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Doctoral Thesis

A Qualitative Exploration of Parenting Experiences with Health Conditions

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Word Count

	Main Text	Appendices (including tables, figures and references)	Total
Thesis abstract	(224)	-	(224)
Literature review	7995	9292	17287
Research paper	8000	8948	16948
Critical appraisal	3943	1378	5321
Ethics section	4275	6844	11119
Total	23829	26292	50675

Thesis Abstract

This thesis examines the experiences of parenting with health conditions, specifically that of cancer and Parkinson’s disease. Paper one is a systematic literature review and meta-synthesis of 20 papers which explore the experiences of persons with cancer when informing their children about their parental cancer. The research identified one superordinate theme of ‘protection’ and four themes of ‘deciding’, ‘telling’, ‘impact’ and ‘support’ that described the process of informing. The findings, recommendations for clinical practice and for future research are discussed at the end of this review.

The second paper is a qualitative study that explores the experience of persons with Parkinson’s when parenting adolescents and young adults. Data were generated using semi-structured interviews and analysed using reflexive thematic analysis. The findings identified four themes of: ‘disclosing’, ‘holding on to the parent I was’, ‘changing as a parent’ and ‘an uncertain future’. These themes captured how the changes parents were subject to, began to impact their parental functioning and identity, leaving them worried about the future for their children. Recommendations for clinical practice and future research are also discussed for this paper.

The final paper is a critical review of the above papers, comparing the two sets of findings and discussing the methodology in more detail. It considers the meaning of the work for the researcher and their role in their research process.

Declaration

The research presented in this thesis has been undertaken for the degree of Doctor of Clinical Psychology at Lancaster University. The presented thesis is the author’s own and has not been submitted elsewhere for the award of any other degree or academic award.

Acknowledgements

My appreciation goes out to those living with Parkinson's who took part in the study; your stories were moving and inspiring. I'd also like to thank those at Parkinson's UK and Parkinsons.Me for your guidance in design and recruitment. I hope that the work we created together has a positive impact for other parents living with Parkinson's.

I am deeply grateful for the support provided by my research supervisor Fiona Eccles, without your thorough guidance and patience I could not have completed this work. My sincerest thanks to Anna Daiches, your straightforward advice helped me keep perspective and stay grounded when things seemed complicated. Also to Clare for being an anchor through the doctoral programme.

My appreciation also goes to those in the cohort who helped me along the way, particularly my 'One Day a Week Colleagues' who even through their own challenges always found the time to support me. You've made training an experience I will always look back on warmly.

On a personal level I'd like to firstly thank Emily, your steadfast care and acceptance helped me push through to the end. I'd also like to thank Debbie, Neil and Sam for helping me get here in the first place. Finally, I'd like to thank those in my family who inspired this research, thoughts of you kept me motivated through the difficult moments.

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Section One: Systematic Literature Review

Informing Children about Parental Cancer: A Systematic Review

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Abstract

This paper brings together the evidence that explores the experience of parents informing their children about their diagnosis of cancer. Twenty papers were analysed using thematic synthesis, which identified a superordinate theme of ‘Protection’ and four further analytical themes of ‘Deciding’, ‘Telling’, ‘Impact’ and ‘Support’. Informing children included discussing the diagnosis and its meaning for the parent. Parents consider the benefits of withholding or disclosing information when deciding what to tell, using several techniques to limit the impact on children. Many parents request support from healthcare professionals.

Keywords: Parenting; cancer; communication

Introduction

Cancer is a physical health condition that causes a variety of forms of abnormal cell division in the body and can negatively affect several physiological systems (Miller, 2018), often requiring substantial medical treatments (Ward and van As-Brooks, 2014; Waks and Winer, 2019; West and Stanley, 2011; Wilt et al., 2008). The condition occurs across the life-span, however the likelihood of specific forms of cancer can vary by demographics such as age (Cook et al., 2009; Gurney et al., 1995) or gender (Madeb and Messing, 2004). Global estimates of cancer incidence vary by country, but in places incidence has been found to be over 400 per 100,000 for males and 300 per 100,000 for females (Torre et al., 2016). Globally, the disease results in over 14 million new cases and 8 million deaths annually (Ferlay et al., 2015), contributing to a substantial number of life years lost to mortality and disability (Jayatilleke et al., 2012; Luengo-Fernandez et al., 2012). Whilst cancer negatively impacts physical health, there are also psychological and sociological consequences (Deshields et al., 2014; Harrington et al., 2010; Teunissen et al., 2007); it is therefore important to understand the cancer experience through a biopsychosocial lens.

One area of psychosocial experience which may be affected by cancer is family life (Lopes et al., 2018; Da Silva et al., 2010; Pai et al., 2007; Sales et al., 1992), such as when a parent develops the condition (Buchbinder et al., 2009). In the United States of America estimates predict that approximately 19.5% of persons experiencing a cancer diagnosis will be aged between 20 and 54 (Howlader et al., 2021), a common age to be starting new or living with established families. Estimates in Norway suggest that parental cancer will occur during the family life cycle for around one in 50 families, with a yearly incidence rate of approximately 0.3% (Syse et al., 2012).

A diagnosis of cancer can impact family systems in several areas, and parents report challenges such as fulfilling role expectations (Park et al., 2017; Cho et al., 2015), maintaining family dynamics (Mazzotti et al., 2012) or managing disruptions to routines (Buchbinder et al., 2009). Significant health difficulties may require parents to adapt their parenting approach and make adjustments to daily life or to family roles (Helseth and Ulfsæt, 2005). Experiencing cancer and the subsequent disruption to family life can therefore have an emotional and physical impact on parents (Park et al., 2016; Bekteshi and Kayser, 2013; Helseth and Ulfsæt, 2005), leading to a reduced quality of life (Park et al., 2018; Park et al., 2016). Children of parents with cancer may also experience psychological distress (Morris et al., 2016), something parents make efforts to manage (Stiffler et al., 2008) and report a desire to protect the children (Mazzotti et al., 2012). However, there may also be positive changes within the family with some parents reporting closer relationships (Helseth and Ulfsæt, 2005; Bekteshi and Kayser, 2013). With studies forecasting increasing incidences of cancer, there is a growing need for healthcare provision (Smittenaar et al., 2016). Given the number of families experiencing cancer it is important health and social care systems understand the experience to provide adequate support.

A significant part of the parental experience of health conditions may be how parents inform their children of the condition. Informing not only includes a name and description of the condition but also what that means in terms of parental experience and progression. When viewed through a lens of social constructivism, the verbal and experiential information communicated from parent to child helps shape a shared understanding of the condition. In turn, this may influence how the condition is experienced within the parent-child dyad. The limited available evidence suggests that this process may not be straightforward. A systematic synthesis of 32 qualitative and quantitative research papers by Oja et al. (2020) explored how interventions supported the process of informing children about parental health concerns across several conditions. Although a majority of the research was focused on parental psychological distress or substance misuse, a smaller number of papers focused on physical health conditions such as cancer and HIV. The review identified a range of benefits; however it was also clear that parents experienced difficulty with knowing how best to disclose information, and felt emotions such as shame or guilt. The review includes research focused on parental cancer; however it is unclear how disclosure is experienced specifically in this group. Although there may be similarities between conditions, differences in the effects of each condition, prognoses, treatments, and societal stigma creates the possibility for parents to take different approaches to informing. A systematic review by Matuszczak-Świgoń and Bakiera (2021) which explores the general parental experience of cancer identified a theme related to disclosure in its findings. This theme was centred on the difficulty parents faced in finding the balance between protecting the child from “overburden” and finding a rational approach to integrating cancer into family life. The paper also discussed a communication style of clarity as a coping strategy; highlighting the importance of selecting and adjusting information based on the child as an individual. However, informing the children about parental cancer was not the focus of this review and therefore it did not report on the process in detail. Additionally, given the broad focus on all parental cancer experiences, screening and selection of data may have excluded relevant information about informing children about parental cancer from the wider literature. Consequently, this review aims to answer the question how do parents with cancer experience informing their children about health-status. In this sense health-status captures the parents’ diagnosis, experience of the condition and what it means for treatment and prognosis.

Method

Design

Although there is a range of literature that explores the experiences of parents with cancer, only a small amount of research focuses on informing children about the diagnosis or health experience (Matuszczak-Świgoń and Bakiera, 2021). However, several papers capture parts of the informing experience within their broader analysis. To answer the research question, this review uses a meta-synthesis approach that aims to bring the research together, highlighting the differences and similarities between the studies (Tong et al., 2012). A qualitative synthesis therefore provides the analytical framework to capture the breadth of experiences facilitating a more complete and higher-order understanding which would not be accessible by reading the papers individually (Sandelowski et al., 1997; Cherry et al., 2014). Although a range of approaches to synthesis exist (Barnett-Page and Thomas, 2009), given the mixture of semantic and latent analysis approaches within the papers, a thematic synthesis approach was selected (Thomas and Harden, 2008). This approach aims to stay ‘close’ to the original data in early analysis through semantic coding and ‘translation’. Translation allows for the development of singular codes that capture similar sentiment from a mixture of analytical methods and reporting styles. Only when this phase of analysis is complete are more interpretative analytical themes developed.

Search Strategy

In order to detect all relevant literature, search terms were broad and aimed at capturing the experiences of parents with cancer. The following psychology, sociology and medical databases were searched for relevant literature: CINAHL, Embase, Medline, PsychInfo & SocIndex. A list of key words and phrases were developed, cross-referenced with database thesauri and reviewed in consultation with an academic librarian. The following search terms were generated and searched for in subject headings and free text: Cancer* OR Carcinoma OR Neoplasm Or Oncology, Parent* OR Mother* OR Father* OR Care giv* OR guardian* and, Qualitative Or Interview Or Focus Group Or Survey. The complete search strategy can be found in Table 1-1. Additionally, the reference lists of included journal articles were searched and titles reviewed for relevance.

[Table 1-1 about here]

Eligibility Criteria

Studies were only included if they were published in English in peer reviewed academic journals. These studies were included if they used data collection methods of interviews, focus groups or surveys to capture qualitative data that was relevant to the research question; at least one clear theme or sub-theme (or equivalent portion of text) had to focus on the informing process. All papers were required to have participants over the age of 18 who had been diagnosed with cancer whilst parenting at least one child or young adult aged under 26. This age range was selected to capture the experience across family life cycles. An upper limit of 25 was selected as in some cultures such as in the UK children are increasingly living with parents for longer periods of time (ONS, 2021). This extends the phase of the family life cycle typically found in the late teens. Furthermore, there is an increasing understanding of the continued neuropsychological development into a person's twenties (Blakemore and Choudhury, 2006; Stiles and Jernigan, 2010). Papers were excluded if there was no clear distinction in the analysis between the experiences of parents and non-parents or between parents and children. Additionally, papers were excluded that included parents diagnosed with a primary disease other than cancer. No exclusion criterion was set with regards to the type of cancer diagnosis. Papers were excluded if they investigated a specific intervention or service.

Screening

Searches recovered 24220 papers of which 6640 duplicates were removed, leaving 17580 papers to be screened by title then abstract. Full texts were retrieved for 140 potentially relevant or ambiguous papers. These texts were screened by the inclusion and exclusion criteria detailed above, leaving 20 papers in the final analysis. The screening process and number of papers excluded at each stage with reasons is outlined in Figure 1-1 below.

[Figure 1-1 about here]

Quality Assessment

To review the quality of the each paper included in the analysis, the Critical Appraisal Skills Programme (CASP) checklist was used (Critical Appraisal Skills Programme, 2021) which consists of a three point assessment system that considers the clarity of methodology. Additionally a scoring mechanism introduced by Feder et al. (2006) as used in Duggleby et al. (2012) which ranged questions from 1 (little information), via 2 (moderate information) to 3 (detailed information) was used to rate each article. Ratings were conducted by the primary researcher, then cross-referenced and discussed with a fellow trainee clinical psychologist. Scores ranged from 14 to 23, a complete list of scores can be found in Table 1-2. The CASP was used to identify the quality of each article in order to scrutinise the weighting of its contribution to the analysis. As studies with a lower rating may meaningfully contribute to findings, the CASP score was not used as a method of exclusion (Bondas & Hall, 2007; Sandelowski, 2006).

[Table 1-2 about here]

Synthesis

Thematic synthesis (Thomas & Harden, 2008) allowed for semantic coding, followed by the formation of descriptive and higher order analytical themes based on the research question. Data consisted of any information relevant to the research question within the analysis section of the papers including direct participant quotes. Additionally, data was also taken and synthesised from clear reporting of results within the discussion section (Thomas & Harden, 2008). The inclusion of the discussion was chosen as it could expand on the analysis in a way that had not been mentioned specifically within the findings.

The synthesis included the following stages: coding and translation, organisation of codes into descriptive themes and the development of analytical themes. Each study was line-by-line coded by the primary researcher in a manner that remained close to the original data (Appendix 1-B). Codes were cross-referenced for consistency and additional coding was completed as relevant. This process created a total of 41 codes which were reviewed for similarities or differences before being organised into a hierarchical structure of descriptive themes. The descriptive themes were considered in relation to the research question to develop analytical themes. Analytical themes were discussed with research supervisors and refined until they captured the essence of each theme. A table of which papers and codes contribute to each theme is included in Appendix 1-C. The quality and focus of contributing papers with regards to each theme was reviewed in order to establish which papers had a greater impact on the final results and to ensure that all themes were supported by the stronger papers.

Results

Characteristics

The final analysis included 20 studies, five of which were focused on exploring the process of parents informing children about parental cancer whilst 15 discussed this process in part. Eighteen studies gathered data using face-to-face individual interviews only, whilst one used focus groups (Davey et al., 2012), and one used a combined focus group and individual interview approach (Loggers et al., 2019). In the analyses, researchers applied principles from grounded theory (Glaser & Strauss, 2017), thematic analysis (Braun & Clarke, 2012), Colaizzi's phenomenological method (Colaizzi, 1978), and interpretive phenomenological analysis (Smith et al., 2009).

Participant numbers ranged from 6 to 47, with 14 papers including women only (Turner et al., 2007; Coyne and Borbasi, 2006; Asbury et al., 2012; Lalayiannis et al., 2018; Loggers et al., 2019; Chin et al., 2020; Shands et al., 2000; Fisher and O'Connor, 2012; Stiffler et al., 2008; Barnes et al., 2000; Strickland et al., 2015; Kim et al., 2012; Kenne Dornel et al., 2018; Fitch et al., 1999), one paper including men only (Elmberger et al., 2002) and the five remaining papers including a mixture of these two genders. Eleven of the papers included participants with breast cancer only (Davey et al., 2012; Turner et al., 2007; Coyne and

Borbasi, 2006; Asbury et al., 2012; Lalayiannis et al., 2018; Chin et al., 2020; Shands et al., 2000; Fisher and O'Connor, 2012; Stiffler et al., 2008; Barnes et al., 2000; Kim et al., 2012), whilst the remaining papers included various forms of cancer across different stages. Children's ages ranged from 0 to 25 years, with a majority of papers covering a wide range of ages. Of the included studies eight were located in North America (Davey et al., 2012; Rashi et al., 2015; Loggers et al., 2019; Shands et al., 2000; Stiffler et al., 2008; Strickland et al., 2015; Houldin and Lewis, 2006; Fitch et al., 1999), five in Europe (Barnes et al., 2000; Elmberger et al., 2002; Lalayiannis et al., 2018; Asbury et al., 2012; Semple and McCance, 2010), three in Asia (Chin et al., 2020; Wang et al., 2020; Kim et al., 2012), three in Australia (Fisher and O'Connor, 2012; Coyne and Borbasi, 2006; Turner et al., 2007) and one in Brazil (Kenne Dornel et al., 2018). A summary of study characteristics can be found in Table 1-3.

[Table 1-3 about here]

Findings

Although occasionally children were present when parents learned of their diagnosis, the majority of parents were made aware of their cancer status before their children. When parents were made aware first, they recognised the significance of being positioned between the cancer experience and their children, facing difficult decisions about communicating cancer-related information. It was clear that the act of informing children about parental cancer was not a single verbal event but an ongoing process that occurred across several interactions which unfolded in varying ways for each parent.

The synthesis identified that within the experience of informing children there was a higher-ordinate theme of 'protection', which was at the core of four themes of 'deciding', ‘telling’, ‘impact’ and ‘support’ that captured the phases of the informing process. It is important to acknowledge that these phases were not necessarily a single linear process but due to the ongoing nature of informing, each theme could occur several times across the family’s experience and in a non-linear fashion. The contributing papers and codes to each theme are captured in Appendix 1-C and the themes are described in detail below.

Protection

Across all studies but one (Fisher and O'Connor, 2012), parents consistently described an underlying desire to protect their children from the impact of learning about parental cancer throughout the decision-making and informing process. Protection in this sense was the desire to do what was best for their child’s wellbeing by preventing them from experiencing harm or distress when being informed. When considering how to manage informing the children, parents framed the acts of disclosing (Loggers et al., 2019; Fitch et al., 1999; Rashi et al., 2015; Wang et al., 2020; Barnes et al., 2000; Lalayiannis et al., 2018; Turner et al., 2007; Kim et al., 2012; Davey et al., 2012; Semple and McCance, 2010; Chin et al., 2020; Stiffler et al., 2008; Kenne Dornel et al., 2018; Strickland et al., 2015; Shands et al., 2000), and withholding (Rashi et al., 2015; Wang et al., 2020; Barnes et al., 2000; Lalayiannis et al., 2018; Turner et al., 2007; Kim et al., 2012; Davey et al., 2012; Semple and McCance, 2010; Chin et al., 2020; Stiffler et al., 2008; Kenne Dornel et al., 2018; Strickland et al., 2015; Asbury et al., 2012; Houldin and Lewis, 2006; Elmberger et al., 2002; Coyne and Borbasi, 2006) of cancer related information as protection.

> “I think it was just, trying to protect them for a bit longer, it’s a mother’s reaction, I just wanted to protect them for as long as I could” (Asbury et al., 2012, p.566).

Protection as an underlying motivation was present across a variety of parent and child demographics such as age, gender, culture, types of cancer, and severity of diagnosis. Although the literature reported an eventual tendency for parents to decide to tell their children, this was not the case for all parents (Wang et al., 2020; Loggers et al., 2019). For those who did disclose information, what was shared or how this was done varied, but always with protection at the heart. Parents were aware of the potential impact of informing children and were reluctant to become the cause of harm; therefore they aimed to shield them from negative outcomes as they disclosed. As they disclosed, parents witnessed childrens' responses and the dyad was subject to relational consequences. These responses and impact on the relationship could alter the parents' assessment about how best to protect as they continued to inform. Throughout this process parents could feel under-supported in carrying the burden of informing, requesting more help and information from organisations and healthcare professionals to ensure they protected their children as best they could. The detail of this process is explored in the themes below.

Deciding

Protecting children required a decision about how much information to disclose, or withhold, and when to do this. Parents were unsure what balance was best and in making this decision they weighed up benefits and costs, whilst considering their individual contextually-specific information.

One important aspect of decision making was how well parents were informed about their cancer. Parents who felt like they did not have all the facts felt uncertain about the present or how cancer would progress. This uncertainty could occur across the cancer experience, such as during the process of diagnosis, in treatment plans or when considering prognosis, leading parents to worry about what to tell their children or how to answer questions (Turner et al., 2007; Kenne Dornel et al., 2018; Barnes et al., 2000; Loggers et al., 2019; Wang et al., 2020; Shands et al., 2000). Uncertainty was influential when deciding if and what information they should share (Asbury et al., 2012; Loggers et al., 2019; Stiffler et al., 2008; Wang et al., 2020), with some delaying disclosure until they felt more confident about the information they had (Asbury et al., 2012; Barnes et al., 2000; Semple and McCance, 2010)

> "…I only told the kids when it was actually confirmed that it was cancer." (Asbury et al., 2012, p.568).

Parents valued honesty and openness in their relationships with their children, which pulled them towards disclosure (Davey et al., 2012; Turner et al., 2007; Asbury et al., 2012; Stiffler et al., 2008; Loggers et al., 2019; Semple and McCance, 2010; Rashi et al., 2015; Kim et al., 2012; Coyne and Borbasi, 2006). For some this was connected to a sense that children had a right to know about parental cancer (Kenne Dornel et al., 2018; Strickland et al., 2015; Barnes et al., 2000), whilst others predicted that if children were not informed openly it would have a detrimental impact on their current or future relationship (Turner et al., 2007; Barnes et al., 2000; Loggers et al., 2019). Therefore, parents thought that an honest approach could allow them to maintain trust within and strengthen the relationship (Turner et al., 2007; Semple and McCance, 2010; Kim et al., 2012).

> "I made the decision that I had to be honest with the children because if things went wrong or there were problems in the future and they found out I hadn't told them the truth they would lose trust in me. They would feel betrayed, and wonder if they

> could believe what else I said to them. Trust is so important." (Turner et al., 2007, p.138).

Additionally, parents thought that disclosure could act as a teachable moment, which would help children mature, but more commonly prepared them for the likelihood of a difficult experience or parental death (Chin et al., 2020; Loggers et al., 2019; Lalayiannis et al., 2018; Rashi et al., 2015; Wang et al., 2020; Barnes et al., 2000; Kenne Dornel et al., 2018; Shands et al., 2000).

The pull towards disclosure was balanced by the consideration that it may cause harm and, therefore withholding would 'shield' children from any negative outcomes (Davey et al., 2012; Houldin and Lewis, 2006; Asbury et al., 2012; Wang et al., 2020; Coyne and Borbasi, 2006). Across the literature, there were particular concerns that the awareness of cancer would have a detrimental emotional impact on children (Houldin and Lewis, 2006; Kenne Dornel et al., 2018; Barnes et al., 2000; Semple and McCance, 2010; Rashi et al., 2015; Wang et al., 2020; Shands et al., 2000) and parents were worried about disruption to their children's' education (Houldin and Lewis, 2006; Strickland et al., 2015; Lalayiannis et al., 2018; Kim et al., 2012; Wang et al., 2020), social life (Houldin and Lewis, 2006) or to important cultural events (Barnes et al., 2000).

> "I am not going to tell my daughters my true diagnosis, they should live a happy childhood. Besides, my elder daughter will take the entrance exams to university next year, so I don't want to bother her studies with my disease either." (Wang et al., 2020, p.5).

A commonly noted consideration across cultures and contexts when deciding if and how to inform children, was seeing the child as an individual (Stiffler et al., 2008; Davey et al., 2012). Parents reflected on the demographic variables which they felt would influence how their child experienced being informed, such as age, gender or personality (Kenne Dornel et al., 2018; Strickland et al., 2015; Asbury et al., 2012; Lalayiannis et al., 2018; Barnes et al., 2000; Semple and McCance, 2010; Chin et al., 2020; Kim et al., 2012; Davey et al., 2012; Wang et al., 2020; Shands et al., 2000). .

