them with their distress?
- What do you think might make it easier for you to help others when they are distressed?
- How did it make you feel when you were compassionate to someone else?
    - Optional: Do you typically feel this way when you are compassionate to others, or do you also feel different emotions and ways towards being compassionate to others?
- Is there anything that makes it harder to show others compassion in general?
- Is there anything that makes it easier to show others compassion in general?
- How often are you in a situation where you could show others compassion?
    - Optional: what do these opportunities look like?
    - Optional: Did showing others compassion feel helpful or unhelpful to how you feel?

<u>Optional sections:</u>
Optional section on professionals and/or family member's and/or friends if not talked about these individuals throughout the interview:

- Are there any reasons for you not discussing these people?
- How important is compassion from or to these people for your wellbeing and how you view compassion?

Prompts depending on answers to question 1 and 2:

- Have these individuals impacted on how you view compassion?
    - If so, how?
- Have professionals/family members/friends offered support you when you have appeared distressed?
    - If so, how?
    - If not, did this impact on how you view other people and/or compassion?
- Does anything make compassion to or from easier or more difficult from these people?
- How many opportunities are you in where professionals/family members/friends could show you compassion?

<u>Ending</u>

- Draw the interview to a close
- Thank the participant for their participation
- Provide space for questions
- Check in with the participant about how they are feeling after the interview, and provide participant with support sheet
- Ask if participants would like to receive a copy of the findings once they have been written up
- Remind participants that consent is a dynamic process and the two weeks in which participants can ask the researcher to withdraw and the researcher will delete any data

- Ask if participants have a name they would like me to use for the write up of the findings

Appendix P: Participant sources of support

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Sources of support

Although it is not our aim, we understand that the interview may increase distress in some participants. We have listed below some support services that you can contact, if you feel you may want some further support, or if you are experiencing difficulties are the interview has taken place:

MENCAP: supports individuals with a learning disability, and parents and caregivers of individuals who have learning disability. MENCAP can be contacted for free Monday-Friday 10am-3pm on: 0808 808 1111, or helpline@mencap.org.uk. Please see their website for more information: mencap.org.uk.

Scope: provides practical information and emotional support for individuals with a disability. Scope can be contacted Monday-Friday 9am-6pm and Saturday-Sunday 10am-6pm for free on: 0808 800 3333. Please see their website for more information: scope.org.uk.

The Challenging Behaviour Foundation: offers information about challenging behaviours to anyone who provides support to a child, young person or adult with a severe learning disability. Their Family Support Service can be contacted Monday-Friday 10am-5pm on: 0300 666 0126, or support@thecbf.org.uk. Please see their website for more information: challengingbehaviour.org.uk.

Carers UK: provides support and advice to anyone who is a caregiver. Carers UK can be contacted Monday-Friday 9am-6pm on: 0808 808 7777, or advice@carersuk.org. Please see their website for more information: carersuk.org.

If you feel you may want some further support with your wellbeing, or if you are experiencing difficulties are the interview has taken place, for mental health support:

MIND: provides support and advice to anyone experiencing difficulties. MIND can be contacted Monday-Friday 9am-6pm on: 0300 123 3393 (Infoline). Please see their website for more information: mind.org.uk.

Samaritans: provides support and advice to anyone experiencing difficulties. Samaritans can be contacted 24 hours a day for free on: 116 123. Please see their website for more information: Samaritans.org.

Appendix Q: Data analysis example of transcript: 'line by line' and emerging themes

Transcript	Initial Codes	Initial Emerging Themes
Researcher (CB) Is there anything else that makes it a bit harder to show yourself compassion?		
Paula No, I don't think so now. I think if if we'd have done this five six years ago, it would have been totally different but yeah, I think as a person I've I've kind of grown to understand that if I'd, like I say, if I don't do that with myself, I'm not the best person I can be for other people	**Importance of self-compassion… Flows interlinked:** The importance of self-compassion, so I can show other people compassion Drive for self-compassion: to be able to be well enough to care for others Learning curve: the need for and how to show self-compassion A journey to self-compassion	Flows of compassion interlinked The importance of self-compassion and drive for engaging in self-compassion: to be able to show others compassion Showing self-compassion and others showing me compassion for me to be able to show others compassion Ability to remain compassionate A journey to self-compassion
Researcher (CB) OK right, so is that maybe a motivator of self-compassion?		
Paula Yeah, yeah		
Researcher (CB) Right		
Paula I think so, but I can understand how it's really difficult for some people depending on the situations that they're in		
Researcher (CB) Yeah, mm, and then is there anything that makes it easier for you to show yourself compassion?		
Paula Just having time. I think that that's the biggest thing, having time. I mean there's a lot of things that need to be done and again I think because I've kind of grown as a person, you you start to look at things differently	**Block to self-compassion:** Time Self-compassion: learning curve	Self-compassion: Time and resources, "many hats that caregivers wear" Self-compassion: learning curve, journey to self-compassion A journey to self-compassion
Researcher (CB) Right		

Paula Like, oh well, that can be left until tomorrow because nothing's going the world's not going to end if I don't do it, that kind of thing Researcher (CB) OK	**Facilitator to self-compassion:** Letting yourself off the hook Stresses and full capacity – responsibilities	Letting yourself off the hook
Paula I need to think about myself because if I'm getting stressed and I've got headaches and all those kinds of things and that's when I you know but difficult, yeah, if if if there's lots of stuff building up and needs to be done then you kind of put yourself to the back. Researcher (CB) OK, right. And then what do you think about the idea of being and showing yourself compassion?	**Resistance to self-compassion:** Prioritising others needs **Facilitators to self-compassion:** Learning curve: learnt the signs of stress and when I need to show myself compassion over time, learning curve of the importance of self-compassion Noticing signs I am becoming stressed	A journey to self-compassion
Paula I think it's one of the most important things that people need to do.	**Importance of showing self-compassion:** Compassion is important Vital for wellbeing	Compassion is vital for wellbeing

Appendix R: The number of participants who contributed to each subtheme

Overarching Theme	Subtheme	Participants that contributed to each subtheme within the overarching themes
Compassion "is not one thing"	Self-compassion: "letting myself off the hook"	Donna Hope Jack Sprat Luna Mia Paula Rita
	Shared experiences: "in the same boat"	Donna Hope Jack Sprat Luna Paula
	Professionals: Translated into support	Donna Hope Jack Sprat Luna Mia Paula Rita
	Others: Does not have to be anything big or fancy	Donna Hope Jack Sprat Luna Mia Paula Rita
Identity: me as a caregiver	The "perfect" caregiver	Donna Hope Jack Sprat Luna Mia Paula
	Showing others compassion: a way of life	Donna Hope Jack Sprat Luna Mia Paula Rita
	A journey to self-compassion	Donna Hope Jack Sprat Luna Mia Paula
"It's a whole range of hats you have to wear as a carer"	"I am doing this on top of everything else"	Donna Hope Jack Sprat Luna Mia Paula Rita

	Importance of compassion: “Passing compassion down the line”	Donna Hope Jack Sprat Luna Mia Paula Rita