> "She's quite inquisitive, she likes to know everything…why, when, how, which I think is good and I'd never hold back, I would tell her you know."(Asbury et al., 2012, p.567).

Parents tended to disclose information more fully to older children, and those with younger children often planned to disclose as they matured. Parents reported a sense that older and more mature children could more easily understand information and would be more prepared to cope as individuals (Kenne Dornel et al., 2018; Strickland et al., 2015; Asbury et al., 2012; Lalayiannis et al., 2018; Semple and McCance, 2010; Chin et al., 2020; Rashi et al., 2015; Wang et al., 2020; Shands et al., 2000). However, in a Taiwanese study parents felt older children would worry more compared to those under 10, due to understanding the meaning of cancer, despite this parents remained more willing to disclose to older children (Chin et al., 2020). In addition to children's individuality, parents also considered factors within the family such as communication styles, relationships or past experiences (Kenne Dornel et al., 2018; Asbury et al., 2012; Lalayiannis et al., 2018; Wang et al., 2020).

Telling

The information used to decide if parents should inform children was also used to decide how to inform them, although many parents felt unsure how best to do this (Semple and McCance, 2010; Loggers et al., 2019; Stiffler et al., 2008; Wang et al., 2020; Houldin and Lewis, 2006). They considered and made use of several methods which allowed them to attempt to control how receiving cancer information was experienced.

Parents filtered the factual content of information to suit what they perceived was in the child’s best interest. For some this meant limiting the information (Lalayiannis et al., 2018; Chin et al., 2020; Wang et al., 2020; Shands et al., 2000) whilst for others it meant as much disclosure as parents were able at each stage (Stiffler et al., 2008; Davey et al., 2012; Shands et al., 2000). Some parents named cancer whilst leaving out some factual detail, specifically any they predicted would cause distress or children would not understand (Turner et al., 2007; Strickland et al., 2015; Chin et al., 2020; Rashi et al., 2015). For others there was a hesitancy to name cancer, preferring to describe it as a general illness whilst detailing the effect on their body (Strickland et al., 2015; Elmberger et al., 2002; Barnes et al., 2000; Chin et al., 2020; Wang et al., 2020). Hesitancy in naming cancer could be due to stigma and preconceived ideas that cancer was terminal, which in the parents’ view would inevitably create unhelpful worry (Turner et al., 2007; Kim et al., 2012; Wang et al., 2020).

> “I have told them it is a serious illness and a tough situation but we did not use the word cancer. They have not had any questions yet, and I do not want to complicate things for them. If you only breathe the word cancer they jump high. They know that I have an illness in my blood, that I have been awfully ill and they my hair has fallen out but that it will grow again and that I will be healthy again.” (Elmberger et al., 2002, p482).

When giving factual detail, parents attempted to simplify the information to make it easier to understand with some doing this by using more basic language and others using simile or metaphor (Kenne Dornel et al., 2018; Turner et al., 2007; Strickland et al., 2015; Asbury et al., 2012; Chin et al., 2020; Rashi et al., 2015; Davey et al., 2012; Fitch et al., 1999). Parents also attempted to frame information in a positive manner in order to communicate a message of hope or reassurance. They did this by focusing on treatment options, parental survivorship and children's safety (Turner et al., 2007; Kenne Dornel et al., 2018; Elmberger et al., 2002; Asbury et al., 2012; Stiffler et al., 2008; Lalayiannis et al., 2018; Barnes et al., 2000; Semple and McCance, 2010; Rashi et al., 2015; Davey et al., 2012; Shands et al., 2000). Focusing on the positive also led to some parents creating hopeful messages for children even when they themselves recognised that outcomes were unknown and their message may not be true.

> "The children have asked if I am going to die. I have said 'No', and that I am having the best possible treatment so that the cancer won't come back. This has been a considered decision as there is so much uncertainty about future treatment developments and given a solitary metastasis this may not happen. The hardest things is feeling that I can't be completely honest. A sense of it being too painful to implant in their mind, distress about something that may not happen, and even if it does the time frame is very uncertain. I don't know the timing of it." (Turner et al., 2007, p.139).

In several studies, parents also highlighted the importance of normalising the experience, which could be achieved by delivering the message in a casual manner or framing the experience as an expected part of everyday life (Asbury et al., 2012; Stiffler et al., 2008; Chin et al., 2020).

> "They worry because you make them worry…so I want my children to know that the illness is an event, neither too big nor too little. It's the way it is, an event that we experience together" (Chin et al., 2020, p.3).

Across cultures, many parents made a conscious decision to filter out information about parental emotional experiences such as their own distress, which could present as putting on a 'strong front'. They did this with the intention of avoiding adding to children's worries (Strickland et al., 2015; Asbury et al., 2012; Lalayiannis et al., 2018; Kim et al., 2012; Davey et al., 2012; Coyne and Borbasi, 2006; Shands et al., 2000). Although talking about parental feelings was rare (Shands et al., 2000), in the Korean study parents felt it was important to allow children to learn about parental vulnerability (Kim et al., 2012).

Informing children did not only happen verbally but also visually and for some parents and this form of disclosure was selected deliberately (Kenne Dornel et al., 2018; Shands et al., 2000). For example, in Taiwan the cultural practice of bathing with children allowed parents to reveal their scars in a normalised manner. These moments invited opportunities for children to learn about what their parent was experiencing (Chin et al., 2020).

> "Like for my scar, when we took a shower together, my boy asked 'mom, how come your breast is gone?' I said 'it was broken, so I cut it off.'" (Chin et al., 2020, p.3).

However, for many parents visual disclosure was not deliberate and as cancer progressed physical or lifestyle change occurred, children witnessed changes such as hair loss, scars or disrupted daily routines (Kenne Dornel et al., 2018; Strickland et al., 2015; Elmberger et al., 2002; Asbury et al., 2012; Barnes et al., 2000; Semple and McCance, 2010; Wang et al., 2020; Shands et al., 2000). Parents attempted to conceal these changes (Strickland et al., 2015; Asbury et al., 2012; Wang et al., 2020), however when that was not possible, they could have reduced control over the informing process (Lalayiannis et al., 2018).

> "I didn't want to tell my son about my cancer diagnosis at the beginning, because I wouldn't like to trigger any negative influence on him. However, after several cycles of chemotherapy, he gradually realised what kind of disease I developed. I realised that concealing was impossible so we broke the news slowly." (Wang et al., 2020, p.7)

Impact

After deciding if and how to inform children a significant part of the parental experience was witnessing the emotional impact. Parents' perceptions were that children could experience psychological and physical distress in response to being informed (Elmberger et al., 2002; Lalayiannis et al., 2018; Wang et al., 2020; Coyne and Borbasi, 2006).

> "…she's actually shown the signs of stress, her hair's gone white so I know it's affected her a lot more than I had thought it had…" (Lalayiannis et al., 2018, p.1229)

Not only was the emotional impact difficult for the children themselves, but studies acknowledged how children's emotions affected the parent as they were left with the additional responsibility of responding to reactions creating additional burden during an already difficult time (Elmberger et al., 2002; Stiffler et al., 2008; Wang et al., 2020).

The impact of informing children was not always clear as some children withdrew or avoided conversation, making it difficult for parents to know if they were telling children in a way that aligned to their aim of protection (Kenne Dornel et al., 2018; Stiffler et al., 2008; Barnes et al., 2000). For some, disclosure was positive and strengthened relationships (Kenne Dornel et al., 2018). Disclosure also allowed for open dialogue and parents were therefore able to monitor children's reactions to information, which made it easier for parents and children to support each other (Davey et al., 2012; Lalayiannis et al., 2018).

> "I think it's brought us a lot closer…this time around you know, than what we were." (Lalayiannis et al., 2018, p.1230).

It was not only disclosing that had an emotional impact, but withholding also had consequences. Withholding created time for children to notice change and therefore opened up opportunities for uncertainty within the children themselves. Parents felt that this invited the possibility for children to begin to guess what was wrong, creating additional and unnecessary worry (Barnes et al., 2000; Semple and McCance, 2010; Wang et al., 2020). In response, parents felt more convinced that disclosure of a difficult truth to relieve distress was more appropriate for their children than living with worrying uncertainty (Davey et al., 2012; Stiffler et al., 2008; Kim et al., 2012; Wang et al., 2020).

> "I used to be concerned about her mood and emotion; she is sensitive and curious about my leaving home for so many days. It's better to tell her than to let her guess and worry." (Wang et al., 2020, p.7).

Support

Many parents reported asking for information or support from professionals during their cancer experience (Wang et al., 2020; Shands et al., 2000). In many studies parents felt unsure about the process of informing, reporting that the information they were given to guide them was inadequate, with some receiving little to no support at all. Inadequate support was reported in both the generic information offered by organisations, such as leaflets or books, and in individual discussions with professionals, such as with medical staff (Turner et al., 2007; Fisher and O'Connor, 2012; Semple and McCance, 2010; Rashi et al., 2015; Coyne and Borbasi, 2006). This left parents feeling they were without guidance in finding the right way to inform their children (Turner et al., 2007). In response to experiencing inadequate support, parents understandably requested more opportunities for specific assistance from services and organisations (Turner et al., 2007; Barnes et al., 2000; Semple and McCance, 2010; Rashi et al., 2015; Wang et al., 2020).

> *"We just didn't know what we were doing…from a parental point of view, I would have liked access to someone and sit with me and say 'Right this is how it is…' and I would have liked some guidance on how to actually tell a child."* (Semple and McCance, 2010, p.1284).

Although a majority of these requests were for more information directly to the parent (Barnes et al., 2000; Semple and McCance, 2010), some parents specifically requested that health care professionals work directly with children to better inform them about cancer (Barnes et al., 2000; Wang et al., 2020).

> *'Moreover, they would prefer that healthcare providers give children a science education on cancer and coping, by lectures or other forms of communication.'* (Wang et al., 2020, p.9).

In a minority of papers parents felt they were prepared to tell their children and did not need additional help (Rashi et al., 2015; Lalayiannis et al., 2018), with those parents who were experiencing cancer for the second time citing it was the significant previous experience of the disease which allowed them to feel prepared (Lalayiannis et al., 2018). Parents with secondary cancer however, continued to request emotional support for children dealing with the consequences of being informed.

> *'…all women said they did not need help or support in telling them, but almost half the women talked about wanting support specifically for their children…'* (Lalayiannis et al., 2018, 1229).

Discussion

The aim of this systematic review was to collate and synthesise the existing data which explores parents' experiences of informing their children about their parental cancer. The systematic search identified 20 published journal articles which contributed to the final thematic synthesis. The analysis outlined themes within the experience of informing children which highlight why a decision to inform is made and how it may occur within the parent-child dyad. Informing children not only captured the transfer of information about diagnosis status but also the understanding of what this meant in terms of present and future lived experiences.

The superordinate theme from the synthesis was protection; parents' aimed to protect children by preventing or reducing the harmful impact of learning about the parental cancer experience. Whilst parents' desire to protect children from the impact of parental cancer has been previously identified when considering the whole cancer experience (Siegel et al., 1999) this synthesis highlights how protecting their children specifically underpins the process of informing.

As parents learn about their own cancer they are typically placed into the position of withholding information from the children, from which they are then faced with the option to disclose, needing to decide when and how they should do this. When informing, parents with cancer weigh up the expected rewards and potential costs of disclosing or withholding. As seen in parents with HIV (Qiao et al., 2013), those with cancer experience concern that knowing about parental ill health could be harmful, predicting that disclosure would result in psychological distress for children and subsequent disruption to education or important family events. Parental concerns about distress are supported in a study by Huizinga et al. (2005b) who found that children who perceive parents to be more seriously ill experience increased levels of stress. However, as disclosure is not only verbal but also visual, if parents choose to withhold information, they must also attempt to conceal any physical, emotional or life-style changes. Attempts to do this whilst parenting as usual can create additional physical or psychological burden (Siegel et al., 1999), and therefore withholding is at parents' own expense. Furthermore, attempts to conceal non-verbal information may also be in vain as children report noticing change and can suspect serious illness and when this occurs without explanation it leaves children feeling excluded from family (Forrest et al., 2006).

Parents also consider the potential rewards of disclosure, predicting that if done in an open and honest way, it will protect the future relationship and protect children from negative outcomes. Research supports these predictions as children have been found to experience worse psychological outcomes when parents struggle to communicate openly about their cancer (Huizinga et al., 2005a; Harris and Zakowski, 2003; Nelson et al., 1994).

Although expected outcomes are considered in decision-making models such as the theory of planned behaviour (TPB; Ajzen, 1991), a perhaps more specific cost-reward appraisal process relevant here is proposed in protection motivation theory as this captures parental assessment of potential harm or reward to the child, the parent themselves and the relationship (PMT; Rogers, 1975). In PMT, the potential rewards of a behaviour (e.g. the status quo which can be maintained by not telling) are balanced against the perceived vulnerability to negative consequences (e.g. whether the child would be upset by not knowing and finding out later). At the same time, there is a balancing of beliefs that an alternative method of action (e.g. telling) will be beneficial against the potential costs of that action (e.g. the child will be upset knowing about parental cancer). Although originally formed as a theory of individual decision making when considering personal (health-related) threats, it has since been applied to parenting contexts (Boniel-Nissim et al., 2020; Beirens et al., 2007; Norman et al., 2003). More specifically, appraisal of alternative methods of action have been shown to play a role in how parents communicate with children about perceived threat (Campis et al., 1989). Despite PMT capturing the process parents undertake in appraising benefits and harms of potential action, it was originally constructed to outline the decision-making between a current behaviour that is understood or perceived to be harmful (e.g. smoking) and a clear beneficial alternative. For parents with cancer both withholding and disclosing could be perceived as harmful or beneficial meaning the model would need to be utilised more flexibly.

The weighing up of disclosing and withholding is also informed by parents’ access to a variety of information. The consideration of external sources of information in decision making has been documented in several theories of behaviour, including PMT and the Reasoned Action Approach (Fishbein and Ajzen, 2010). The information considered by parents includes written resources provided by services (e.g. charity website information) and through conversations with healthcare professionals. Parents also considered specific knowledge about their children, such as gender, personality, and age. As reported by parents with HIV (Qiao et al., 2013), parents with cancer disclose more detail to children as they get older, a strategy supported by Ellis et al. (2017) who found that children’s information needs change as they age.

Confidence in a person’s own ability to enact certain behaviours successfully has been termed self-efficacy (Bandura, 1977). The importance of self-efficacy for behavioural decision making is demonstrated by its contribution to behavioural models such as PMT, the TPB and the Health Action Process Approach (HAPA; Schwarzer and Luszczynska, 2008) Parents with cancer highlight the role of self-efficacy when making decisions about how to inform their child, questioning their own disclosure skills and ability to answer questions. Not only has self-efficacy in parents been shown to influence parenting behaviour but also outcomes for children across a broad range of contexts (Jones and Prinz, 2005). Self-efficacy may therefore be an important factor in determining how the informing process is experienced within the dyad and the potential outcome for children.

Due to the evolving nature of the parental cancer experience and a developing child the informing process is one that occurs over time. This gives parents the opportunity to witness the impact of their choices which may alter their appraisals of the methods they used and their own self-efficacy subsequently informing future decision making. The impact may be positive or negative, in some dyads parents reported strengthened relationships, whilst other children become avoidant or distressed. The iterative nature of this process is not captured in behavioural models such as PMT or HAPA and may be better understood through theories of learning such as Kolb's learning cycle (Kolb, 2014), which proposes that in an on-going and circular manner, people's experiences allow for critical reflection then conceptualisation to inform future behaviour.

Limitations and Future Research

This systematic review identified 20 papers eligible for review, however the identification of these papers was made more difficult due to a lack of clear definition in search terms or article titles between research that explored the experiences of parents who were diagnosed with cancer and parents whose children were diagnosed with cancer. The introduction of methods by journal publications and databases to easily distinguish between these two circumstances would be to the benefit of those conducting systematic reviews.

Of the 20 included papers in the review, only five focused on informing children about parental cancer. Two of the five had some of the lowest CASP scores in the analysis however the analysis was strengthened through triangulation via the inclusion of higher quality papers that in part focused on informing. Of the studies included in the synthesis, 14 targeted the experience of mothers whilst only one targeted the experience of fathers (Elmberger et al., 2002), although five included fathers (Davey et al., 2012; Rashi et al., 2015; Semple and McCance, 2010; Wang et al., 2020; Houldin and Lewis, 2006). Only one of the papers including fathers had a research question focused on informing children and the single paper that focused on fathers had a small amount of related data. The bias in gender in the research and therefore this synthesis does not represent the estimated proportion of families who have a mother diagnosed with cancer (56%) and a father diagnosed with cancer (44%) (Syse et al., 2012). The synthesis therefore underrepresents fathers in its analysis who may experience significant differences in their cancer experience (Wessels et al., 2010; Clarke et al., 2006) and informing others (Hilton et al., 2009). Although protection as a superordinate-theme can be found in the paper which focuses on fathers (Elmberger et al., 2002), this paper does not contribute to the themes of *Deciding* or *Support.* Future research should focus on father's experiences of informing children, particularly in their experiences of organisational and professional support.

Research suggests that the experiences of single parents with cancer may be more difficult than those who are in a relationship (Lewis et al., 1996). Although, some studies in this synthesis included single parents, they were often a minority and no studies exclusively focused on this group. The low numbers of single parents recruited in included studies may have meant that specific experiences were not identified in their analyses and therefore this synthesis is unable to consider the potential differences. Future research exploring the experiences of single parents would better inform clinical practice when supporting this group.

The potential differences in type and severity of cancer may result in a wide range of experiences or impairment for those with the condition. Given the potential for the large range of consequences for daily life, it is likely that these differences influence how parents inform children. Although there was variation in type and severity of cancer across the available research, studies often included a range of diagnoses making it difficult to evaluate how variation affects communication. Therefore a greater depth of research that targets specific type and severity whilst considering the influence of intersectional psychosocial factors is needed to develop the findings of this review.

Clinical Implications

Although many parental cancer interventions documented in the academic literature are those which target communication between parents and children (Inhestern et al., 2016), this review identified that parents find it difficult to access information about communication, suggesting the interventions are not widely available in healthcare systems. Services should therefore consider ensuring training and access to appropriate interventions are available.

Uncertainty about their cancer influences parental decision making when informing children about their health and those who are better informed may find it easier to disclose information and respond to questions. Although many charitable and health organisations offer written information about cancer and informing children (American Cancer Society, 2016; MacMillan, 2019), parents did not feel this covered the range of information they needed. Parents specifically request that written communication should offer more detail that explores a wider range of potential experiences. Parents feel that healthcare staff avoid or do not provide opportunities to discuss how to inform children, leaving parents feeling abandoned. Therefore written information should be offered in parallel to appointments with suitably trained staff who can discuss the specific context of each parent's situation and the process of informing children as individuals. As much of the decision making process is individual to the systemic context and individual variables in the family, there may be no 'right' way to inform children. Therefore, parental decision making could be facilitated in a reflective space provided by health professionals with the aim of improving self-efficacy in communication skills and preparation for emotive family moments. As the informing process is one that is ongoing, interventions should be offered throughout the parental cancer experience.

Conclusion

This synthesis of the literature explores the experiences of parents with cancer when informing their children about their condition. It highlights parent's overall aim to protect their children from any harmful impact of learning of parental ill health and the process they undertake to achieve this. The review includes discussion about elements of the process of informing including: parental decision making, strategies used by parents, experiencing the impact of informing and experiences of professional support. Efforts should be made to improve access to a wider range of information and healthcare professionals should provide opportunities to specifically discuss informing children. Future research is needed to understand this experience in more depth, particularly for fathers and single parents.

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Table 1-1. Search Terms

Key Concepts [a]	Search Terms	Subject or Free Text	Data Bases Searched
Concept 1	Cancer* OR Carcinoma OR Neoplasm Or Oncology	Free Text	CINHAL, Embase, Medline, PsychInfo & SocIndex
Concept 2	Parent* OR Mother* OR Father* OR Care giv* OR guardian*	Free Text	
Concept 3	Qualitative Or Interview Or Focus Group Or Survey	Subject	

[a] Combined subject and free-text search terms using concepts = [1] AND [2] AND [3] AND

Figure 1-1. PRISMA Flow Diagram (Moher et al., 2009)

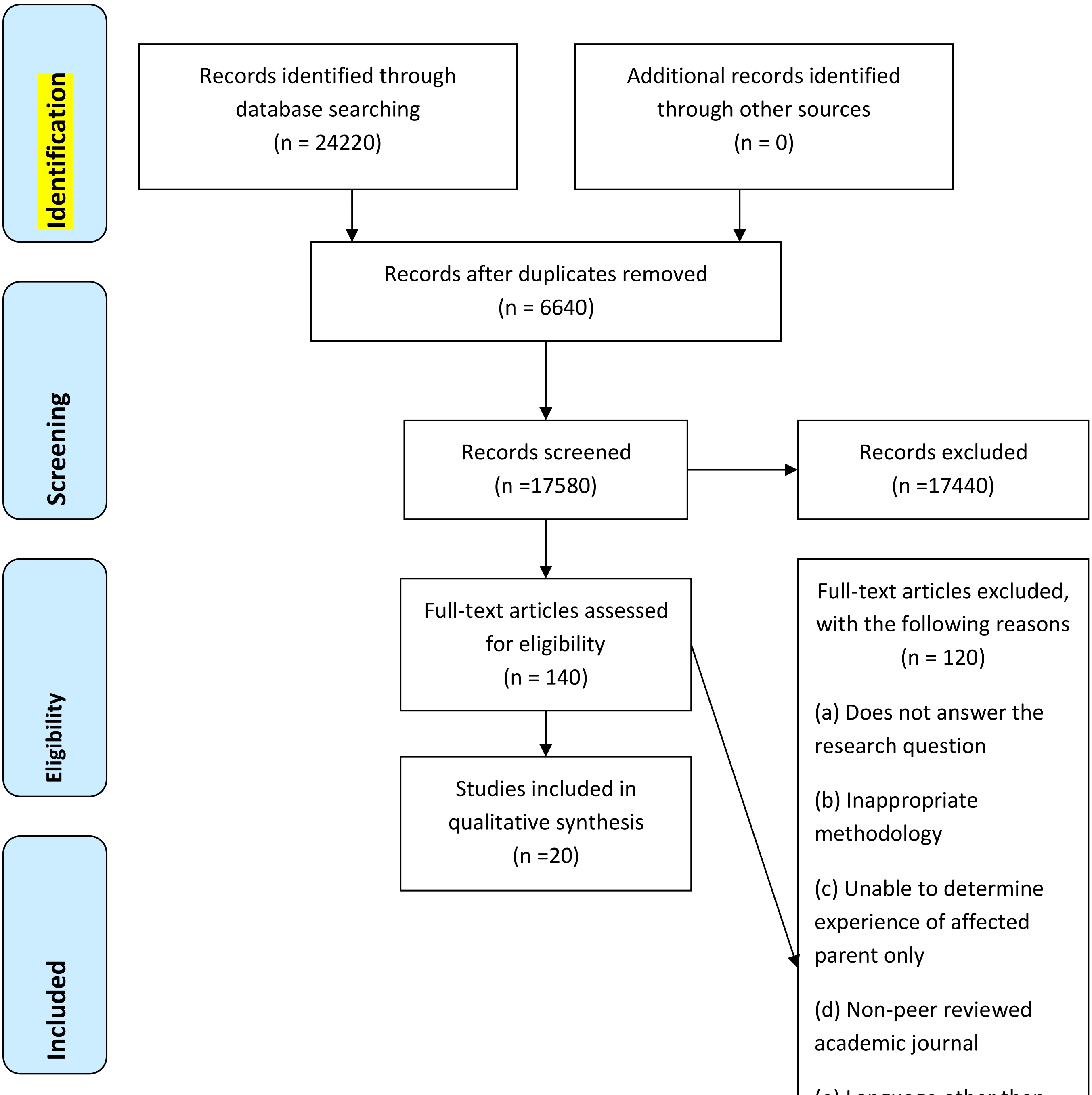

Table 1-2: CASP Scores of the Reviewed Articles

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total
Asbury et al. (2012)	Yes	Yes	3	3	3	1	3	3	3	3	22
Barnes et al. (2000)	Yes	Yes	1	3	2	1	3	2	2	2	16
Chin et al. (2020)	Yes	Yes	1	2	3	1	2	3	3	3	18
Coyne and Borbasi (2006)	Yes	Yes	1	2	2	1	1	3	3	3	16
Davey et al. (2012)	Yes	Yes	3	3	3	2	3	3	3	3	23
Emberger et al. (2002)	Yes	Yes	3	3	3	3	3	2	3	3	23
Fisher and O’Connor (2012)	Yes	Yes	3	3	3	1	3	3	3	3	22
Fitch et al. (1999)	Yes	Yes	2	3	2	1	1	2	2	1	14
Houldin and Lewis (2006)	Yes	Yes	1	3	2	2	2	3	3	3	19
Kenne-Dornel et al.	Yes	Yes	3	1	2	1	2	2	3	1	15

(2018)											
Kim et al. (2012)	Yes	Yes	1	3	2	1	2	3	3	3	18
Lalayiannis et al. (2018)	Yes	Yes	3	3	3	1	3	3	3	3	22

Table 1-2 Continued. CASP Scores of the Reviewed Articles

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total
Loggers et al. (2015)	Yes	Yes	3	3	3	1	3	3	3	3	22
Rashi et al. (2015)	Yes	Yes	1	2	3	1	3	1	3	3	17
Semple and McCance (2010)	Yes	Yes	1	3	3	2	3	3	3	3	22
Shands et al. (2000)	Yes	Yes	2	2	3	1	1	3	3	2	17
Stiffler et al. (2008)	Yes	Yes	2	3	3	1	2	3	3	3	20
Strickland et al. (2015)	Yes	Yes	3	2	3	1	3	3	3	3	21
Turner et al. (2007)	Yes	Yes	1	3	2	1	2	1	3	3	16
Wang et al. (2020)	Yes	Yes	3	3	3	1	3	3	3	3	22

Table 1-3: Summary of Peer-Reviewed Articles Included in the Meta-Synthesis

Study	*N*	Research Design	Analysis	Parent gender	Age Range	Cancer type	Child's Age Range	Ethnicity	Country	Relevant Findings
Asbury et al. (2012)	10	Interview	Thematic Analysis	Mothers	Not given	Primary breast	2-24	Not given	UK	Protecting the children, maintain normality, minimise own needs, using knowledge of the relationship and child, considering children's information needs, when and what to tell, giving and keeping information,
Barnes et al. (2000)	32	Interview	Thematic Analysis	Mothers	31-52	Breast	Not given	Not given	UK	Reasons for withholding, timing of disclosure, ways to help communication, belief in communicating, to keep trust, alleviation of distress and help mothers want
Chin et al. (2020)	16	Interview	Content Analysis	Mothers	37-55	Breast	2-11	Not given	Taiwan	Limiting disclosure to complement children, visual disclosure and ordinary life event
Coyne and	6	Interview	Thematic	Mothers	29-43	Breast	1-15	Not given	Australia	Concerned how to explain, emotional to

Borbasi (2006)			Analysis							inform, shielding from emotions.

Table 1-3 continued: Summary of Peer-Reviewed Articles Included in the Meta-Synthesis

Study	*N*	Research Design	Analysis	Parent gender	Age Range	Cancer type	Child's Age	Ethnicity	Country	Relevant Findings
Davey et al. (2012)	9	Focus Group	Content	Mothers & Fathers	34-56	Breast	11-18	African American	USA	Important to be open, shielding from worry and children respond differently.
Elmberger et al. (2002)	8	Interview	Informed by Grounded Theory	Fathers	28-54	Breast, Lymphoma, Unspecified	0-23	Not given	Sweden	Not naming cancer, wait and see attitude, protecting and children's emotions are difficult to handle.
Fisher and O'Connor (2012)	8	Interview	Multiple Case Analysis	Mothers	31-42	Breast	0-8	Not given	Australia	Lack of information made communication difficult, researched how to tell children.

Study	*N*	Research Design	Analysis	Parent gender	Age	Cancer type	Child's Age	Ethnicity	Country	Relevant Findings
Fitch et al. (1999)	47	Interview	Content and Theme Analysis	Mothers	33-51	Ocular, melanoma, breast, gynaecological, lung, lymphoma, leukaemia, gastrointestinal,	4-18	Not given	Canada	Many told their children, many chose not to talk about death or prognosis, age was an influential factor, mothers were open to questions, children overhear things.
Houldin and Lewis (2006)	14	Interview	Content Analysis	Mothers & Fathers	27 - 67	Colorectal	2 - 25	1 African American, 1 Asian, 12 Caucasian	USA	Parents struggle with telling, parents withhold and parents don't know how to talk

Study	*N*	Research Design	Analysis	Parent gender	Age	Cancer type	Child’s Age	Ethnicity	Country	Relevant Findings
Kenne-Dornel et al. (2018)	10	Interview	Thematic Analysis	Mothers	31- 51	Intestinal, uterine, ovarian, head and neck,	1 - 20	Not given	Brazil	Clear disclosure, preparing children, only when necessary, brings them closer, avoidant children, some do not disclose, protection, uncertainty, visual disclosure
Kim et al. (2012)	7	Interview	Colaizzi Method	Mothers	39 - 47	Breast	5 - 18	Not given	South Korea	Choosing not to disclose, revealing to share strength, considering the child’s age, importance of facts
Lalayiannis et al. (2018)	7	Interview	IPA	Mothers	Not given	Secondary breast	12 - 19	Not given	UK	Easier to tell the second time, intuitive decisions, the only choice, hopeful messages to children, children’s characteristics influence decisions, children need support

Loggers et al. (2015)	9	Interview & Focus Group	Thematic Analysis	Mothers	25 - 47	Breast, thyroid, ovarian	Unclear	Mexican American	USA	Intention to discuss, acknowledging difficulty, inability to reassure, valuing openness, preparing children.
Study	*N*	Research Design	Analysis	Parent gender	Age	Cancer type	Child's Age	Ethnicity	Country	Relevant Findings
Rashi et al. (2015)	12	Interview	Undefined Qualitative Analysis	Mothers & Fathers	33 - 67	Breast, Colorectal, Colon & Liver, Choloangiocarcinoma, Leukaemia, Lymphoma, Myeloma, Melanoma, Uterine, Nasophary	0-22	Not given	Canada	Parents disclose selectively, projecting positivity and tailoring information to children.

						ngeal				
Semple and McCance (2010)	12	Interview	Cognitive Mapping	Mothers & Fathers	Not given	Head and neck	Unclear	Not given	UK	Fear of telling, perceptive of change, lack of support, timing, open and honest, appropriate language.
Study	*N*	Research Design	Analysis	Parent gender	Age	Cancer type	Child's Age	Ethnicity	Country	Relevant Findings
Shands et al. (2000)	19	Interview	Content Analysis	Mothers	30 - 47	Breast	7 - 12	Caucasian	USA	Mother's communicate differently, make it positive, remaining open to questions, talking about feelings, explaining treatment to children and showing children.
Stiffler et al. (2008)	8	Interview	Colaizzi Method	Mothers	37 - 46	Breast	13 - 24	Not given	USA	Mothers try to tell, unrelenting decision making, prioritising the parenting role, and hope must be communicated.
Strickland et	18	Interview	Grounded	Mothers	27-45	Breast,	Unclear	Not given	Canada	Customise exposure, tailoring verbal

al. (2015)			Theory			non-ovarian reproductive				disclosure, selectively shielding from emotions and visual exposure.
Turner et al. (2007)	8	Interview	Thematic	Mothers	39 - 57	Breast	2 - 13	Not given	Australia	No enough assistance from professionals, telling at the point of diagnosis, being open with children, maintain hope, not being too explicit and drawing on experience.
Study	*N*	Research Design	Analysis	Parent gender	Age	Cancer type	Child’s Age	Ethnicity	Country	Relevant Findings
Wang et al. (2020)	18	Interview	Colaizzi Method	Mothers & Fathers	29 - 46	Breast, thyroid, lung, gastric, carcinoma,	6 - 18	Not given	China	Inappropriate to disclose the diagnosis, too young to understand, disclosure may cause adverse effects, being fearful to face the emotional responses, not knowing methods, diagnosis couldn’t be concealed,

						cervical, ovarian, lymphoma, neuroblastoma				children are tough enough, avoid worrying, opportunity to grow up, avoiding naming, discussing information, encouragement, meaning of life and death, direct disclosure, gradual disclosure, reflecting and unmet needs

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Manuscript Submission Guidelines: Journal of Health Psychology

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(b) Critical reviews of the literature
(c) Theoretical contributions and commentaries
(d) Intervention studies
(e) Brief reports
(e) Signed editorials (about 1000 words) on significant issues.

Intervention studies

Publication guidelines for intervention studies are published in Volume 15, Issue 1, pp. 5-7.The journal normally publishes papers reporting intervention studies of up to 8,000 words allowing 500 words per table and figure.

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Please consult the Editorial concerning “Publication Guidelines for Intervention Studies in the Journal of Health Psychology” by David F. Marks J Health Psychol January 2010 vol. 15 no. 1 5-7: http://www.sagepub.com/content/15/1/5.full.pdf+html The criteria for publication include the application of the CONSORT, TREND and PRISMA statements.

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For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient’s actual written informed consent with your article, as this in itself breaches the patient’s confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient’s hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

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also some information on the software used for the analysis, including its version, is required;

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Authors must provide a separate readme PDF listing all included files and documenting the purpose and format of each file provided, as well as instructing a user on how a replication can be conducted.

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Concept replication*:* The submitted article questions the validity of the original study. An alternative measurement or operationalisation is proposed which yields different substantive results.

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2. The author must:

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2. report all pre-registered analyses in the text, or, if there were changes in the analysis plan following preregistration, those changes must be disclosed with explanation for the changes clearly distinguish in text analyses that were preregistered from those that were not, such as having separate sections in the results for confirmatory and exploratory analyses (these changes are added as a separate document linked to the text of the main paper)

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Authors must follow the Guidelines to Reduce Bias in Language of the Publication Manual of the American Psychological Association (6th ed). These guidelines relate to level of specificity, labels, participation, gender, sexual orientation, racial and ethnic identity, disabilities and age. Authors should also be sensitive to issues of social class, religion and culture.

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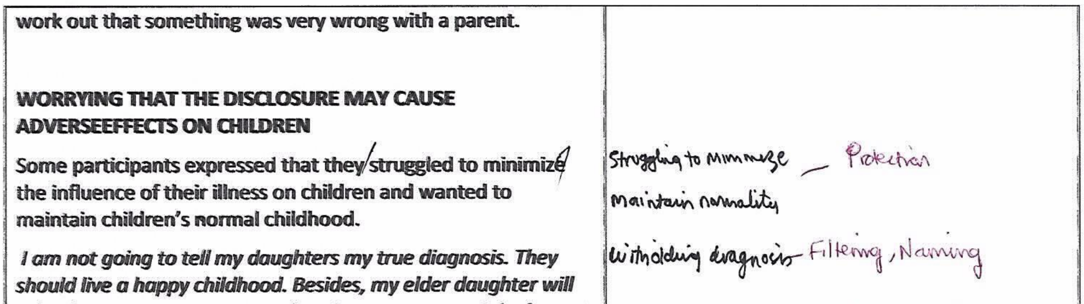
Appendix 1-B

Sample Coding Extract



work out that something was very wrong with a parent.	
WORRYING THAT THE DISCLOSURE MAY CAUSE ADVERSEEFFECTS ON CHILDREN	
Some participants expressed that they struggled to minimize the influence of their illness on children and wanted to maintain children's normal childhood.	Struggling to minimize — Protection Maintain normality
I am not going to tell my daughters my true diagnosis. They should live a happy childhood. Besides, my elder daughter will	Withholding diagnosis — Filtering, Naming

Appendix 1-C

Theme Identification Across Papers

Codes	Descriptive Theme	Analytical Theme	Superordinate Theme	Relevant Studies
Deciding, Open and Honest, Monitoring, Relationships, Avoiding Uncertainty, Preparing, Teaching, Unsure how to Tell, Emotional Harm, Disruption	Intrinsic Values of Disclosing or Withholding	Deciding	Protection	Asbury et al. (2012), Barnes et al. (2000), Chin et al. (2020), Coyne and Borbasi (2006), Davey et al. (2012), Elmberger et al. (2002), Fisher and O'Connor (2012), Fitch et al. (1999), Houldin and Lewis (2006), Kenne-Dornel et al. (2018), Kim et al. (2012), Lalayiannis et al. (2018), Loggers et al. (2015), Rashi et al. (2015), Semple and McCance (2010), Shands et al. (2000), Stiffler et al. (2008), Strickland et al. (2015), Turner et al. (2007), Wang et al. (2020)
Child Qualities, Age, Gender, Personality	Child Factors	Deciding	Protection	Asbury et al. (2012), Barnes et al. (2000), Chin et al. (2020), Davey et al. (2012), Fitch et al. (1999), Kenne-Dornel et al. (2018), Kim et al. (2012), Lalayiannis et al. (2018), Rashi et al. (2015), Semple and McCance (2010), Shands et al. (2000), Stiffler et al. (2008), Strickland et al. (2015), Wang et al. (2020)
Family Qualities, Communication, Experiences, Relationally Informed	Family Factors	Deciding	Protection	Asbury et al. (2012), Kenne-Dornel et al. (2018), Lalayiannis et al. 2018),

Appendix 1-C continued. Theme Identification Across Papers

Codes	Descriptive Theme	Analytical Theme	Superordinate Theme	Relevant Studies
Simplifying, Emotional Shielding, Naming, Filtering, Positivity, Normalising, Visual Disclosure	How Parents Tell	Telling	Protection	Asbury et al. (2012), Barnes et al. (2000), Chin et al. (2020), Coyne and Borbasi (2006), Davey et al. (2012), Elmberger et al. (2002), Fitch et al. (1999), Kenne-Dornel et al. (2018), Kim et al. (2012), Lalayiannis et al. (2018), Rashi et al. (2015), Semple and McCance (2010), Shands et al. (2000), Stiffler et al. (2008), Strickland et al. (2015), Turner et al. (2007), Wang et al. (2020)
Avoidance, Emotional Impact	Negative Impact	Impact	Protection	Coyne and Borbasi (2006), Barnes et al. (2000), Elmberger et al. (2002), Kenne-Dornel et al. (2018) Lalayiannis et al. (2018), Stiffler et al. (2008), Wang et al. (2020)
Stronger Relationships	Positive Impact	Impact	Protection	Kenne-Dornel et al. (2018) Lalayiannis et al. (2018)
Not Enough Support, Not Specific Enough	Inadequate Support	Support	Protection	Coyne and Borbasi (2006), Barnes et al. (2000), Fisher and O’Connor (2012), Lalayiannis et al. (2018), Rashi et al. (2015), Semple and McCance (2010), Turner et al. (2007)

Appendix 1-C continued. Theme Identification Across Papers

Codes	Descriptive Theme	Analytical Theme	Superordinate Theme	Relevant Studies
Support for Parents, Support for Children, Support not Needed	Asking for Support	Support	Protection	Barnes et al. (2000), Rashi et al. (2015), Lalayiannis et al. (2018), Semple and McCance (2010), Shands et al. (2000), Wang et al. (2020)

Section Two: Research Paper

What are the Experiences of Persons with Parkinson's When Parenting Adolescent Children and Young Adults?

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Abstract

Objectives

Parkinson’s disease can impact a person’s physical, psychological, and cognitive functioning and those with the condition face significant challenges to daily living. Although often thought of as a condition of older age, many develop Parkinson’s under the age of 65. For those with early-onset, one aspect of daily life which may be affected is parenting. At present there is no academic research which specifically explores the effect of Parkinson’s on the parental experience. Therefore, this qualitative study aims to explore the experience of person’s with Parkinson’s who are parenting adolescent and young adult children.

Method

Semi-structured one-to-one interviews were conducted with nine parents diagnosed with Parkinson’s whilst parenting children aged between 12 and 25. Data were analysed using reflexive thematic analysis.

Results

Four themes captured the process which parents move through following a diagnosis of Parkinson’s: disclosing, holding on to the parent I was, changing as a parent and an uncertain future.

Conclusion

Following a diagnosis parents are faced with the emotive process of informing their children about Parkinson’s. Whilst initially parents may face little change to family life, progression leads to changes in parental identity and to parenting practices. As the condition progresses,

parents also experience worries for the future, particularly how it might affect their children. Parents should be provided with information about possible parenting experiences whilst being offered a space for psychological intervention which considers identity and values.

Introduction

Parkinson's disease (hereafter Parkinson's) is a neurodegenerative health condition characterised by the experience of significant motor impairment. Those with Parkinson's typically experience progressive difficulty across motor and non-motor domains. Common motor difficulties include bradykinesia, tremor, and muscle rigidity (Sveinbjornsdottir, 2016). However, falls, dystonia and freezing (Politis et al., 2010) are also frequent. Non-motor difficulties are also common (Witjas et al., 2002) and include fatigue (Den Oudsten, Lucas-Carrasco, Green, & Whoqol-Dis Group, 2011), disrupted sleep (Menza, Dobkin, Marin, & Bienfait, 2010), pain (Ha & Jankovic, 2012) or difficulty swallowing (Pflug et al., 2018) amongst others (Lim & Lang, 2010; Witjas et al., 2002). Those with Parkinson's can also experience cognitive impairment, particularly in some aspects of executive functioning (Kudlicka, Clare, & Hindle, 2011), and a substantial proportion develop dementia as the condition progresses (Bosboom, Stoffers, & Wolters, 2004), although cognitive deficits can vary in profile and severity (Tremblay, Achim, Macoir, & Monetta, 2013). In the UK Parkinson's has an estimated prevalence of between 139 to 142 per 100,000 (Walker, Hand, Jones, Wood, & Gray, 2010; Wickremaratchi, Ben-Shlomo, & Morris, 2009). Globally it is more likely to be diagnosed in males and the incidence increases with age (Hirsch, Jette, Frolkis, Steeves, & Pringsheim, 2016), with an average age of onset of 67.7 for males and 69.3 for females (Wickremaratchi et al., 2009). Although risk of diagnosis increases with age, in the UK estimates suggest that for 3.6% of persons onset occurs by the age of 45 and for 5.4% by the age of 50 (Wickremaratchi et al., 2009). When Parkinson's develops earlier in the lifespan, it is referred to as 'young' or 'early' onset.

Due to the wide variety of symptoms, completing activities of daily living can be challenging (Den Oudsten et al., 2011; Hariz & Forsgren, 2011) and become increasingly difficult as the condition progresses. Additionally, there can be significant emotional difficulties such as apathy, low mood, anxiety, and panic (Walsh & Bennett, 2001). Depression is experienced by approximately 7-35% (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008) and anxiety in approximately 31% (Broen, Narayen, Kuijf, Dissanayaka, & Leentjens, 2016). Emotional difficulties can be influenced by several factors (Garlovsky, Overton, & Simpson, 2016), one of which is early-onset (Kostic et al., 1994), as persons are more likely to experience psychological distress than those with later onset (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2003; Wickremaratchi et al., 2009). With no cure for Parkinson's, management is achieved through a combination of medication (Connolly & Lang, 2014), physical (Tomlinson et al., 2012) and psychological interventions (Zarotti et al., 2020).

Parkinson's can understandably impact a person's lived experience and its effects on social functioning are broad (Perepezko et al., 2019). One area which may be affected is family relationships. Whilst only a handful studies document the impact of parental Parkinson's on children (Grimshaw, 1991; Schrag, Morley, Quinn, & Jahanshahi, 2004a, 2004c), no previous studies focus solely on relationships with children or the experience of parents. One study by Fleming, Tolson, and Schartau (2004) explores the wider experience of women with Parkinson's which includes parental experiences within the analysis. Mothers in this group reported the desire to protect children and to continue to fulfil expectations whilst comparing their parenting ability to societal norms. This study however only focused in part on parenting, limiting its exploration of the experience and also excluded fathers. Within the analysis it included the experiences of grandmothers and the children of participants were aged between five and thirty five so only broad generalisations were possible regarding parenting experience. The lack of thorough investigation into parenting may be in part due to Parkinson's being considered a health condition of older age (Hermanns, 2013; Moore & Knowles, 2006). Early onset, lengthened survival, and increases in the average age of conception could make it increasingly likely that persons with Parkinson's could be parenting children or young adults, and their experience is not well understood.

A small body of research explores parenting with other arguably similar motor-neurodegenerative conditions (MNDCs) such as multiple sclerosis (MS), Huntington's disease (HD) and amyotrophic lateral sclerosis (ALS). Parents with MNDCs report concerns that their health status will be harmful for their children (Prunty, Sharpe, Butow, & Fulcher, 2008; Willson, Tetley, Lloyd, Messmer Uccelli, & MacKian, 2018). In response, they have been found to prioritise children over their own needs (Foley, Timonen, & Hardiman, 2014; Willson et al., 2018), placing their experience in the background (Payne & McPherson, 2010). Although parents with MNDCs experience barriers, such as cognitive and physical fatigue (Bakshi, 2003; Pakenham, Tilling, & Cretchley, 2012), they have reported "pushing through" to meet expectations (Parton, Ussher, Natoli, & Perz, 2018). However as a result, some parents perceive their parenting as less competent, which can affect wellbeing (Blundell Jones, Walsh, & Isaac, 2014; Harrison & Stuifbergen, 2002; Messmer Uccelli, Ponzio, & Traversa, 2019), although this may not be universal (Haynes-Lawrence & West, 2018; Messmer Uccelli & Ponzio, 2018). Additionally, MNDCs often mean a reduced life-expectancy (Leray, Moreau, Fromont, & Edan, 2016; Rodrigues et al., 2017) which has been connected to a sense of loss for future parenthood (Locock, Ziebland, & Dumelow, 2009), making a condition more difficult to accept (Foley et al., 2014). Parents with MNDCs also voice concerns that their children are exposed to loss before the parent's death, through witnessing deterioration (Brown, 2003).

In a qualitative study exploring young-onset Parkinson's, parents suggested that as capability deteriorates they can experience a sense of loss for the parenting role (Ravenek, Rudman, Jenkins, & Spaulding, 2017). Although those with young-onset have reported needing support from partners or spouses (Carter, Lyons, Stewart, Archbold, & Scobee, 2010; Fleming et al., 2004) it is unclear how much parenting help is required. For those with MS, it has been documented that partners do provide specific parenting support (Farber, Kern, & Brusilovsky, 2015). Outside of support other coping strategies for parenting with an MNDC include the rejection of idealised norms, focusing on current capability (Willson et al., 2018) and, finding alternative ways to parent, such as prioritising their role in children's emotional development (Parton et al., 2018; D. Payne & McPherson, 2010).

The similarities of Parkinson's to other MNDCs may allow us to have some insight into the potential parental experiences. However, the literature is limited and there are differences between the conditions. In comparison to MS and HD, Parkinson's typically has a later onset therefore the typical ages of parents and children are older. Those with MS can often experience relapsing-remitting patterns and therefore have periods of relatively stable health interjected with periods of difficulty. Although those with Parkinson's experience fluctuating difficulty, it is typically on a daily basis and connected to the wearing off of medication. ALS progresses rapidly, and person often experience severe difficulty within months of onset. In contrast, those with young-onset Parkinson's experience more gradual progression. Despite a reduced life-expectancy for those with Parkinson's, it is longer than those with ALS and with greater capability (Ishihara, Cheesbrough, Brayne, & Schrag, 2007). The differences in the experience of conditions and the timing within the family life-cycle means that predicting the experiences of parents with Parkinson's based on other MNDCs is imperfect, therefore to what extent parents with Parkinson's need support is unclear. Charitable organisations which focus on Parkinson's produce resources aimed at parents (e.g. UK Parkinson's Excellence Network, 2019). However, the lack of targeted research in the evidence base has meant that, despite the clear potential for difficulty, professional guidelines do not exist for the health and social care of parents with Parkinson's, justifying the need for specific research.

The care needs of children and therefore the demands placed on parents change throughout the life-cycle of the family. Babies and young children typically rely on parents to care for them in a more direct and physical way. As children become adolescents, their independence increases and parental responsibility changes. The changing relationship can continue past 18 and a growing number of children are continuing to live within the family home (ONS, 2021). Consequently this study will explore the experiences of persons with Parkinson's who are parenting adolescents and young adults aged from 12 to 25.

Method

Design

Due to the lack of previous research and the potential for a broad range of experiences this study used a qualitative approach that permits a rich understanding of the experiences of groups of people (Beeson, 1997; Sandelowski, 1995). It aims to capture the range and depth of shared experiences through conducting one-to-one semi-structured interviews. This study takes a critical-realist (Bhaskar, 2013) epistemological stance with the consideration that patterns of social contexts shape experiences of specific groups and those within those groups are able to reflect on and talk about their individual experiences. Furthermore the researcher brings a personal and professional lens when interpreting those experiences. A reflexive thematic analysis (TA) approach (Braun & Clarke, 2006) was chosen as it flexibly accommodates a wide range of theoretical and procedural approaches such as using data from one-to-one interviews, (Douglas, Hamilton, & Grubs, 2009) that explore experiences (Malik & Coulson, 2008; Moller, Timms, & Alilovic, 2009) as found in this paper. Additionally, reflexive TA considers the researchers position within the research process accepting an inability to completely remove oneself from the analysis and a requirement to explicitly consider decision making (Braun & Clarke, 2006).

Ethical Considerations

Ethical approval was granted by Lancaster University Faculty of Health and Medicine Research Ethics Committee. All participants were offered the opportunity to discuss the study prior to taking consent. Consent was given verbally and audio recorded using Microsoft Teams before the interviews commenced. All participants and their children were assigned pseudonyms, and all other potentially identifiable information was removed from the transcripts. All participant information and data was stored in a password protected file on an approved secure informatics system. Participants were offered the opportunity for debrief and were provided with guidance on services to contact should they experience psychological distress.

Procedure

Research advertising materials (Section four Appendix 2-A), the participant information sheet (Section four Appendix 2–B), verbal consent form (Section four Appendix 2-C), feedback verbal consent form (Section four Appendix 2–D) and the interview topic guide (Section four Appendix 2-E) were designed by the author in collaboration with persons with Parkinson’s accessed via Parkinson’s UK. Advertising materials and the participant information sheet were shared with prospective participants via research mailing lists of two charities Parkinson’s U.K. and Parkinsons.Me. Parkinson’s U.K. also hosted the study information on the Take Part Hub, a web page designated to host Parkinson’s research. Additionally, the study was advertised via a professional Twitter handle. Potential participants were sent the advertising flyer, the participant information sheet, and the consent form before arranging interviews. Participants were interviewed individually via a telephone- or the Microsoft Teams video-calling service. Interviews were preceded by discussing the participant information sheet and an opportunity for questions. Participants were given the opportunity to structure the interview across multiple days, to take breaks and to have someone else present. Interviews lasted between 47 and 70 minutes.

Participants

To be included parents had to be aged over 18 (no upper age limit), living in the UK and able to speak fluent English. All participants had a diagnosis of Parkinson’s for at least 12 months prior to their interview. At the time of their interview participants’ children were required to be aged between 12 and 35. Additionally, all participants reported no additional health conditions which impacted parenting.

Fourteen persons showed interest, of which nine consented to participate. Of the five who were not included in the study, four did not meet the inclusion criteria whilst one failed to respond to the follow up invitation. Four participants identified as men, five as women, and all lived in the UK. The age of participants ranged from 45 to 60. All participants were in relationships with the co-parent of their children. These couples all had one or more additional children and at least one child who remained at home. A full range of participant demographics can be found in Table 2-1.

[Table 2-1 about here]

Analysis

Analysis followed reflexive thematic analysis (RTA) procedures as described in (Braun & Clarke, 2006). All interviews were transcribed verbatim by the author. Following interviews, the author made reflective notes, which were reviewed throughout the analysis phase. On completion of transcription, familiarisation with the data was achieved through reading and re-reading each transcript. Line by line coding was conducted (Appendix 2-B) and semantic codes, close to the participants' own words were generated. Early concepts and descriptive themes were identified from the codes (Appendix 2-C) which were then reviewed for viability and coherence with the supervisory team (Storey, 2007). At this stage themes were placed into a visual map which highlighted how they were organised within the process of experiences (Douglas et al., 2009). Themes were refined which included combining descriptive themes and the creation of analytical themes (Appendix 2-C). Finally, themes were named and defined before being written up.

Quality

The study was guided by qualitative research guidelines described by (Yardley, 2008) with the aim of maximizing sensitivity, commitment, rigour, impact and transparency of the research. Although coding was inductive and remained close to the data, it was done in the context of the researcher's own context and knowledge. This context includes a relative who was diagnosed with young-onset Parkinson's. However, the researcher was not aware of this fact when the children were adolescents or young adults; therefore their daily experiences were not salient concepts. Nevertheless the relationship likely influenced the emotional response of the researcher, particularly to data that pertained to the parents' concerns for the future. Given the hermeneutic nature of RTA it is argued that a researcher's bias cannot be suspended (Braun and Clarke, 2019), therefore a diary was used to facilitate awareness of the researcher's orientation towards the data and promote transparency (Cohen & Crabtree, 2008). Transparency was also enabled by the inclusion of examples of coding (Appendix 2-B) and theme formation (Appendix 2-C). Coding and themes were discussed with the supervisory team who had extensive knowledge of the academic literature covering Parkinson's and of clinical psychological practice with families. This helped to improve sensitivity to the context of the experience (Yardley, 2000) and as a consequence themes were adjusted. Additionally, themes were transparently grounded in the data by use of quotations throughout.

Results

Findings

The analysis identified four themes of: disclosing, holding on to the parent I was, changing as a parent and an uncertain future. These four themes captured the process which parents moved through following their symptom onset and diagnosis.

Theme 1: Disclosing

This theme captures the moment when parents with Parkinson's take the difficult action of disclosing their diagnosis, moving into a new phase of family life. It describes the conflicted emotions they face and the actions they consider in managing the impact on their children.

For all parents, disclosing the diagnosis was highlighted as a highly significant moment. It came following a time when parents had gone through a long and emotional process of discovering the cause of confusing changes to their physical and cognitive state. Although receiving their diagnosis allowed parents to better understand recent challenges, it was the beginning of new worry, with some concerns focused on how this would impact their children. Disclosing their new understanding to children became a challenge in itself. Although the importance of disclosing was highlighted by clinicians, charities and family, to parents this was a more complicated decision. For some parents this decision was made as an individual whilst others considered this with their partner.

> It’s very easy for professionals to say to you “oh you need to tell such a body” but sometimes you need to find the right time, the right moment, the right way (Jaqueline).

Parents anticipated that through disclosure they would also be sharing the worry and uncertainty they experienced themselves. Despite disclosure being seen as inevitable, a desire to protect meant it was typically delayed, although this was not the case for all parents. This delay ranged from months to years depending on the individual context. For some, a delay granted parents the opportunity to develop their understanding, allowing them to feel prepared to manage the process of disclosure. For others, delay was guided by timing, with parents attempting to find a moment that would have the least impact. In deciding the moment, parents considered children’s emotional states, geographic location or events such as exams and holidays.

> My daughter, a guy in her class she sat next to in chemistry, committed suicide, so she had her own traumas to deal with, so we took the decision that we wouldn’t tell the kids until after she had done her A-levels (Rodney).

When disclosure occurred, parents’ desire to protect persisted through attempts to minimise distress. Parents aimed to be calm and reassuring; highlighting that Parkinson’s did not mean imminent death whilst downplaying potentially severe outcomes.

> But that’s just the way I found to break the news, not being dramatic about the diagnosis…it depends on the way you tell them, you can make things nicer, you can put it in better colours (Sofia).

Despite parents’ efforts, disclosure became a shared emotional moment for families and parents felt that sharing knowledge of the condition was an introduction of parental vulnerability and possibly death.

> Stacey asked “does it mean you’re going to die?” and I said “No, not too soon” and I was feeling sorry for the kids (Sofia).

Theme 2: Holding on to the parent I was

This second theme illustrates how following the disclosure there was a temporary return to a version of family life they had before the diagnosis. Parents had a continued physical and cognitive ability which they appreciated and had taken steps to resist deterioration for the benefit of their children.

In the early phase of Parkinson’s, there was minimal change to the physical, cognitive or psychological health of parents and therefore Parkinson’s had little impact on their lives. Remaining physically unchanged enabled parents to maintain a parenting style consistent with their approach pre-disclosure.

> Right now I can do physically everything I could do before and so there’s no difference, there’s no demonstrable difference whatsoever (Jaqueline).

Following disclosure concerned children had initially responded by being more supportive, however a return to typical parental functioning led to this going back to how things were before Parkinson’s.

> He was doing extra things, I would come home and if he was home already he’d have done the tea and things like that. And that went on for a few months and gradually he saw well it seems like nothings really changed, so he gradually eased off (Diane).

Although families were aware of Parkinson’s, it was as if the condition existed in the background rather than being the dominant focus, and in some instances it seemed as if children had not considered Parkinson’s at all. Even on days where parents experienced increased effects of the condition, relative consistency allowed parents to preserve the pre-Parkinson’s relationship with children and continue to be treated as if the diagnosis had never occurred.

> I think there’s times when I’m feeling really tired or washed out or my tablets are not working and I just want to curl up on the sofa, and the children still come to me and say, “oh can you help with this or can you do that?” And so obviously in my head that means they obviously don’t see me as any different and they just see me as dad and the Parkinson’s isn’t a big thing for them (Nigel).

Parents felt that continuing to parent as if Parkinson’s was not affecting them would prevent the condition from becoming an obstacle to children’s participation in life. Therefore parents felt a strong desire to remain unchanged, placing increased importance on maintaining functioning or at least slowing a decline in capability.

> Actually how am I going to support my family and keep working and supporting my children? Doing exercise if that helps me stay fit and help me fight this disease for longer then I'll keep on doing it (Nigel).

Living as they had done pre-Parkinson's became an act of parenting in itself where carrying on with social activity or employment despite Parkinson's was a physical demonstration of resilience and was seen as an opportunity to teach children desirable values.

> But the way I see it nothing's changed, I get up for work, I do a good job and I want my kids to see that as well, it's that kind of role model behaviour, there may be something but it's not going to affect anything…Those are the behaviours and values I want my children to see (Jaqueline).

This physical demonstration was matched by verbal reassurance, reinforcing parents' communication of stability. However, maintaining an image of an unchanging parent required parents to seem unaffected by any early challenges, feeling pressured to hide and therefore shield children from what parents felt was unnecessary distress.

> And protecting them, just because even if it was the case…I probably wouldn't want them to know. I would probably try and kid them if that was possible for as long as possible, because if I did fall over tomorrow when I was out for a walk and if I did know it was Parkinson's, I would probably still tell them it wasn't because I don't want them worrying about me (Harriet).

Theme 3: Changing as a parent

This theme describes a period of transition in which the family dynamics they had previously held onto changed in spite of their efforts. It was a distressing time for parents as they started to realise a declining ability to provide care. This theme also captures the conflicting early experiences of receiving support from their children.

As Parkinson's progressed and parents began to face increasing challenges, it became a barrier to living as they had done previously. Effects of Parkinson's such as fatigue or impaired cognition made management of parenting effortful and therefore meeting expectations, fulfilling responsibilities or engaging in family activities difficult.

> Spending time with them, playing games, reading, taking them out for walks, all the usual dad stuff, that's more difficult now (Karl).

Although many participants remained in employment, for some this was no longer the case. For one father this was particularly difficult as it meant he was not the role model he expected to be.

> I expected to still be working, because I've retired now, retired on ill health grounds. So I expected to still be working and a role model for them on that basis (Karl).

The development of Parkinson's meant parents re-evaluated their perspective on what parenting meant and what was important. As a result some adjusted their approaches to routine parenting. For one participant this meant trying to maintain predictability, increasing control over her children's lives and behaviour.

> I like things to be kind of nailed down, obviously in life and in particular children they're not. I think personality wise I'm like that anyway but the Parkinson's definitely exacerbates that and you like certainty I think (Karen).

Whilst for others it meant relaxing as a parent, re-prioritising valued experiences together rather than worrying about daily tasks.

> What's important is being a family, being happy, being healthy… (Jaqueline).

Parents could find themselves faced with a difficult choice between prioritising the management of Parkinson's, parenting responsibilities or their personal desires. A majority of participants prioritised the needs of their children. However, for others Parkinson's was the catalyst that allowed them to begin to justify an increasing requirement to put their own needs first.

> Sometimes there isn't room for being fine for them and doing all the Parkinson's stuff and having anything else interesting going on, like hobbies, that would make me feel like I was just being an interesting human being as well as a parent (Karen).

As Parkinson's progressed and parents began to adjust the balance of their focus of care from children to themselves, they also began to become the receivers of care. The majority, but not all parents increasingly accepted children's offers of practical support with an increasing acceptance of both spontaneous and requested participation in domestic tasks such as cooking, cleaning or gardening.

> It would take me three or four times longer than it would take my wife to do the same amount of chopping. And she's [daughter] is aware of that so she will come and assist me…sometimes without being asked or sometimes I will ask her (Karl).

Emotional support was also offered and came as encouragement or communicating an understanding of what their parents faced.

> …I had to do these exercises every day. So I set up an app thing which would give me different noises at the end of each exercise…They all knew I was doing it every day and my eldest son…every time he heard the noise he started saying “well done mum” (Karen).

These emerging acts of care typically left parents feeling conflicted, on one hand they found it encouraging and helpful. However on the other even small acts of care represented the beginnings of becoming a burden.

> Yeah, it’s frustrating on one hand because she has to come over, well she doesn’t have to come over, but she does come over and assist me and help, because it just takes so long if I do it myself (Karl).

> Well weird in the sense that it’s kind of a reversal of that parent child thing, isn’t it? Because normally as a parent you’re the one that tends to do everything for your children and look after them and care for them, but you know for that very small moment he was kind of having to do something for me and help look after me (Nigel).

As Parkinson’s began to restrict and dictate how parents and children interacted, it also began to define parental identity. Although one participant felt that Parkinson’s had enabled her to become a more fun mother, most participants began to view themselves through a negative lens and as a worse parent compared to others, or their previous able selves.

> It means to me that I don’t think that I am as good a dad as I could be and would have been had Parkinson’s not interacted in and impacted on my life (Karl).

> A failure to my children because they wanted their mother, they want a supportive mother, and I won't be able to be a supportive mother (Sofia).

Not only did parents' identity change in their own eyes but also in the eyes of their children. Whilst children began to see their parents differently following the disclosure of the diagnosis, the continuous exposure of children to the effects of Parkinson's on their parents facilitated the evolution of that identity over time. Exposure could occur voluntarily as parents decided to be open with their difficulties or involuntarily due to a failing ability to participate in life as they once had. Parents felt that their children's previous perception of them as a parent was replaced by one that was more vulnerable.

> And just them realising they you're actually human, whereas they think you're their parent or their mum and you are always going to be there, and that sort of mortality I suppose. Not in a sense of dying I don't mean that, but in terms of just not quite being as perfect as what they might think you are (Harriet).

However, some parents said they felt that Parkinson's was something the children had grew up with and therefore a parent with Parkinson's was ordinary for them.

Theme 4: An uncertain future

This final theme focuses on how the certainties of decline removed a future parents had once hoped for, whilst the variation in progression and varying family circumstance replaced previous expectations with an unknown future. Parents now predicted and planned for a deteriorating condition and how this could affect their children.

As parents experienced a deteriorating condition they acknowledged a shrinking world and a family life-cycle that had been brought forward in time. This created a sense of loss for the ambitions and family experiences that Parkinson's had taken away from them.

> …so expectations of the things that I might be able to do with my teenage children have changed and that's a bit sad. And there will probably be other things that can be done but they wouldn't involve lots of stamina or walking long distances anymore or things that involve too much hardship, sleeping on the ground. It's you know, at some point one probably gives up on those things, but I wasn't expecting to yet and I think there was something that I envisaged at this point of parenting (Karen).

Parents also mourned for the loss of a life for their children that was free from the worry and responsibility that came with a parent who may develop physical impairment.

> I want them to have their own lives and you know I don't want anything stopping that you know…I want them to achieve the moon and more, and I don't want them to be held back by a sick mother (Harriet).

The course of parents' lives and their condition was now unknown, meaning a desired future was replaced by one that was uncertain and for many the only certainty remaining was an inevitable physical and cognitive deterioration. Parents' consideration turned to how they would function not only as an individual but also as a parent. They doubted the longevity of their ability to maintain a parenting role and support their children as they had been supported by their own parents. Similarly some parents were also unsure of their ability to provide financially as they had either taken or expected an early retirement.

Parents also shared concerns about participation in important cultural milestones, with one father questioning his ability to participate in his daughter's wedding.

> And it's strange really, having that picture in my head of if my eldest daughter gets married and thinking will I be able to walk down the aisle with her, will I be able to stand up and do the father's speech....(Nigel).

The earlier mentioned discomfort about burdensomeness to children became a distressing expectation for parents, perpetuated by witnessing older and more disabled persons with Parkinson's. They expressed concern and disapproval that they would soon rely on their children who would have an increasing role as carers.

> I suppose one of the things I worry about to do with my children particularly, is that there's a sense that, I don't know how long five, ten, fifteen, years' time I may be more dependent, I may be more physically needy. And I suppose I worry about how that might impact on my children in terms of feeling like they have responsibility to come and support either me or my wife (Nigel).

Parents' desire to protect extended into their unknown future. In response to uncertainty parents attempted to retain some control through planning. Parents adjusted their approaches with some guiding children to become more independent whilst one other made plans for others to care for her younger children when she became unable. Although for many parents Parkinson's had not yet meant an end to a working career and for one parent insurance had left them in an improved financial position, parents also felt the need to ensure financial security for their children.

Discussion

The present study explored the impact that Parkinson's can have on the experience of parenting. It highlights the difficult experience of disclosing the diagnosis to children and the desire to protect children from the emotional and practical consequences of Parkinson's by aiming to maintain pre-diagnosis family structures and relationships. It describes how despite adjustment to parenting perceptions and practices, a deteriorating condition resulted in changes to parent-child relationships both in activity and identity. Additionally, it captures the sense of loss parents have for an expected future that could be replaced with worrying uncertainty and the anticipation of increased burdensomeness.

Following the shock of their diagnosis, parents were faced with the decision to disclose their news to children. The majority of participants felt that by telling children they would be sharing the emotional burden and therefore often chose to delay disclosure to protect children, this reflected a previous study on women's experiences of Parkinson's (Fleming et al., 2004). The present study confirms more clearly that this occurs for parents of adolescent children or young adults and that it also applies to fathers. Difficulty discussing a diagnosis with children has also been found for parents with MS as it opened up opportunity for questions they were unable to answer, with some choosing to withhold their diagnosis until a later stage (Bostrom & Nilsagard, 2016; Nilsagård & Boström, 2015). The experience of parents with Parkinson's here was similar, as they used the delay to further understand their diagnosis before talking. Many parents had specific concerns that children's emotional reactions would become a barrier to academic success; however no research has been conducted on this specific impact of disclosure.

The second and third themes from the analysis (holding on to the parent I was and changing as a parent), can be viewed through the lens of the Family Adjustment Adaptation Response Model (FAAR; Patterson & Garwick, 1994). The FAAR proposes that in response to chronic illness families go through two stages - adjustment and adaptation. Adjustment occurs in the early stages of a condition, and in the context of parenting it is the stage in which families are able resist the emerging changes to parent's health and continue to meet the demands of current family dynamics. By doing this the family protect the established parental identity and their function within the family. When adjustment becomes difficult to sustain, families move into the adaption phase. This is a period in which parents can no longer maintain family role functioning as easily, requiring changes to functioning and how they view themselves as parents. The adjustment stage of the FAAR was supported by theme 2 of the present study as parents and children were required to make only minor changes in order to continue in their already established roles. Additionally, parents' also reported a desire to hold onto this status quo, resisting change by attempting to slow the progression of the disease and limit its influence on family life. A desire to resist change has also been shown to persist into more advanced stages of the condition (Charlton & Barrow, 2002). For most participants, slowing progression meant maintaining cognitive and physical function through the adoption of exercise into their daily lives, which has been shown to physiologically benefit those with Parkinson's (Goodwin, Richards, Taylor, Taylor, & Campbell, 2008; Gronek et al., 2021) as well as using medication (Murman, 2012).

Despite defiance in the face of change, participants encountered increasing physical and cognitive challenges which moved families into the adaptation phase of the FAAR (theme 3). One particular challenge for parents with Parkinson's was the presence of fatigue. The presence of fatigue has previously been reported as a challenge to mothers with MS and rheumatoid arthritis (White, White, & Fox, 2009). As the study by White et al recruited mothers with much younger children (12 to 45 months) it suggests that fatigue may be a challenge for parents regardless of the children's age. Fatigue limited parents with Parkinson's capacity to engage in activity with and for their children, which led to difficult parental emotions. This supports previous research that shows an increased perception of inability to successfully undertake the parenting role is correlated with increased parenting stress for those with other chronic illnesses (Zelkowitz, Looper, Mustafa, Purden, & Baron, 2013). As predicted by the FAAR, in response to barriers parents adapted in different ways such as through changing parenting practice or perspectives. Whilst one mother reported that she increased control over her children's lives, other parents relinquished control. The parents who let go, felt they needed to carefully choose when to use valuable energy whilst becoming more passive about less important aspects of family life, such as domestic tasks. This demonstrated that when physical and cognitive energy was limited many parents with Parkinson's prioritised spending it on valued family activity.

As parents' condition deteriorated they became receivers of early acts of care and parents feared that they would become a burden whilst their children were relatively young. Evidence suggests those with early onset Parkinson's are likely to eventually require care at home, which can involve children (Hassan et al., 2012) and over 40% of children aged 12 and above feel the care they provide is a necessity (Schrag, Morley, Quinn, & Jahanshahi, 2004b). Additionally, children who provide care are likely to experience significant disruption to family functioning, an increased sense of daily burden (Jahanshahi & Sheikh, 2007; Schrag et al., 2004b) and a reduced quality of life (Morley, Selai, Schrag, Jahanshahi, & Thompson, 2011).

Participants also reported changes to their identity, something not captured by the FAAR model. This made it necessary to draw on an alternative theory of biographical disruption (Bury, 1982), to fully understand the parental experience. Biographical disruption views the development of a chronic illness such as Parkinson's as a significant life event that disrupts an individuals formed understanding of themselves and how they interact with the world. Chronic illness in this sense occurs as a disrupting force on two levels, both functional (the daily practical consequences) and symbolic (the attached cultural imagery) (Bury, 1982; Williams, 2000). Biographical disruption has previously been observed in those diagnosed with other chronic illnesses (Asbring, 2001; Wilson, 2007). In the context of this study, Parkinson's became a symbolically disruptive force to parental identity, moving participants away from an expected understanding of themselves as parents at this life stage. As observed previously in mothers with Parkinson's (Fleming et al., 2004), participants in this study spoke negatively about their parenting capability, comparing to former selves and social expectations, ultimately regarding themselves as a worse or "failed" parent. One example of this was the lost identity of a successful parent-provider. This led parents to feel limited in their opportunity to demonstrate they were coping with Parkinson's and restricted their ability to teach children valuable lessons about the importance of work.

Although parental identity could also change in the eyes of their children, the perceived repulsed and embarrassed reaction of children as identified by (Fleming et al., 2004) was not replicated here, perhaps because in the current study all parents were at a less advanced stage of Parkinson's. Furthermore, some parents felt that disruption to identity had not occurred for younger teens due to the perception of their parent being formed as Parkinson's was progressing, thus parents felt it was "all children had ever known" and was 'normal' for them. This is reflected in the results in a study by Schrag et al., (2004b) who found that for children of parents with Parkinson's, 89.7% of those aged 12 to 24 felt that it was normal to be involved in household domestic duties compared to only 58.3% of children older than 24.

Previously, older persons with Parkinson's have reported a sense of loss for a desired future replaced by one of uncertainty (Charlton & Barrow, 2002) something that was echoed in the present study by younger persons within the context of family. Children may also experience concerns for the future (Morley et al., 2011) and this could explain why parents felt the need to provide ongoing reassurance and to hide their own fears. In response to a lost future, those with Parkinson's of all ages have been reported to respond by shifting their attitude to making the most of an able present (Bramley & Eatough, 2005; Smith & Shaw, 2017). This was supported by this study in which a majority of the parents discussed experiencing a similar response, aiming to make the most of their time with their families.

Limitations and Future Research

Adequate sample sizes are an issue of debate in qualitative research. Although (Braun & Clarke, 2013) recommend a sample of ten to twenty for a professional doctoral thesis, it has been argued that theoretical saturation in thematic analysis can occur after twelve interviews, but that relevant themes may be evident after six (Guest, Bunce, & Johnson, 2006). In part, the sample size in this study may have been influenced by individual responses to the COVID-19 pandemic. For many people, adapting to the logistical, health and emotional demands of the pandemic may have taken priority over research participation. This may have been particularly difficult for parents given that their children may have been restricted from attending school in person, increasing parental demands and reducing privacy. However, arbitrary application of sample size may not be a reason to discount results (Vasileiou, Barnett, Thorpe, & Young, 2018) and there are previous examples of TA analyses with similar numbers of participants (Isman, Mahmoud Warsame, Johansson, Fried, & Berggren, 2013). In this study clear themes were able to be drawn from a data that were experienced across the sample and in part this may have been due to the homogenous nature of included participants which can reduce the sample size needed for in depth study of a particular group (Malterud, Siersma, & Guassora, 2016). Although the supervisory team had extensive experience in relation to the research question, participants were not consulted with regards to credibility checks following the formation of themes which could have benefited the analysis (Elliott, Fischer, & Rennie, 1999).

The sample was small which may have contributed to its homogenous nature in terms of nationality, and culture which therefore restricts the relevance of the understanding generated from the analysis to the experiences of a narrow group. Although there were clear themes, a larger sample may have given the study opportunity to expand patterns in the data into fully formed themes. Much of the research on parents with MNDCs has been conducted in Europe and North America, giving the evidence based a western-centric view. This was also the case with this study as all participants developed Parkinson’s whilst living in the UK. However, one participant was born and raised in South America and although they expressed experiencing cultural differences and were more religious than their fellow participants, their experiences were otherwise broadly similar. Nonetheless, given the potential differences of gender roles and expectations of parents across cultures, future research should be conducted that focuses on individuals from different social groups. No participants in the sample experienced a more advanced stage of the condition, with very few experiencing significant physical barriers. As these barriers can be severe for those with more advanced stages of Parkinson's those persons may have different experiences to participants in this study. Therefore future research should focus on parents who experience significant physical and cognitive difficulty. An understanding of those with more severe forms of Parkinson's, may also be more benefit to clinical practice as it can inform those supporting parents with the most need. This study only recruited parents who were in heterosexual relationships and all of the partners were also biological parents of their children. Some parents may not have a partner at the time of their diagnosis whilst others may face relationship difficulty and separation as a result of Parkinson's (Fleming et al., 2004; Ravenek et al., 2017). The results of this study therefore do not represent the experience of single parents. Single parents with MS have reported feeling vulnerable, finding it difficult to manage emotional issues (Bostrom & Nilsagard, 2016). Although participants in this study experienced a sense of burdensomeness, this could be a more significant factor for single parents with Parkinson's as observed in single mothers with MS (Blundell Jones et al., 2014; Bostrom & Nilsagard, 2016). Future research should consider the experiences of parents in a broader range of relationships.

Parents in this study predicted a developing reliance on their children which left them feeling uneasy. Specific research could seek to measure the interaction between perceived or predicated burden and psychological distress. Parents also held concerns that their children would experience distress when told about parental Parkinson's. As the current literature gives no insight into the accuracy of parental concerns, future research should explore children's experiences and the consequences of being informed.

Clinical Implications

Participants had the significant and difficult experience of telling their children about Parkinson's. Services should provide guidance or at least signpost parents to information (Parkinsons UK, 2018) which supports them to disclose the information in an appropriate way. As the condition progresses, parents may feel as if they are a burden to children, and wider research investigating the experience of persons with movement disorders has suggested that perceived burdensomeness may act as a mediator between physical impairment and low mood (Dempsey, Karver, Labouliere, Zesiewicz, & De Nadai, 2012). Therefore those parents who do perceive their Parkinson's as having a detrimental effect on children's quality of life may be at more risk of emotional difficulty. Families should be offered interventions that allow parents to distribute care needs to those other than children. Psychological therapy for those with chronic health conditions is complex (Dobbie & Mellor, 2008) and traditionally cognitive-behavioural approaches have been demonstrated to be beneficial for psychological distress for those with Parkinson's (Koychev & Okai, 2017). Additionally, a range of alternative therapies have also been considered (Zarotti et al., 2020) however specific exploration of psychological therapy for distress related to parenting has not been conducted. Given parents difficulties with identity, clinical trials that evaluate the impact of finding preferred identities through narrative therapeutic approaches (Morgan, 2000; Payne, 2006) could be considered. Similarly, parents in this study found benefit in re-focusing on values as they began to face restrictions ability to meet parental demands. Acceptance and Commitment therapy (Hayes, Strosahl, & Wilson,

2009) helps persons to consider their values and has previously been shown to help those with chronic health conditions (Graham, Gouick, Krahe, & Gillanders, 2016). Parents also worry about if and how they will physically and cognitively deteriorate whilst their children are still young. Parents attempt to prepare their children both financially and as individuals for this eventuality. Services should provide financial advice for parents who face significant impairment and the possibility of lost employment.

Conclusion

Participants in this study discussed challenges to parenting whilst living with Parkinson's. Although there may be a period of time where parents with Parkinson's are able to maintain capability, Parkinson's begins to disrupt functioning and identity even in the conditions early stages. Consequently, parents feel they have lost an expected family future and must prepare their children for increasing parental impairment. This process may be understood through the FAAR model (Patterson & Garwick, 1994), however more research is needed to underestand parental experiences more broadly.

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Table 2-1: Participant Pseudonyms and Demographics

Pseudonym	Gender	Age	Age of Children	Approximate Time Since Diagnosis
Sofia	Female	55	10, 12, 14, 16	1-2 years
Nigel	Male	47	17, 20, 22	5-6 years
Karl	Male	52	12, 15	3-4 years
Harriet	Female	56	23, 26	1-2 years
Paul	Male	55	17, 21	7-8 years
Rodney	Male	60	19, 24	1-2 years
Karen	Female	50	13, 16	4-5 years
Diane	Female	57	23, 28	4-5 years
Jaqueline	Female	45	12, 15	1-2 years

Appendix 2-A

Guidelines for Publication for the *British Journal of Health Psychology*

BJHP AUTHOR GUIDELINES

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, manuscripts should be submitted online at http://www.editorialmanager.com/bjhp

Click here for more details on how to use **Editorial Manager**.

All papers published in the ***British Journal of Health Psychology*** are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

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This journal will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The British Journal of Health Psychology publishes original research on all aspects of psychology related to health, health-related behaviour and illness across the lifespan including:

- experimental and clinical research on aetiology
- management of acute and chronic illness
- responses to ill-health
- screening and medical procedures
- psychosocial mediators of health-related behaviours
- influence of emotion on health and health-related behaviours
- psychosocial processes relevant to disease outcomes
- psychological interventions in health and disease
- emotional and behavioural responses to ill health, screening and medical procedures
- psychological aspects of prevention

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- theoretical papers which report analyses on established theories in health psychology;
- we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses); and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

All systematic reviews must be pre-registered. The pre-registered details should be given in the methods section but blinded for peer review (i.e., ‘the review was preregistered at [BLINDED]’); the details can be added at proof stage. Registration documents should be uploaded as title page files when possible, so that they are available to the Editor but not to reviewers.

Please refer to the separate guidelines for **Registered Reports**.

COVID-19 Research
The BJHP has received an overwhelming number of COVID-19 related submissions. We can only consider papers that are providing new and novel data on COVID-19. We particularly welcome submissions of intervention studies. Furthermore, rapid peer review for COVID-19 submissions has now ended. COVID-19 papers will now be handled alongside other standard submissions.

4. PREPARING THE SUBMISSION

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Before you submit, you will need:

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Abstract

For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found **here**.

Keywords

Please provide appropriate keywords.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Statement of Contribution

All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

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As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors.

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Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

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Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

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- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.
- **Effect size:** In normal circumstances, effect size should be incorporated.

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Author Guidelines updated April 2019

Appendix 2-B

Sample Transcript

		And I said I said it's not for me it's for my boys I can't do it to	“Here we go another health issue” that she puts her boys through.
27:40		them again because of the meningitis, I just thought you know	
		here we go, another health issue.	
27:50		So it's quite interesting I thought about them immediately,	“I thought about them immediately” her boys.
		right at the beginning.	

28:00	I	You said that you couldn't do it to them, what had you	
		done in the past? What had it felt like you had done?	
28:10	P7	Not quite sure what I meant, I didn’t want them to be living	She predicted her children to be living in a worried, stressful environment.
		I suppose I didn’t want them to be living in a worried, stressful	
		environment .	
28:20	P7	And I suppose I thought that perhaps whilst I had the meningitis	Using previous experience of poor health to predict future experience of Parkinson’s.
		you know there must have been a certain amount of worry	
28:30	P7	Well I know, you know, like I said the little one did have,	Would Parkinson’s mean a loss of a normal carefree childhood?
		you know when he remembered at the end of school and it	
28:40		wasn't a normal time for them and I just I just wanted them to	
		have a normal carefree time.	
28:50	P7	I don't want them to have a mum who needs worrying about	She doesn’t want to be the reason her children worry
	P7	or looking after all and that was it really.	She doesn’t want them to have a mum who needs looking after.
	I	And you said that after you received the diagnosis, it sounded	
29:00		like your thoughts have already gone to your children already,	
		but there was a year where you wanted to figure things out?	
29:10	P7	Yes, so I didn't tell them. I told my best friends and my family.	Not just deciding when but if she will tell her children.
		And that was it, really. Because I thought I just need to,	
29:20		well, I didn't know if or when I would tell them,	
	P7	but I knew that I wanted to be able to do it calmly	She wanted to tell them calmly so they could feel as confident as her she wouldn’t disappear anytime soon.
		and in a way where they feel confident reasons recently confident	
29:30		that things were OK.	
		Because I was also quite clear I hadn't been diagnosed with a	
29:40		brain tumour, it wasn't that I was going to disappear in 6 months	
		time, so it wasn’t yeah.	
	P7	I had time to sort of process it myself before telling them.	Processing herself before explaining to her children.
29:50	P7	And I think I didn’t tell people, partly not telling them, but	A hidden Parkinson’s was an opportunity to escape Parkinson’s and be seen as her previous self.
30:00		definitely not telling all the mum’s at the school gate and that	
30:10		kind of things was just having bits of life which were normal.	
		You know at the school gate, chatting about inconsequential	
30:20		things was a bit of relief, sometimes when I spent a day sort	
		of reading about something or doing lots of exercise to keep us	
30:30		mobile as possible, you know that that sort of side of things. I	
		think it was, it was quite nice just to have the freedom just to	
30:40		be the same as I was before the diagnosis somehow.	
	I	Yeah, please correct me if I'm wrong, but are you suggesting	Parkinson’s was now filling her daily life.
		that you do your days in the house when the kids went there	
30:50		were filled with filled with Parkinson's, they were filled with	
		research and reading?	
	P7	There was a lot more, yeah, there was a lot more than there had	
		been and I think.	
31:00	P7	So the way I have sort of approached Parkinson so far, has been	She took an active approach to management (exercise, diet, rest and
31:10		sort of lots of targeted exercise and good diet and rest	
31:20		and mindfulness, there main things I think.	

			mindfulness).
	P7	And all of those things take time, particularly the rest bit of it	Parkinson’s now took up her time
31:30		so that there's enough left when they come home from school.	There’s enough left for when they come home from school.
	P7	Not to just go all day and then when they come home from	
		school have to rest.	
	I	Yeah.	
31:40	P7	So I think that's what the days were for as long as well	
		as all the other stuff, the house management.	
31:50	I	It sounds like Parkinson's created additional tasks to do to manage	Parkinson’s is itself a task and a barrier.
		it?	
32:00	P7	Yeah, definitely with less ability to do the multi-tasking.	
		so it was kind of like ugh, it was more tiring.	Managing Parkinson’s and being a parent is tiring.
	I	You talked about not wanting to be tired, but it does sound	
32:10		extremely tiring.	
	P7	Yes, yes.	
	I	Were there days where the amount of tasks and staying on top of	Parkinson’s meant prioritising things in her life.
32:20		things was too much?	
	P7	Sometimes but I think I got quite good at prioritising.	
32:30	I	Which things took priority?	
	P7	The exercise because, yeah otherwise later down the line	Maintaining her physical ability through exercise was important.
32:40		then I wouldn’t be able to function.	
32:50	P7	And the rest well kind of taking the opportunity when there wasn’t	Interacting with other’s whilst doing tasks was mentally tiring for her.
33:00		anybody else who was talking to me or I had to interact with	
33:10		just to keep single focus. It was the having to multi-focus	
		that that was most tiring I think it mentally.	
	I	OK.	
33:20	P7	By I really wanted to make sure there is enough left in the tank	Making sure enough was “left in the tank” for the boys was important
		for when the boys came home from school.	
	I	I'm interested in this sense of them making sure there’s	
33:30		enough left in the tank, what was it that was important to you	
33:40		to lead to making that decision to identifying that value?	
	P7	I wanted them to have a parent available, so my	Parkinson’s meant she needed to reserve her energy to be the available parent.
33:50		husband would be at work till I don't know seven or something.	
	P7	And I think secondary school children I initially thought that	Children continue to need her after school so she must save her energy for them.
34:00		primary school children needed you after school and then they’d	
		be fine, but actually I think secondary school children often do	
		as well because they need to, they might want to say something	
34:10		or ask about something.	
34:20	P7	This where my oldest son is well is not particularly good at getting	She needs the energy to “nudge” her son into homework
		down to his homework, so just somebody to give him a nudge.	
34:30		Say come on, sit down and do it,	
	P7	and then you can, you know, do something fun afterwards	She needs enough energy to be available without hyper-managing them.
34:40		so but without being sort of managing them as in hyper-managing	
34:50		them is being available.	
	P7	I think that's the key word that comes to mind and that means	Parkinson’s fatigue means

35:00	P7	you can be there physically, but if you're too tired you're not	she can be there physically but not available to her children
		actually available.	
35:10	I	And it sounds like you do not through the day and this desire to	
		be available you are really pushing towards making that happen,	
35:20		what was it like after school after the diagnosis?	
	P7	That was so we're really talking about when they're 12 plus	The children being older made parenting with Parkinson's easier.
35:30		aren't we, yeah. I think it was fine, I think I was very thankful	
35:40		that they were 12 plus,	
	P7	because it would involve chivvying them a bit to do homework	She needs energy to chivvy them to do homework
35:50	P7	Or seeing whether they wanted to have a mate round	She needs to save energy in case they want a friend to visit
		making that really easy for them,	
	P7	cooking food.	She needs to save energy to cook.
36:00	P7	Compared to people I know with Parkinson's, who've got smaller	Parenting older children is easier because you don't have to make sure they are safe like younger children.
		children. You're not actually making sure they're safe as in	
36:10		I don't know falling out the window.	
36:20	P7	The other end of that, as the teenagers get a bit older,	As teenagers get older the demands of parenting last later in the day.
		I suppose there is an element of making sure they're safe but	
36:30		and then you're coming into a whole different ball game because	
36:40		after school stretches from 4:30 when they get home to	
		suddenly the 16 year old is out till 10.	
36:50	P7	And then there is an element of keeping them safe physically and	As teenagers get older parenting demands change to keeping them safe in the world rather than the home
		giving that phone call and getting are you on your way	
		home.	
37:00		So it's it's quite an interesting span sort of the 12, to 13 to 16.	
	I	It seems like it's time for changing demands is a parent?	
37:10	P7	Yeah and Parkinson's makes it easier to get for me anyway to get	Parkinson's makes it easier to become stressed as a parent.
37:20		Stressed.	
	P7	things make me anxious much more easily.	Parkinson's makes her anxious more easily as a parent
37:30	P7	So not being in situations that made me anxious is quite useful	She avoids situations that make her anxious as a parent.
	P7	And so in some ways it's probably I've been able to just sort of	For her own health she has to "pick her battles" and be flexible with her boundary setting.
37:40		go well what is worth fighting about,	
		with the older ones say, does he really have to be back at 9 or	
37:50		can we say, yes 10 o'clock is fine. You know what, pick your	
		battles. And I think that's been quite healthy.	
38:00		In another sense,	
38:10	P7	sometimes I might have to say now you know I get stressed	To manage her parenting stress and therefore her Parkinson's she negotiates
		about things like that so what are we going to do about XYZ	
38:20		You know? Are you going to, do you promise me you will pick up	

		your phone when I ring just because you know I get a	in advance with her children asking them to empathise with her situation.
		bit stressed and then will it will be fine, as long as we are in	
38:30		communication I don't mind what happens.	
		Yeah it's sort of setting up things in advance.	

Appendix 2-C

Forming Themes from Early Concepts

Early concepts	Descriptive themes	Final themes
Hidden from children, helpful to understand, a drawn out process, an emotional discovery.	A diagnostic journey	Disclosing
Encouraged to tell children, time to understand, waiting and holding back to protect, softening the blow, reasons to delay, an inevitable emotional moment, children become worried.	Telling the children	Disclosing
Unchanging physically, unchanging life and work, unchanging parenting ability, unchanging parenting style, unchanging relationships, hiding worries or details, being an example.	An unchanging parent	Holding on to the parent I was
Desire to stay the same, staying the same for the children, act as if it is not there, continuing to be an example, maintaining functioning, a reassuring parent, hiding Parkinson’s.	Holding on to the parent I was	Holding on to the parent I was

Appendix 2-C continued. Forming themes from early concepts

Early concepts	Descriptive themes	Final themes
Creating difficulty, limitations or demands, affecting what parents can do for and with children, parents emotions.	Parkinson’s is affecting parenting	Changing as a parent
Becoming Parkinson’s, changing identity as a parent, changing identity to children.	Becoming Parkinson’s	Changing as a parent
Adapting perspectives, adapting parenting style, facing tough decisions, what do I prioritise?, A new normal for children.	Adapting to Parkinson’s	Changing as a parent
Emotionally supportive children, practical support, positive response to support, negative response to support.	Supportive Children	Changing as a parent
Shortened life, advancing time line, shrinking world, slipping away	Advancing life	An uncertain future
Lost dreams and hopes for children, lost dreams and hopes for self, family milestones.	A lost future	An uncertain future
Uncertain life ahead, uncertain life as a parent, uncertain life for children, only one thing is certain; it will get worse	An uncertain new future	An uncertain future
Preparing finances, independent children, ongoing care.	Preparing	An uncertain future

Section Three: Critical Appraisal

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Introduction

This critical appraisal documents the motivation to investigate the experiences of parents with Parkinson's and cancer. It summarises the findings of both papers and considers them in relation to each other. In addition it considers further the strengths and limitations of the research methodologies.

Why the Research Focus?

Working within psychological care I have historically been drawn to understanding and supporting those with physical health conditions, this has meant I have spent a considerable portion of my career to date working within a health setting. Although this gave me some direction when considering a thesis topic, my arrival at the specific research questions is guided by more personal experiences. My interest is influenced by my connection to an older relative who lives with the condition. Although my salient knowledge of this person is of an older figure whose children are adults, he was the first and for a long time only person I had known who had developed Parkinson's at a young age. The warmth he has demonstrated throughout his life to those around him likely led to my own feelings of admiration towards him and in turn a desire to generate a piece of work that could be valuable to the Parkinson's community.

Like many people across the U.K. cancer has affected my family and friends; a majority of those I have known with the condition have died. Whilst considering research questions, a member of my family had survived cancer, only for one of his sons to die with the disease a year later. Sadly, after the loss of his son, the father's cancer relapsed leading to his own passing. I noticed that throughout his experience of cancer the position of being a parent was important to him and created difficult dilemmas, one of which was the decision and timing to tell his children. The systematic review allowed me to find another area in which I could find personal significance in the purposeful contribution to an evidence base. The personal connection to those who had experienced Parkinson's and cancer added to my motivation to complete a meaningful piece of work. However, it also should be considered in the context of my personal response to the data and the potential influence on my analysis, this is to be discussed later in this paper.

Findings

Paper one was a meta-synthesis exploring the research question "what are the experiences of parents with cancer when informing their children about health status". In terms of health status this research included not only the experience of informing children about the diagnosis itself, but also what this meant in terms of the understanding cancer, the parental experience of the condition and the potential consequences for the family. It included 20 papers that either focused on the question or included relevant sections within the analysis. The meta-synthesis identified an overarching theme of 'protection' which captured parents desire to ensure that no harm came to their children during the informing process. Protection as an aim ran throughout the sub themes of 'deciding', 'telling', 'impact' and 'support', guiding parents' actions at each stage. For those parents with cancer, informing children was a difficult decision and requires consideration of many complex variables. At present parents feel under-supported in the process and services should seek to provide more specific interventions.

The second paper was a reflexive thematic analysis using qualitative data from interview studies. It explored the experience of persons with Parkinson's who were parenting adolescents and young adults. The research paper identified four themes describing the parents' experiences: 'disclosing', 'holding on to the parent I was', 'changing as a parent' and 'an uncertain future'. These themes described the process that parents moved through following learning about their diagnosis of Parkinson's. For parents with Parkinson's the analysis describes the difficult transition between being a physically well-functioning parent to one who is beginning to face impairment. In this experience parents facing barriers begin to make adjustments to parenting behaviour and values. It explores how these changes cause a shift in parental identity, in the eyes of the parents and children themselves which can cause emotional difficulty. This may reflect other parents with chronic health conditions, however the daily experiences for Parkinson's should be considered specifically to allow opportunity for the development of targeted interventions. Clinical psychologists are well positioned in terms of expertise to facilitate the development and implementation of interventions that support parents across their illness experiences. Although the findings have been reported and discussed elsewhere in this thesis the relationship between the two papers has yet to be discussed.

When comparing the experience of parents with cancer and parents with Parkinson's it is important to recognise the differences in the wider disease experience. Cancer is more prevalent than Parkinson's (Maddams et al., 2012; Walker et al., 2010; Wickremaratchi et al., 2009) and as a result impacts many more persons in terms of their own health or indirectly through social networks. Cancer also receives a large proportion of research funding (Luengo-Fernandez et al., 2015) which in turn allows health services and charitable organisations to make supportive information available to the public. Given the prevalence and access to well informed organisations, families may tend to have a larger amount of knowledge and lived experience of cancer compared to other conditions, such as Parkinson’s. However, in countries such as the UK and the USA, organisations like Parkinson’s UK and The Parkinson’s Foundation also provide access to a wide range of informative materials, therefore, differences in public knowledge between cancer and Parkinson’s may not be as large as between cancer and other health conditions. Although those with Parkinson’s can experience a wide range of health impairments (Politis et al., 2010; Sveinbjornsdottir, 2016) cancer can develop across biological systems impacting any aspect of bodily functioning (Miller, 2018). Therefore the impact on parents and families may vary widely. Within the range of current medical science Parkinson’s is not curable; therefore treatment focuses on the management of symptom severity and improvement of functionality (Connolly & Lang, 2014; Tomlinson et al., 2012; Zarotti et al., 2020). Treatment for cancer however can be palliative (Clark, 2007) or focus on cure (Delaney et al., 2005; Iwamoto, 2013), although depending on the type and stage of cancer outcomes can vary (Schofield et al., 2006). The difference in treatment options and their side effects likely influence the family experience of parental health conditions.

Despite the differences in consequences for health and options for treatment, there are some similarities, one of which is the need to inform family and the two studies both comment on the experience of informing children. For parents with cancer, the process of telling their children about their condition was difficult and this was reflected by parents with Parkinson’s, who in some cases described it as the hardest part of the parental experience. Both sets of parents lived through a point in time where they were the keepers of knowledge about the conditions and faced a decision about if and how they should inform children. Although, deciding if and how to inform was not explored in depth for those with Parkinson's in paper two, this was the focus of paper one. Decision making for parents with cancer was understood through models of behaviour theory such as the theory of planned behaviour (TPA;(Ajzen, 1991) protection motivation theory (Rogers, 1975) and health action process approach (Schwarzer & Luszczynska, 2008). Generally, it could be said of these models that they describe a process in which weighing up of a variety of information informs an appraisal of a situation, creating intentions that lead to behaviours. This linear view of behaviour fails to acknowledge that parents were typically influenced by an already formed aim of protection and decision making was therefore centred on how to achieve this. Some elements of behavioural models were absent in the data, such as the consideration of 'subjective norms' found in the TPA (Ajzen, 1991). Subjective norms refer to an individual's understanding of how behaviour will be perceived by with wider population. Although cultural and social beliefs were mentioned in papers, this was infrequent and there was insufficient data available to draw out any consideration related to subjective norms in the discussion. However, the understanding of how subjective norms and other elements of theories influence decision making may be limited due to these areas not being the focus of questions by the original researchers. Furthermore, the inductive nature of the original analyses may have limited exploration of elements of decision making that were not immediately apparent to the participants themselves. Therefore future research could consider qualitative study that explores parental experiences in relation to current theory. For those with cancer, children noticed dramatic physical and behavioural change. Parkinson's usually progresses more slowly than cancer and treatment often results in fewer striking visual changes requiring less time in hospital. Taking into account the early visual differences between cancer and Parkinson's, decision making and the eventual process of telling children may have occurred at different rates for each set of parents, as some with Parkinson’s felt they could withhold the information for several years. However, this does not mean Parkinson’s was not detected by children before they were told, as was seen in one case where a father was told by his teenage daughter that she had noticed him losing his balance. The generic health behaviour models mentioned above do not incorporate how physical and behavioural change of parents as a result of their illness may reduce the level of control they have over the informing process. Therefore any exploration of theory should consider expanding models to account for the role of visual change over time. Both sets of parents similarly attempted to communicate reassuring messages of hope with regards to condition progression and treatment. This may have represented a desire to protect children from the harms of knowing about their parent’s condition. Protection was the overarching theme in paper one and it ran throughout the process of informing children about parental cancer. Although protection was not an explicitly identified theme for those with Parkinson’s, the idea of protection can nonetheless be seen throughout, e.g., when considering how to tell children about the condition, in elements of trying to carry on as before as parents and when preparing for the future.

In terms of informing children paper one identified the narrow range of evidence available that described the experience of informing children. There was a notable absence of similar literature across many health conditions, including Parkinson’s which has no papers dedicated to this experience. Given the significance identified by parents with Parkinson’s and the complexity of the process identified for parents with cancer, this area of understanding may benefit from more targeted research.

Methodological Considerations

The meta-synthesis was intended to explore the experiences of parenting with cancer. However, a paper was published in January 2021 as my study was underway (Matuszczak-Świgoń & Bakiera, 2021), reading this paper I had noticed that the informing experience had not been extensively explored and therefore I changed the focus of the review rescreening the original search. Two of the five papers which focused on experiences of informing did not contribute to the final theme of *Support*. However, the three remaining papers were reinforced by five additional papers. Although, this was the least number of papers that contributed to a theme, several of these papers were high quality. The synthesis excluded papers focused on evaluating specific interventions and therefore may not have included all the relevant data for this theme (Oja et al., 2020). The synthesis could benefit from inclusion of further research that explores outcomes and experiences of interventions designed to support parents informing children.

The synthesis included 20 papers in the analysis, although this included papers from a range of countries globally, there were many regions that were not included such as Africa, Central America, Central Asia or South Asia. Additionally, the only paper from South America (Kenne Dornel et al., 2018) was rated as one of the papers with the lowest quality. As international differences healthcare systems and cultural perspectives may play a role in the experience of illness (Chen et al., 2012; Mehnert & Koch, 2005; Silbermann & Hassan, 2011) the synthesis neglects to explore the experiences of parents within those regions and therefore does not capture a complete global experience. It is also important to note the limited number of papers from each region, particularly South America, meant that thematic synthesis culturally and geographically de-contextualises the analysis from the original papers. Therefore, cultural variations within the experience such as informing facilitating the opportunity for children to engage in acts of filial piety, the Chinese cultural practice of repaying parents through acts of care (Wang et al., 2020) are lost from the synthesis. It would be beneficial for future synthesis if there was high quality qualitative research with a wider global coverage that focused on the process of informing children about parental cancer. A large number of papers in the meta-synthesis focused on breast cancer (Asbury et al., 2012; Barnes et al., 2000; Chin et al., 2020; Coyne & Borbasi, 2006; Davey et al., 2012; Fisher & O'Connor, 2012; Kim et al., 2012; Lalayiannis et al., 2018; Shands et al., 2000; Stiffler et al., 2008; Turner et al., 2007), although the remaining papers included a range of cancer types. As cancers can vary in biological symptoms, cancer severity, prognosis and treatment options, the synthesis may therefore fail to capture the potential difference in experiences between cancers. Future research should explore how and to what extent variations impact parental decision making throughout the informing process.

In the empirical paper (paper two), the original intention was to recruit between 15 and 20 participants. However, only 9 participants took part in the study. Attempts were made to recruit more participants by broadening the recruitment criteria from currently parenting children aged between 12 and 25 to those recently parenting children within this age range, however this was unsuccessful. Despite the lower than desired number of participants a clear set of themes were drawn from the data. Several qualitative methods aim for data saturation, which is the point at which the addition of participants would not result in further development of new concepts (Guest et al., 2006). It remains unclear if new themes may have developed with a larger sample. The determination of the sample size in the design of this study was based on studies which investigate data saturation in qualitative research (Hagaman & Wutich, 2017) although evidence suggests themes may be apparent from as early as six studies (Francis et al., 2010; Young & Casey, 2019). Given that an aim of the sample size is to determine the minimum number of participants who provide a sufficiently rich understanding when answering a unique research question (Patton, 2015) within a particular study design, it may have been more appropriate to consider the information power of the sample more specifically (Malterud et al., 2016) in study design. When considering suggestions made by Malterud et al. (2016), this study likely benefited from the narrow range of variables demonstrated in the participant group adding specificity to the data. Additionally, my own clinical experience of facilitating rapport when discussing personal difficulty likely facilitated rich conversations about emotive topics. However, given the broadness of the research question and inductive nature of the analysis, more participants may have allowed the researcher to better understand the nuance of the data and participants' experiences (Hennink et al., 2017). Although the homogenous nature of the participant group likely improved the analysis, it restricted the research to the experiences of a narrow group of persons. This research excluded the experience of parents of young children, those with advanced conditions and single parents. Future Parkinson's research should consider exploring these experiences more specifically.

Although the original design was for interviews to take place in person where possible, the COVID-19 pandemic meant all interviews were conducted remotely via video or telephone call. This may have limited who was able to participant in the research to those with access to technology, those who felt comfortable using these technologies and those with the physical capability to be understood using telephone or laptop microphones (Deakin & Wakefield, 2014). However remote interviews have been used to provide access to those who do not feel comfortable with asking researchers to travel for face-to-face meetings (Hanna, 2012) and to allow flexible movement of interview dates and times (Holt, 2010). For those who opted for telephone conversations this clearly limited communication via facial expression, removing non-verbal cues in the interview process, some of this may have also been lost during video calls (Deakin & Wakefield, 2014). Some have argued that there are benefits to this as it allows researchers to remain at the textual level of the data (Holt, 2010). The impact of COVID-19 on the parental experience was considered during interviews. Although, some parents had mentioned changes to family life such as spending more time together or having less time to exercise, the pandemic seemed to have little apparent impact on parent's accounts of their experiences.

Initially the researcher aimed to use participant feedback to ensure the analysis in paper two resonated with participant's experiences to improve trustworthiness of the analysis (Thomas, 2017; Creswell, 1998) by reducing the impact of bias in the researchers interpretation (Mason, 2002). Although this was not intended to be used within the empirical paper itself, it was intended to be used within this critical appraisal. Due to time constraints this process was not achieved before the deadline for submission. On reflection, the use of feedback to confirm validity of results could be at odds with the epistemological stance of this paper as the analysis represents the reflections on experiences of participants and the interpretations of the researcher at a specific moment in time, rather than the discovery of an objective truth. A participant's recollection of experience and subsequent meaning making may change due to the development of several individual and contextual factors over time. Additionally, abstraction of individual stories to themes, may mean the participant experiences difficulty recognising their contribution to the final piece of work, placing the participant at risk of distress (Birt et al., 2016).

Delays to the thesis process were in part contributed to by the impact of the COVID-19 pandemic on project start and recruitment. Furthermore, publication of a paper that explored the original research question of the systematic review resulted in additional allocation of time for the development of a new question and changes to the screening process. Although the researcher consulted with a research supervisor who had extensive understanding of Parkinson's literature and a secondary supervisor who had clinical experience of working with families, triangulation of the analysis could have been improved by the inclusion of participant feedback. Participant feedback will therefore be sought prior to publication.

The empirical paper used reflexive thematic analysis (RTA) as its methodology. It has been argued that thematic analysis is not in fact a methodology in itself but a framework that facilitates varying approaches to analysing qualitative data (Braun & Clarke, 2006, 2019). Unlike alternative methods such as interpretative phenomenological analysis (Smith, 2009), RTA does not have a defined ontological and epistemological position, therefore researchers must considerately and explicitly set this out during research design (Braun & Clarke, 2019). This paper took a critical realist stance which proposes that although there are objective truths, any understanding is relative to the individual. Although critical realism argues that individual understandings are situated within the different cultural and historical contexts of the individual (Bhaskar, 2013), the aim of the analysis was to find patterns of common experiences reported across the data.

The RTA process requires a researcher to both code and draw out themes from the data, therefore considerations of the hermeneutic element of the analysis cannot be set aside. Other qualitative analytical methods identify the context of the researcher within the hermeneutic process of analysis (Smith et al., 2009) and it is acknowledged in RTA that the researcher cannot separate their own context from their analysis and it has been suggested that researchers critically engage with their role in interpretation (Braun & Clarke, 2006). I took several steps to account for my role in the analysis. Inductive semantic coding was selected as to facilitate a process that initially remained as close to the original data as possible, allowing the analysis to be grounded in the experience of participants rather than my own assumptions. Additionally, I kept a reflective diary was kept in which I noted my own reactions to the interviews and the data.

Reflexivity, that is the conscious consideration by the researcher of their relationships with all aspects of the research process such as design, data collection and analysis (Hertz, 1997), is deemed an important part of reflexive thematic analysis (Braun & Clarke, 2019). As a trainee clinical psychologist reflection is a common element of professional practice (BPS, 2017) this assisted the reflexive process at a research level as I was in the habit of considering my own stance but also the relationship between myself and a client (in this case participant). Clinically, these reflections occurred during the conversation itself but also afterwards, often facilitated by a supervisor. Given my personal and professional experience of Parkinson’s was one of significant physical impairment I was surprised when some participants discussed an ability to parent as ‘normal’. Early in my analysis this may have led me to discount the importance of the codes which later became theme 2 of my empirical paper ‘holding on to the parent I was’. However, reflecting through my diary allowed me to factor this in to a ‘narrative’ that was later discussed with the supervisory team. Reflexivity was also beneficial during data collection and allowed me to make adjustments to interview techniques. Early on in interviews I noted in my diary my tendency to ask questions that explored participants’ emotional responses to events and sought out the meanings they were making from their experience. This was likely related to my experience working as a trainee clinical psychologist and was reflected upon with my research supervisor. My interview style was further influenced by my clinical skills, occasionally using summarising and reflecting techniques. At times these techniques and questions led to participant considerations that they later described as thoughts they had previously been unaware of. This highlights the influence of the researcher in not only interpretation of the data but also in the interview process and data generation (Finlay, 2002). As I became more comfortable with the interview process, I noticed I also began to openly acknowledge emotional difficulty more freely, allowing participants to feel genuinely heard. At the end of interviews this had been commented on by participants and likely made me more inclined to provide this in subsequent interviews. When designing the interview schedule one third of the questions focused on the parental experience before Parkinson’s. As I moved through the interviews it became increasingly apparent that although this provided a grounding context for each individual it also meant a large amount of the data was not relevant to the research question. I noticed that this led me to focus my time more on experiencing after diagnosis than before.

Conclusion

This research has explored the complexity of the parental experience whilst experiencing illness. Both papers identify how consideration of children’s wellbeing occurs at different stages across the parental experience. It is highlighted that parents need to be supported in order to be satisfied in their parenting roles and ability to do the best for their children. However, more research is needed to understand parental experiences and how best to support parents, in particular for those diagnosed with Parkinson’s.

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Section Four: Ethics Proposal

John Cunningham

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

Ethics Application

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

Title of Project: What impact does Parkinson's have on the experience of parenting?

Name of applicant/researcher: Mr John Cunningham
ACP ID number (if applicable)*: **Funding source (if applicable)**
Grant code (if applicable):

Type of study
Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**
Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE
1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist (Student)

2. Contact information for applicant:
E-mail: j.cunningham4@lancaster.ac.uk **Telephone**: [redacted]

Address: Doctorate in Clinical Psychology, C16 Furness College, Lancaster University, Bailrigg, Lancaster, LA1 4YG

3. **Names and appointments of all members of the research team (including degree where applicable)**

Mr John Cunningham
Trainee Clinical Psychologist, Studying for DClinPsy

Dr Fiona Eccles
Lecturer, DClinPsy, Lancaster University
Dr Anna Daiches
Clinical Director, DClinPsy, Lancaster University

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website
DClinPsy Thesis

4. Project supervisor(s), if different from applicant:

Dr Fiona Eccles
Lecturer, Lancaster University

Dr Anna Daiches
Clinical Director, DClinPsy, Lancaster University

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:

Dr Fiona Eccles
Lecturer, Lancaster University

Dr Anna Daiches
Clinical Director, DClinPsy, Lancaster University

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:
2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk
3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'
4c. If yes, where relevant has permission / agreement been secured from the website moderator?
4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users?

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain?
6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?
b. How will the confidentiality and anonymity of participants who provided the original data be maintained?
9. What are the plans for dissemination of findings from the research?
10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE
Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

This study aims to explore the experiences of parenting whilst living with Parkinson's. People who are parents and have Parkinson's will be interviewed to learn about their experiences. These interviews will include a set of questions which allows the interviewee to openly discuss their experience. Interviewees will be recruited through existing Parkinson's support charities from the UK and via Twitter. Initial recruitment will include persons who are currently parenting a child or young person, however, should this not reach the numbers necessary the study will expand to include those who have historic experience of parenting this age group. Interviews will be transcribed and then analysed using thematic analysis; a method which seeks to identify common themes across the interviews.

2. **Anticipated project dates (month and year only**)

Start date: March 2020 End date: March 2021

Data Collection and Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

The sample of participants will be persons aged over 18 (no upper age limit) with no discrimination in gender. The sample will initially aim to recruit between 12 and 15 participants (but may need up to 20, depending on results of the analysis) who are living in the United Kingdom. They are required to have a diagnosis of Parkinson's which will have been made at least 12 months prior to their youngest child turning 24, as this will give at least one year's experience of parenting a child/young person under 25 while the participant was living with the diagnosis. Participants should not be living with another chronic health or psychological condition which the participant feels has a significant impact on their lives. In order to complete the interview and as the student researcher only speaks English, participants must also be fluent in English. Participants must be willing and able to answer interview questions about their experience of parenting. Participants must be able to access a telephone or video calling service. Participants should be able and willing to spend approximately 60 minutes engaging in an interview. This information will be self-reported.

Initial recruitment will invite those with Parkinson's currently parenting a child or young adult aged between 12 and 24. Should this fail to reach the target sample size, recruitment will then invite those with historic experience of parenting a child/young adult of this age while living with Parkinson's. It is important that the research maximises its clinical relevance. As social structures change over time, experiences closer to the present day will have more relevance to future clinical practice. By the year 2008 the Disability Discrimination Act (2005) and its amendments were in effect. Additionally, social media use was beginning (Our World in Data, 2019), and Parkinson's UK started their online peer support forum (Parkinson's UK), both becoming a potential means for previously isolated persons to connect with peers. Therefore, when recruiting in phase 2 (historic experiences) this study will recruit persons who were parenting children aged 12-24 with Parkinson's during or following the year 2008.

This study aims to look at the experience of parenting older children and young adults as there is likely to be differences in the experience of parenting younger children to the experience of parenting older children and young adults. The age limits of child within the experience are based on the following rationale. In the U.K. a child usually attends secondary school from the age of 11 (England, Wales and N.I.) or 12 (Scotland) and this is an age often used as a lower limit when conducting research which explores the experience of children of parents with motor neurodegenerative diseases such as Parkinson's (Morley, Selai, Schrag, Jahanshahi, & Thompson, 2011, Schrag et al., 2004a, 2004b). Therefore this study will set the lower age limit at 12. In the U.K. a child legally becomes an adult at the age of 18. For parents with disability, legislation which has the potential to impact the functioning of the dyad and influence the experience of parenting also use 18 as the cut off for childhood (Care Act 2014, Children and Families Act 2014). However, the experience of parenting is not only dictated by legislation, but several other variables and the end of a parenting experience may be signified by other social and relational milestones. These milestones may occur at ages which are different from the 'typical' parent-child experience. From early on parent-child dyads may see parents in a cared for role, resulting in a shift of power to children (Frank, Tatum & Tucker, 1999). Although some changes in parent-child relationships may happen earlier when parents have a chronic condition, other changes may happen later. Reports by Dearden and Becker (2004) suggest several affected social milestones for young carers, including leaving the home, financial independence and relationships. Additionally, studies also report a decreased likelihood for young adults who are carers to be in employment (Yeandle and Buckner, 2007) and have continued carer burden during higher education (National Union of Students). This study should consider the dyads in which children may be young carers of parents with Parkinson's and the additional years that may be needed to capture the transition out of a parenting experience. Multiple services within the U.K. often use the age of 25 to dictate the end of being a young carer (The Carers Trust, The Universities and College Admission Service, The Children's Society) therefore this research study will also use this as a bench mark for setting an upper age limit for the children of potential participants.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Recruitment will be in the UK through Twitter, Parkinson's UK and Parkinsons.Me. Parkinson's UK and Parkinsons.Me will contact persons who have consented to be part of their study recruitment lists, sending them the advertising flyer and participant information sheet. The study may also be advertised on the Parkinson's UK Take Part Hub, a web page which hosts information for Parkinson's related research studies. Parkinson's UK and Parkinsons.Me may also advertise the study via their social media channels, mailing lists and local groups. Additionally, the study will be advertised via a professional Twitter account (handle @JC_Psychology) with tweets and replies directing persons to review the advertising flyer and participant information sheet, which will invite potential participants to contact the researcher directly via e-mail, telephone, post or twitter to discuss the study. The advertising flyer and participant information sheet may also be hosted on a Lancaster University DClinPsy webpage. Potential participants will be able to contact the researcher via e-mail, telephone or Twitter to discuss the project. Contact information will be taken at this stage, to allow the researcher to contact and arrange interview dates, location and method and a verbal consent instruction form will be sent for information.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Collection

A semi structured interview guided by the interview topic guide will be used to collect the data. Participants will be interviewed via telephone or video call. If circumstances permit the interviews may take place in person at a later date. For those outside of the North West of England interviews will be conducted by telephone or video call. It is important that the collection phase can be flexible in its delivery to accommodate the needs of the participants. This may mean that interviews can include breaks or be split across different days. If travelling to an interview the researcher will contact the participants to confirm the interview appointment. As interviews progress a second interview may be required in order to explore additional information from participants that may have been missed.

Participants will be asked if they wish to be sent a copy of the themes. If they have consented, participants will be sent a lay summary of the themes. They will then be invited to offer feedback on the summary. The feedback may be given via e-mail or verbally via telephone or video call (Birt, Scott, Cavers, Campbell & Walter, 2016). Participants may choose how feedback is recorded either via e-mail, via written notes or not at all. The participant will be asked to verbally consent to this before the feedback is given. With their consent these comments may be used in the final write up.

Analysis

As the experience of parenting with Parkinson's disease is absent in the current literature, it is proposed to take an inductive approach to analysis to allow for this understudied group to form the foundation of an evidence base, rather than using a deductive approach dictated by existing psychological theory. Analysis will be guided by the steps set out by Braun & Clarke (2006). The researcher will read through the completed transcript. Initial codes will be identified on a second reading. Coded transcripts will be reviewed for emerging themes. Emerging themes will be reviewed and grouped into super-ordinate themes where appropriate. Codes within themes will be compared with the original transcripts to ensure they are understood in their original context. The thematic analysis will attend to the core principles of validity and quality in qualitative research, i.e., sensitivity to context, rigour, coherence, transparency and importance as set out by Yardley (2000, 2008).

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

During the project contact information will be stored in a password protected file on the Lancaster University virtual private network (VPN) or a Lancaster University approved secure cloud (e.g. OneDrive) separate to any audio recordings of interviews or transcriptions. Video interviews will be conducted and recorded using Microsoft teams (only audio will be recorded). The audio from telephone interviews is to be recorded by the microphone on my personal computer sending data to my Lancaster University Microsoft Teams account. The audio recordings from video and telephone interviews will be transcribed by Microsoft Teams, if found to be sufficient the transcripts will be then edited manually. If they are found to be insufficient recordings will be transcribed manually. Recordings and transcriptions from Microsoft Teams are stored by Microsoft in the Streams application. They will be downloaded to my personal computer, then immediately uploaded to and stored on the VPN or approved secured cloud as soon as practicably possible. The laptop device is accessed only by myself and is pin protected. The recordings and transcriptions will then be deleted from the laptop, Microsoft Teams and Microsoft Streams. The VPN or the secure cloud are password protected university informatics systems and the raw audio data and transcripts will be accessible only to the researcher, the research co-ordinator and the research supervisors. The VPN/secure cloud copy of the audio interview data will be deleted once the thesis has been examined. The transcripts, feedback and audio recordings of consent will be stored for 10 years by the DClinPsy research co-ordinator. The research co-ordinator will delete the data after 10 years under the direction of research supervisors.

7. Will audio or video recording take place?

Audio recording will take place

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

Microsoft Teams will record the audio from video and mobile telephone call interviews. The account used to record on Microsoft Teams is supplied by Lancaster University. The recording generates a transcript and files are created within Teams and the connected Streams function. The recording and the transcripts will then be downloaded to my personal computer before being immediately transferred to the Lancaster University VPN or secure cloud. The data will be deleted from Microsoft Teams, Streams and the personal computer once transferred to the Lancaster University VPN/secure cloud. My personal computer is pin protected but not encrypted therefore will be stored in a non-publically accessible location.

b. What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Audio recordings will be made using my Lancaster University Microsoft Teams account. The recording and transcript digital files are created in Microsoft Teams and Streams. These files will then be downloaded to my personal computer before being immediately transferred to the Lancaster University VPN or approved secure cloud Once transferred to a Lancaster VPN/secure cloud the data on Microsoft Teams, Streams and my personal computer will be deleted. Once the thesis has been examined all electronic copies of the audio recordings of the interview will be deleted. As consent will be verbal recordings only, the audio recordings of the consent process will be stored for 10 years by the DClinPsy research co-ordinator and then will be destroyed under the direction of the research supervisors.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

Data will be stored by the research coordinator of the DClinPsy under the direction of the research supervisor for 10 years.

8b. Are there any restrictions on sharing your data?

Due to the ideographic nature of descriptions of experience, data will only be accessible to the researcher, supervisor and DClinPsy research co-ordinator.

9. Consent
a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law?

Yes

b. Detail the procedure you will use for obtaining consent?

Consent will be recorded verbally only. Participants will not be required to sign and return a written consent form. Participants in the study will be supplied with the participant information sheet, the verbal consent instruction form and the opportunity to discuss the study prior giving verbal consent. At the point of interview participants will again have an opportunity to discuss the study and each individual item for consent as listed on the verbal consent instruction form with the researcher. The researcher will then take verbal consent for each item, including the optional consent items and to be sent a summary of the analysis. Participants will later be contacted to give feedback and a secondary verbal consent process for the feedback will be conducted. This secondary process will take place as feedback may occur several weeks later during which time person's consent to feedback may change. Consent will be verbally recorded using Microsoft Teams

10. What discomfort (including psychological e.g. distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

This subject may be a personal and emotive topic to talk about with a researcher. Should the interview cause distress several measures could be taken to support participants, these measures will be discussed before beginning the interview. Participants will be reminded that participation is voluntary. When setting up the interview, participants may request the presence of a trusted person, with the intention to provide support should they need it. The researcher or participant can also stop the interview at any time. Further, there is the option for interviews to be divided into manageable sections with breaks of negotiable length and, interviews may be divided over multiple days. Participants will be provided with contacts to relevant charities and healthcare providers who can provide support. Additionally, should the participants which to talk with a member of Lancaster University who is not the researcher, they will be provided with the contact details for the research supervisors. Should the researcher consider the participant or another member of the public, including their children to be at significant risk of harm they will consult with their research supervisors in the first instance or if unavailable, another member of the clinical staff at Lancaster University to discuss appropriate action. Persons considered to be at risk would be directed to discuss concerns with their GP, Parkinson's nurse or another appropriate professional. Should any risk require immediate assessment or support, persons will be directed to attend an accident and emergency department. Should children be considered at risk the researcher will discuss this with their supervisor and may need to contact appropriate organisations.

Participants can withdraw their data for up to two weeks after the interview. However, after two weeks the data may be anonymised and organised into themes. The researcher will attempt to remove individual data after this point, but this may not be possible.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

As part of studying within Lancaster University I have regular supervisor contact. Additionally, as a student I have access to the Lancaster University Counselling and Mental Health service. When conducting interviews and particularly when lone working the researchers will adhere to Lancaster University's guidance on fieldwork. The interviewer will leave the details of the interview (e.g., participant, date, time, location) in a password protected online file with a fellow trainee. The researcher and fellow trainee will agree upon a set time to contact following the interview. The researcher will contact the fellow trainee when the interview has ended and the information in the file will be deleted. If this telephone call does not take place, the fellow trainee will initially attempt to contact the researcher via telephone, e-mail and text. Should there be no reply the fellow trainee will access the password protected document, alerting the university and relevant authorities.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

No direct benefits for taking part in the study are anticipated for participants. However, participants may find some benefit in sharing their experience.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

None.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

Yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Participants will agree a pseudonym with the researcher to make data including transcription, analysis and inclusion in the report anonymous. Effort will be made to ensure that verbatim quotes used in the write up do not contain identifying details. As interviews may take place over video web services, participants will be reminded that these methods cannot be guaranteed to be secure. Confidentiality may need to be broken should the researcher feel the participant or any other person is placed directly at risk of serious harm.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

I worked with Parkinson's UK and experts by experience to gather feedback on the design and materials for the study. Their feedback resulted in changes to a several items.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

I will seek publication in appropriate journals and plain English summaries will be sent to contributing partners and participants. It will also be written up in a DClinPsy thesis and, presented at the Lancaster University DClinPsy presentation day. The work may also be presented at appropriate conferences, special interest groups and training events.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

None.

SECTION FOUR: Signature

Applicant electronic signature: Date: 03/02/20

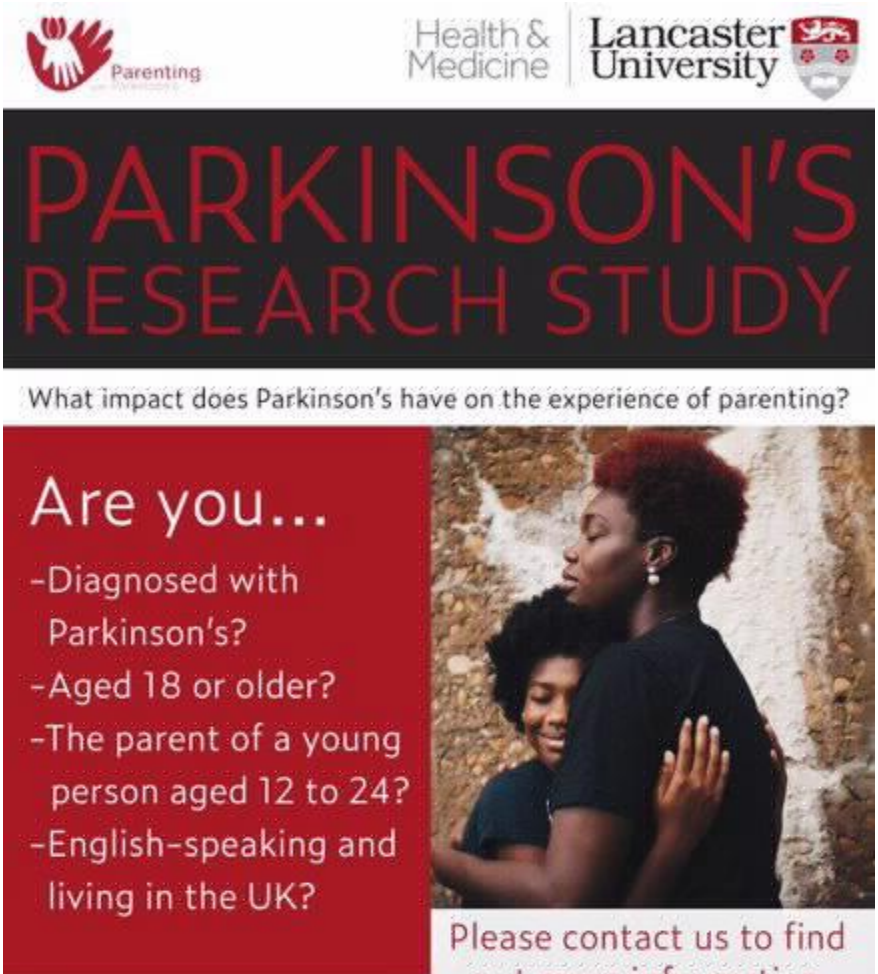
Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review.

Project Supervisor name (if applicable): Dr Fiona Eccles and Anna Daiches

Date application discussed: 29/02/20

Appendix 4 - A

Advertising Flyers



Parenting

Health & Medicine

Lancaster University

PARKINSON'S RESEARCH STUDY

What impact does Parkinson's have on the experience of parenting?

Are you...

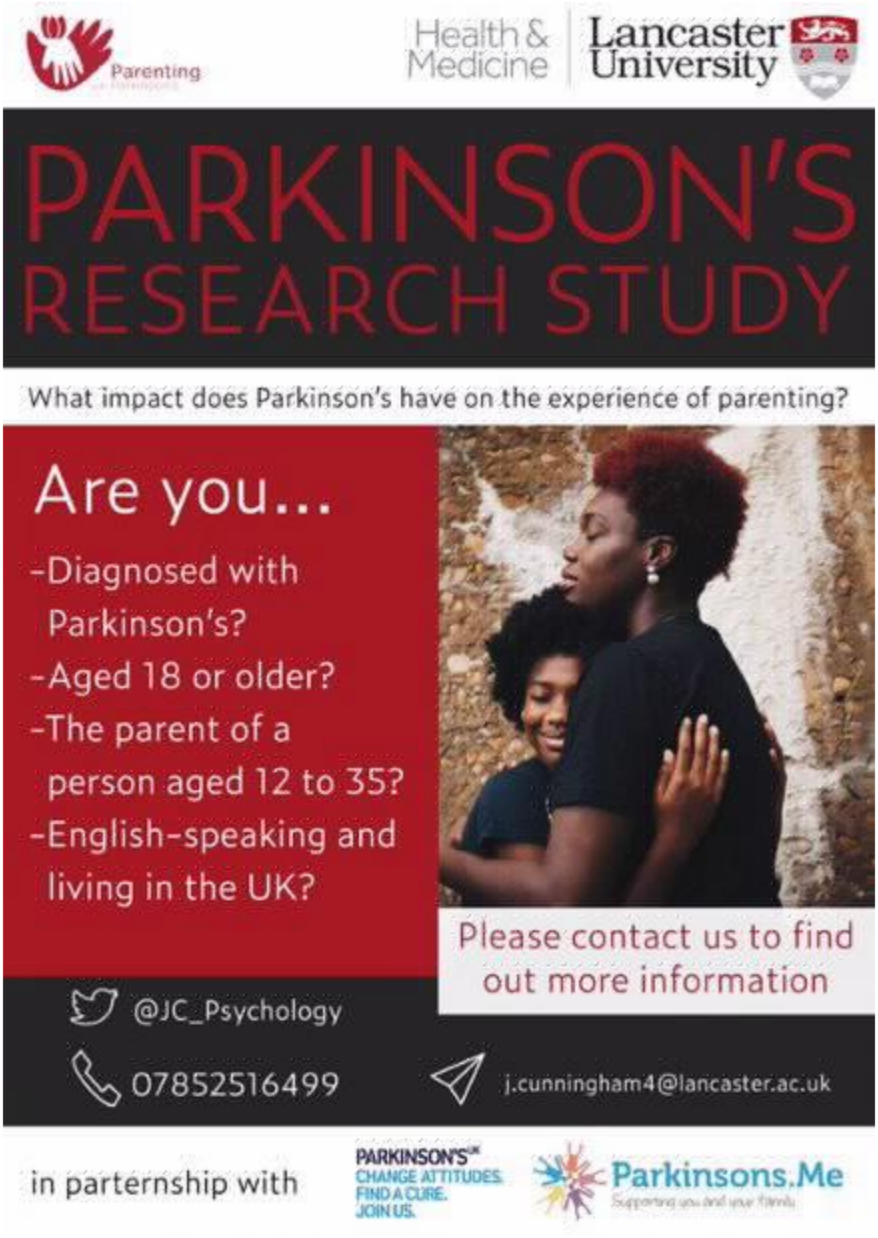
-Diagnosed with Parkinson's?

-Aged 18 or older?

-The parent of a young person aged 12 to 24?

-English-speaking and living in the UK?

Please contact us to find



Parenting

Health & Medicine

Lancaster University

PARKINSON'S RESEARCH STUDY

What impact does Parkinson's have on the experience of parenting?

Are you...

-Diagnosed with Parkinson's?

-Aged 18 or older?

-The parent of a person aged 12 to 35?

-English-speaking and living in the UK?

Please contact us to find out more information

@JC_Psychology

☎ 07852516499

j.cunningham4@lancaster.ac.uk

in parternship with

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Parkinsons.Me
Supporting you and your family

Appendix 4 – B

Participant Information Sheet

What impact does Parkinson’s have on the experience of parenting?

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is John Cunningham and I am conducting this research as a student on the Doctorate in Clinical Psychology programme at Lancaster University.

What is the study about?

The purpose of this study is to develop an understanding of what impact Parkinson’s can have on the experience of parenting. It is hoped that this may help better support parents in the future.

Why have I been approached?

You have been approached because the study requires information from persons who have experience of parenting whilst living with Parkinson’s. In particular we are interested in looking at the experience of parenting older children/young adults.

Do I have to take part?

No. It’s completely up to you to decide whether you take part in this study.

Are there any requirements to taking part?

In order to take part you need to meet the follow criteria:

- Be over the age of 18.
- Have been diagnosed with Parkinson’s disease for at least 12 months.
- Be currently parenting a child or young adult aged between 12 and 24 years.
- Be conversationally fluent in English.
- Be able to access a telephone or a video calling service.
- Should future circumstances permit persons in the North West of England may be able to agree to an interview in person.
- Be able and willing to spend approximately 60 minutes taking part in an interview.
- Not consider yourself to be living with another chronic health or psychological condition as well as Parkinson’s which you feel has a significant impact on your experience of parenting. Such as but not limited to: An advanced form of another neurodegenerative disease, severe brain injury, advanced heart disease. However, the researcher will discuss this at the start of the interview.

What will I be asked to do if I take part?

I will contact you to answer questions you may have and to confirm your participation in the study. Should you decide to participate I will agree a date with you in order a telephone or

video interview. If future circumstances permit I can only conduct face-to-face interviews in the North West of England because that is where I am based. The interview will focus on your own experience of being a parent whilst diagnosed with Parkinson's. It will take approximately an hour; however, it is possible to take breaks and may be split across different days if needed. The interview will be audio recorded and this recording will be both transcribed and analysed by me. The analysis will seek to find common themes across individual experiences. You may be invited to answer further clarifying questions later in the study (though you can decline to take part in this second phase).
A summary of the results will be provided if you choose and a telephone or video call can be arranged to give you the opportunity to comment on the results. Alternatively, you may wish to provide any comments via e-mail. With your consent this anonymous feedback may be included in a final write up.

Will my data be identifiable?
The information you provide is anonymous. Any data collected for this study will be stored securely and only the supervisors who are assisting me with this study and I will have access to this data.

- Recordings, transcriptions, feedback and personal contact data will be stored in a secure computer network location approved by Lancaster University.
- Physical copies of any data will be secured in a locked filing cabinet, in a non-publicly accessible building.
- Your personal contact data will be confidential and will be kept separately from your interview responses.
- The files on the network will be encrypted (that is no-one other than the researchers will be able to access them) and the network itself is password protected.
- Audio recordings of the interview will be deleted once the project has been submitted for examination.
- The security of telephone or video calling services cannot be guaranteed.
- The transcribed version of your interview will be made anonymous by removing any identifying information including your name. Direct quotations from your interview may be used in the reports or publications from the study, and therefore your name will not be attached to them.
- Any feedback you give will be anonymised however, it may be used in the final write up of the study.
- Transcripts and feedback will be stored for 10 years by Lancaster University and then deleted.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to my supervisors or other relevant organisations about this. Where possible, I will tell you if I must do this and we can discuss how this is done.

Can I withdraw my data?
Should you wish to withdraw your data, you can request this by contacting me directly. If this is done within two weeks of the interview or giving feedback your data will be deleted. If two weeks has passed then I will do my best to remove your data from the study,

however, once data has been anonymised and organised into themes for analysis this may not be possible.

What will happen to the results?
The results will be summarised and reported in a doctoral thesis and will be presented at the Lancaster University Doctorate in Clinical Psychology presentation day. This thesis will be stored online and will be accessible to the general public after an embargo period. It will also be submitted for consideration for publication in an academic or professional journal. Plain English summaries will be available for participants should they wish to receive a copy. Plain English summaries will also be sent to Parkinson's U.K. and Parkinsons.ME. The work may also be presented at appropriate conferences, special interest groups and training events. All dissemination of results will anonymise your personal data.

Are there any risks?
There are no risks anticipated with participating in this study. However, should you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
Although you may find participation interesting, there are no direct benefits in taking part.

Who has reviewed the project?
This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the main researcher:

Mr John Cunningham
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
Lancaster University
Lancaster
LA1 4YT
Tel: 07852516499
e-mail: j.cunningham4@lancaster.ac.uk

Or alternatively a member of the research team:

Dr Fiona Eccles
Lecturer
Doctorate in Clinical Psychology
Division of Health Research
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4YT

Tel: +44 (0)1524592807
e-mail: f.eccles@lancaster.ac.uk

Dr Anna Daiches
Clinical Director
Doctorate in Clinical Psychology
Division of Health Research
Faculty of Health and Medicine
Lancaster University
LA1 4YT
Tel: +44 (0)1524 594406
e-mail: a.daiches@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr. Ian Smith
Research Director
Division of Health Research
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1
Tel: +44 (0) 1524 592282
e-mail: i.smith@lancaster.ac.uk

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor Roger Pickup
Associate Dean for Research
Faculty of Health and Medicine
Division of Biomedical and Life Sciences
Lancaster University
Lancaster
LA1 4YG
Tel: +44 (0)1524 593746
e-mail: r.pickup@lancaster.ac.uk

Resources in the event of distress
Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Your own **GP, a Parkinson's nurse or healthcare team if you have one.**

Emergency Services 999 (UK)
Tel: 999

NHS 111
A 24-hour non-emergency health service
Tel: 111
Textphone: 108001 111
Web: 111.nhs.uk

Parkinson's UK
A U.K. based charity who offers advice and support for those living with Parkinson's Web:
Web: www.parkinsons.org.uk
Tel: 0808 800 0303 (free and confidential)
Parkinsons.Me
A U.K. based charity who offer advice and support to families affected by Parkinson's
Web: www.parkinsons.me
e-mail: parkinsons.me@gmail.com

Appendix 4–C

Verbal Consent Instruction Form

What impact does Parkinson’s impact the experience of parenting?

We are asking if you would like to take part in a research project that seeks to develop an understanding of the impact Parkinson’s may have on the experience of parenting. Before you consent to participating in the study, we ask that you read the attached participant information sheet. Participation in the study is optional. The researcher will answer any questions you may have. Should you wish to participate, at the start of interview the researcher will read each of the numbered statements below and ask for verbal consent. Consent should be given individually for each statement. This consent process will be audio recorded at the start of the interview and stored in a secure location approved by Lancaster University as outlined in the participant information sheet. If you have any questions or queries before completing the consent process, please contact the principal researcher:

Mr John Cunningham
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
Lancaster University
Lancaster
LA1 4YT
United Kingdom
Tel: 07852516499
e-mail: j.cunningham4@lancaster.ac.uk

When asked please state your full name and the date.

Verbal Consent Statements

The researcher will now read aloud the following questions. Please choose from the designated responses, you may decline to answer and this will be understood as not giving consent, agreement, or confirming understanding for that specific statement.

1. Can you confirm that you have read the participant information sheet and fully understand what is expected of you within this study?
   Please respond: I have / I have not

2. Can you confirm that you have had the opportunity to ask any questions and to have them answered?
   Please respond: I have / I have not

3. Do you understand that your interview will be audio recorded and then typed into an anonymised written transcript?
   Please respond: I do / I do not

4. Do you understand that audio recordings of the interview will be kept until the research project has been examined?
   Please respond: I do / I do not

5. Do you understand that your participation is voluntary and that you are free to request to withdraw from the study at any time without giving any reason, without your medical care or legal rights being affected?
   Please respond: I do / I do not

6. Do you understand that two weeks following your interview your data may have been anonymised and merged into themes and it might not be possible for it to be withdrawn, though every attempt will be made to extract your data, up to the point of submission?
   Please respond: I do / I do not

7. Do you understand that the information from your interview will be pooled with other participants' responses, anonymised and may be published?
   Please respond: I do / I do not

8. Do you consent to information and quotations from your interview being used in reports, conferences, presentations and training events?
   Please respond: I do / I do not

9. Do you understand that the researcher will discuss data with their supervisors as needed?
   Please respond: I do / I do not

10. Do you understand that any information you give will remain anonymous unless it is thought that there is a risk of harm to yourself or others, in which case the researcher may need to share this information with their research supervisors and other organisations?

Please respond: I do / I do not

11. Do you consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished?

Please respond: I do / I do not

12. Do you consent to take part in the above study?

Please respond: I do / I do not

13. Do you wish to be sent a summary of the analysis? (optional)

Please response: I do / I do not

Thank you. The researcher will now end the current recording.

Appendix 4 - D

Feedback Verbal Consent Instruction Form

What impact does Parkinson's impact the experience of parenting?

Thank you for taking part in the research project. Before you consent to participating in the feedback, we ask that you read the attached participant information sheet. Participation in giving feedback is optional. The researcher will answer any questions you may have. Should you wish to participate, the researcher will contact you to read each of the numbered statements below and ask for verbal consent. Consent should be given individually for each statement. This consent process will be audio recorded and stored in a secure location approved by Lancaster University as outlined in the participant information sheet. For those who choose e-mail feedback the conversation will then end and you should e-mail your feedback to j.cunningham4@lancaster.ac.uk. For those who choose to give verbal feedback the researcher will stop the recoding and the feedback conversation will then begin. If you have any questions or queries before completing the consent process, please contact the principal researcher:

Mr John Cunningham
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
Lancaster University
Lancaster
LA1 4YT
United Kingdom
Tel: 07852516499
e-mail: j.cunningham4@lancaster.ac.uk

When asked please state your full name and the date.

Verbal Consent Statements

The researcher will now read aloud the following questions. Please choose from the designated responses, you may decline to answer and this will be understood as not giving consent, agreement, or confirming understanding for that specific statement.

1. Can you confirm that you have read the participant information sheet and fully understand what is expected of you within the feedback process?
   Please respond: I have / I have not

2. Can you confirm that you have had the opportunity to ask any questions and to have them answered?
   Please respond: I have / I have not

3. Do you wish to participate in giving feedback? (optional)
   Please respond: I do / I do not

4. How do you wish to give your feedback? (optional)
   Please respond: Verbal / e-mail

5. Do you consent to the researcher taking written notes of any feedback you give? (If verbal & optional)
   Please respond: I do / I do not

6. Do you consent to your feedback being used anonymously in the final write up of the study? (optional)
   Please respond: I do / I do not

7. Do you understand that the researcher will discuss your feedback with their supervisors as needed?
   Please respond: I do / I do not

8. Do you consent to Lancaster University keeping copies of your feedback for 10 years after the study has finished?
   Please respond: I do / I do not

9. Do you understand that two weeks following giving feedback your data may have been anonymised and it might not be possible for it to be withdrawn, though every attempt will be made to extract your data, up to the point of submission?
   Please respond: I do / I do not

Thank you. The researcher will now end the current recording.

Appendix 4 - E

Interview Topic Guide

This interview topic guide has been created for the purpose of guiding the interview for the research study. Although, it is intended to be used flexibly it is an indication of the types of questions used to elicit information from the participants.

Before we begin there are a number of areas to discuss to ensure that the interview can be conducted in the best possible way.

Appreciation for taking part in the study
Introduction, names, role and university
Discuss confidentiality and anonymity
Negotiate the structure of the interview, right not to answer and self-care options
Introduce debrief concept and what this will involve
Discuss risk and sharing of risk
Review and confirm consent Information

Confirm DOB and age
Are you in a relationship? If so who with?
How many children do you have? How old are they now? What should we call them in the interview?
Do your children live with you? If no, what is their living situation? Have they ever lived with you? If yes when did this change?
When did you receive a diagnosis of Parkinson's disease?

1) What was life like before being diagnosed with Parkinson's?
Prompts: family and roles, relationships, social, health, work, domestic, financial, spiritual.

2) Could you tell me how your life was when you were diagnosed with Parkinson’s?
Prompt: family and roles, relationships, activities of daily living (ADLs), emotional, health, domestic, work, financial, social, spiritual, coping.

3) Did things change with progression of Parkinson’s?
Prompt: better/worse, changed/the same, any difference between children, coping.

Debrief

Acknowledge participation and show appreciation to the participant.
Check the well-being of the participant and other present persons.
Remind the participant of information on the Participant Information Sheet.
Give an opportunity for the participant to ask any questions.

Appendix 4- F

Research Protocol

What impact does Parkinson's have on the experience of parenting?

Introduction

Living with a motor neurodegenerative disease, that is a degenerative disease which causes clear motor impairment, can disrupt areas of daily living. For adults of childbearing age, one important area which may be affected is parenting (Røthing, Malterud, & Frich, 2014; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2003). At present, the majority of the research into parental motor neurodegenerative disease focuses on multiple sclerosis (MS) and Huntington's disease (HD). Although, the current literature is limited in its depth, this research begins to identify challenges to a person's ability to parent when living with MS or HD. Identified challenges created by parental disability currently include fatigue (Messmer, Uccelli, & Ponzio, 2018) and reduced communication ability (Miller, Noble, Jones, & Burn, 2006). Eventually, parental disability may lead to an increased difficulty in not only caring for their children but also for themselves (Fleming, Tolson, & Schartau, 2004). When this occurs the carer role may be assumed, in part or in full, by their child (Moberg, Larsen, & Brodsgaard, 2017). This carer role change can cause relational strain for both parents and children (Peters & Esses, 1985). Outcomes for families with parental motor neurodegenerative disease demonstrate potential for a negative impact on children's academic, social and domestic life (Kavanaugh, 2014). They also demonstrate a negative impact on children's mental health (Schrag, Morley, Quinn & Jahanashahi, 2004a, 2004b).

At present, there is no academic research which explores the experience of parents with Parkinson's disease (PD). The few studies which focus on PD within the parent-child dyad investigate the experience and outcomes for children raised by persons with PD. This may be due to PD being typically thought of as a disease of older age, but for 5% of persons onset will begin before the age of 50, and 31% below the age of 65 (Wickremaratchi et al., 2009). Currently, no published data exists that captures the number of those who are parents with PD, but in a society where a growing number of persons conceive at a later age, there is an increasing chance that persons diagnosed with PD may already be or become parents. Although, there are some similarities in the symptomology of PD to HD or MS, the experience of parents diagnosed with these conditions should not be assumed to be the same. PD can differ from MS and HD in a number of ways. MS often has a relapse-remitting pattern to the condition, in which a person can experience a fluctuation in the intensity of their symptomology, whereas PD is degenerative of becomes progressively worse over time. Additionally, HD and MS are diagnosed often much earlier in life, meaning that challenges to family and parental life may come earlier in the family life cycle. The genetic component to HD gives a 50% chance of inheriting the disease from a parent; again this is different to PD and may lead to variation in experience.

The disparity in research has led to an evidence base which can inform clinical and social practice for families with parental MS, yet guidelines do not exist for those with PD, despite the clear potential for difficulty (Morley, Selai, Schrag, Jahanshahi, & Thompson, 2011). Charitable organisations based in the U.K. which focus on support for persons with

Parkinson’s produce limited resources aimed at improving the lives of parents (e.g., UK Parkinson’s Excellence Network, 2019).

Consequently this study will aim to investigate the experience of parenting while living with Parkinson’s. The experience of parenting is likely to differ across stages of a child’s life and therefore this study will focus on parent-child dyads that include older children/young adults. Due to the lack of research in this area and the potential for a broad range of experiences this study will use a qualitative approach to enable an in-depth study of this issue.

Method

Participants

The study will aim to recruit persons with Parkinson’s who have experience of parenting. The study will require enough participants to reach theoretical sufficiency (Dey, 2012). The literature suggests that saturation can occur after 12 interviews but may be apparent even after six (Guest, Bunce and Johnson, 2006), dependent on homogeneity of the sample. Increased heterogeneity in the sample could mean that the range of experiences increases. As this occurs the sample may have to also increase to explore any new experiences. While saturation and theoretical sufficiency are not the same, some of same considerations apply. Therefore, initially this study will aim to recruit between 12 and 15 participants but may require more to reach theoretical sufficiency. It is anticipated that this study would not require more than 20 participants.

This study aims to look at the experience of parenting older children and young adults. There is likely to be differences in the experience of parenting younger children to the experience of parenting older children and young adults. This is likely due to changes in the independence of the child and their psychosocial needs but also the child’s ability to begin to provide care for parents when needed. In the U.K. a child usually attends secondary school from the age of 11 (England, Wales and N.I.) or 12 (Scotland) and this is an age often used as a lower limit when conducting research which explores the experience of children with motor neurodegenerative diseases such as Parkinson’s (Morley, Selai, Schrag, Jahanshahi, & Thompson, 2011; Schrag et al., 2004a, 2004b). Therefore this study will set the lower age limit at 12.

In the U.K. a child legally becomes an adult at the age of 18. For parents with disability, legislation which has the potential to impact the functioning of the dyad and influence the experience of parenting also use 18 as the cut off for childhood (Care Act 2014; Children and Families Act 2014). However, the experience of parenting is not only dictated by legislation, but several other variables and the end of a parenting experience may be signified by other social and relational milestones. These milestones may occur at ages which are different from the ‘typical’ parent-child experience. From early on dyads may see parents in a cared for role, resulting in a shift of power to children (Frank, Tatum & Tucker, 1999). Although some changes in parent-child relationships may happen earlier when parents have a chronic condition, other changes may happen later. Reports by Dearden and Becker (2004) suggest several affected social milestones for young carers, including leaving the home, financial independence and relationships. Additionally, studies also report a decreased likelihood for young adults who are carers to be in employment (Yeandle and Buckner, 2007) and have continued carer burden during higher education (National Union of Students). This study should consider the dyads in which children may be young carers of parents with Parkinson’s and the additional years that may be needed to capture the transition out of parenting. Multiple services within the U.K. often use the age of 25 to dictate the end of being a young carer (e.g. The Carers Trust, The Universities and College Admission Service, The Children's Society) therefore this research study will also use this as a bench mark for setting an upper age limit for the children of potential participants.

Therefore initial recruitment will invite those with Parkinson's currently parenting a child or young person aged 12-24. Should this fail to reach the target sample size, recruitment will then invite those with historic experience of parenting a child of this age while living with Parkinson's. It is important that the research maximises its clinical relevance. As social structures change over time, experiences closer to the present day and within the U.K. will have more relevance to future clinical practice. By the year 2008 the Disability Discrimination Act (2005) and its amendments were in effect. Additionally, social media use was beginning (Our World in Data, 2019), and Parkinson's UK started their online peer support forum (Parkinson's UK), both becoming a potential means for previously isolated persons to connect with peers. Therefore, when recruiting in phase 2 (historic experiences) this study will recruit persons who were parenting children aged 12-24 with Parkinson's during or following the year 2008.

Inclusion Criteria

- The parent is aged 18 or over.
- Has been diagnosed with Parkinson's for at least 12 months.
- Is either currently parenting a child between 12 years and 24 years whilst diagnosed with Parkinson's or has experienced parenthood whilst diagnosed with Parkinson's to a child aged between 12 and 24 years after 01/01/2008 (this child or young adult would now be aged between 24 and 35 years).
- Experienced parenthood whilst living with Parkinson's for at least 12 months.

- Conversationally fluent in English.
- Participants must be able to access a telephone or a video calling service.
- Participants should be able and willing to spend approximately 60 minutes engaging in an interview

Exclusion Criteria

- Diagnosed after their youngest child turned 24.
- Living with another chronic health or psychological condition which the participant feels has a significant impact on their experience of parenting.

Design

Data collection will involve a semi structured interview with open ended questions to be conducted across a single or multiple interviews. These interviews may take place in person, via telephone or via a video call. It is important that the collection phase can be flexible in its delivery to accommodate the needs of the participants. This may mean that interviews include breaks or may be split across different days. Some participants may be invited to answer additional clarifying questions at a later point based on data from later interviews. Using qualitative analysis will allow for the voice of the participants to contribute to an evidence base.

Data will be analysed using thematic analysis. Once the themes have been constructed, the information will be sent to participants and they will be invited to comment on the themes. Experts by experience were consulted via Parkinson’s U.K. They commented on the design of the study and the materials and changes were made in response to their feedback.

Materials

- Advertising flyer for current parents
- Advertising flyer for historic parents
- Participant Information Sheet for current parents
- Participant Information Sheet for historic parents
- Verbal Consent Instruction Form
- Feedback Verbal Consent Instruction Form
- Interview topic guide
- Digital recording device
- Research telephone

Procedure

Recruitment

Recruitment will be in the UK through Twitter, Parkinson's UK and Parkinsons.Me. Parkinson's UK and Parksons.Me will contact persons who have consented to be part of their study recruitment lists, sending them the advertising flyer and participant information sheet. The study may also be advertised on the Parkinson's UK Take Part Hub, a web page which hosts information for Parkinson's related research studies. Parkinson's UK and Parkinsons.Me may also advertise the study via their social media channels, mailing lists or local groups. Additionally, the study will be advertised via a professional Twitter account (handle @JC_Psychology) with tweets and replies directing persons to review the advertising flyer and participant information sheet, which will invite potential participants to contact the researcher directly via e-mail, telephone, post or twitter to discuss the study. The advertising flyer and participant information sheet may also be hosted on a Lancaster University DClinPsy webpage.

Initial recruitment will invite those with Parkinson’s currently parenting a child or young adult aged between 12 and 24. Should this fail to reach the target sample size, recruitment will then invite those with historic experience of being diagnosed with Parkinson’s whilst parenting a child or young person between the ages of 12 and 24 for at least 12 months after the year 2008 (the child would now be aged between 24 and 35).

Arranging and Conducting Interviews

Once the potential participant has been in touch, the researcher will contact the participant to discuss the study and if the person still wishes to take part to arrange the interview date, method and location. Participants will then be sent a copy of the verbal consent instruction form for information. Participants will be offered interviews by telephone and via Microsoft Teams online video call as appropriate. Should circumstances permit in future interviews may be offered in person for those living in the North West of England. If travelling to an interview the researcher will contact the participant via telephone to confirm the appointment. Verbal consent will be taken prior to beginning the interview and be recorded using the digital recording device. This will be recorded separately from the main interview. Participants will have received a copy of the verbal consent instruction form and therefore the consent questions in advance so they can have time to look through these before the interview. Participants will not be required to complete and return a written consent form.

The researcher will use the interview topic guide to inform the interview. The interview will take approximately 60 minutes. Interviews may be completed in one continuous block or contain breaks as needed. Once the interview is complete the participant will be reminded of the relevant information on the participant information sheet. As interviews progress a second interview may be required in order to explore additional information from participants that may have been missed. The interview will be audio recorded using a DClinPsy digital recording device. Participants can accept or decline this invitation for a second interview.

Analysis

After each interview the data will be transcribed by the researcher. The transcriptions will then be analysed using thematic analysis, completed from an inductive stance and guided by the steps set out by Braun and Clarke (2006). The researcher will read through the completed transcript. Initial codes will be identified on a second reading. Coded transcripts will be reviewed for emerging themes. Emerging themes will be reviewed and grouped into super-ordinate themes where appropriate. Codes within themes will be compared with the original transcripts to ensure they are understood in their original context. The thematic analysis will attend to the core principles of validity and quality in qualitative research, i.e., sensitivity to context, rigour, coherence, transparency and importance as set out by Yardley (2000, 2008).

Feedback to participants

Participants will be asked if they wish to be sent a copy of the themes. If they have consented, participants will be sent a lay summary of the themes. They will then be invited to offer feedback on the summary. The feedback may be given via e-mail or verbally via telephone or video call (Birt, Scott, Cavers, Campbell & Walter, 2016). Participants may choose how feedback is recorded either via e-mail, via written notes or not at all. The participant will be asked to verbally consent to this before the feedback is given. With their consent these comments may be used in the final write up.

Dissemination

I will seek publication in appropriate journals and plain English summaries will be sent to contributing partners and participants. It will also be written up in a DClinPsy thesis and, presented at the Lancaster University DClinPsy presentation day. The work may also be presented at appropriate conferences, special interest groups and training events.

Ethical concerns

Data management

Video interviews will be conducted and the audio will be recorded using my Lancaster University Microsoft teams account. The telephone interviews are to be recorded by the microphone on my personal computer to my Lancaster University Microsoft Teams account. My personal computer is pin protected but is not encrypted and therefore it will be stored in a non-publicly accessible location. The audio recordings from video and telephone interviews will be transcribed by Microsoft Teams then if found to be sufficient edited manually. If transcriptions are found to be insufficient they will be manually transcribed. Recordings and transcriptions from Microsoft Teams are stored by Microsoft in the Streams application. The recordings will be downloaded to my personal computer then the data will be immediately transferred to the Lancaster University VPN or a secure cloud approved by the university (e.g. OneDrive). This data will be deleted from Microsoft Teams, Streams and my personal computer . The VPN (or secure cloud) is a password protected university informatics system and the raw audio data and transcripts will be accessible only to the researcher, the DClinPsy research co-ordinator and the research supervisors. The VPN/cloud copy of the audio data will be deleted once the thesis has been examined. The transcripts, feedback and audio recordings of consent will be stored for 10 years by the DClinPsy research co-ordinator. The research co-ordinator will delete the data after 10 years under the direction of research supervisors.

Withdrawal of data

Participants can withdraw their data for up to two weeks after the interview. However, after two weeks the data may be anonymised and organised into themes. The researcher will attempt to remove individual data after this point, but this may not be possible.

Risk to participants

The research study aims to improve the academic understanding of parenting while living with Parkinson's. This subject may be a personal and emotive topic to talk about with a researcher. Should the interview cause distress several measures could be taken to support participants, these measures will be discussed before beginning the interview. When setting up the interview, participants may request the presence of a trusted person, with the intention to provide support should they need it. The researcher or participant can also stop the interview at any time. Further, there is the option for interviews to be divided into manageable sections with breaks of negotiable length and, interviews may be divided over multiple days. Participants will be provided with contacts to relevant charities and healthcare providers who can provide support. Additionally, should the participants which to talk with a member of Lancaster University who is not the researcher, they will be provided with the contact details for the research supervisors. Should the researcher consider the participant or another member of the public, including their children to be at significant risk of harm they will consult with their research supervisors in the first instance or if unavailable, another member of the clinical staff at Lancaster University to discuss appropriate action. Persons considered to be at risk of harm to themselves would be directed to discuss concerns with their GP, Parkinson's nurse or another appropriate professional. Should any risk require immediate assessment or support, persons will be directed to attend an accident and emergency department. Should children be considered at risk the researcher will discuss this with their supervisor and may need to contact appropriate organisations.

Risk to researchers

When conducting interviews and particularly when lone working the researchers will adhere to Lancaster University's guidance on fieldwork. The researcher will leave the details of the interview (e.g., participant, date, time, location) in a password protected online file with a fellow trainee. The researcher and fellow trainee will agree upon a set time to contact following the interview. The researcher will contact the fellow trainee when the interview is ended and the information in the file will be deleted. If this telephone call does not take place, the fellow trainee will initially attempt to contact the researcher via telephone, e-mail and text. Should there be no reply the fellow trainee will access the password protected document, alerting the university and relevant authorities.

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Appendix 4 – G

Ethics Committee Approval Letter

Applicant: John Cunningham
Supervisor: Fiona Eccles and Anna
DaichesDepartment: Health Research
FHMREC Reference: FHMREC19056

23 April 2020

Dear John

Re: What impact does Parkinson's have on the experience of parenting?

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirementsin order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adversereactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to theResearch Ethics Officer for approval.

Please contact me if you have any queries or require further

information.Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R.E. Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.