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## **Doctoral Thesis**

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# Parents, Adverse Childhood Experiences and Psychological Distress

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# **Table of Word Count**

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#### Thesis Abstract

International prevalence rates of both Adverse Childhood Experiences (ACEs) and Mental Health Difficulties (MHD) are consistently high. Research has also repeatedly identified strong positive correlations between these two widespread public health issues, both of which demonstrate intergenerational continuity and broad negative health and social outcomes. Due to these intergenerational risks, this thesis attempts to contribute to the knowledge base regarding aspects of both ACEs and MHD, from a familial perspective.

Chapter one synthesises qualitative literature regarding the way in which children of parents who experience MHD make sense of their parent's MHD. The review analysed findings across 14 studies, which produced three overarching themes. Children's understanding of their parent's MHD seemingly operated within a biopsychosocial model. This conceptualisation had numerous effects on their life and impacted on their perception of mental health more generally. Clinical implications for services working with children, parents and families, alongside limitations and recommendations for future research are discussed.

Chapter two presents a research paper that aimed to understand how parents experienced routine enquiry about their own ACEs. Thematic analysis produced three themes across eleven semi-structured interviews, from seven participants. The findings proposed a five-stage chronological model of ACE enquiry, which seemed to incorporate a process of post-disclosure behaviour change. However, results also raise important clinical issues associated with power dynamics. Theoretical contributions and clinical recommendations are presented in relation to trauma enquiry and disclosure literature.

Finally, chapter three offers a summary of the research findings and reflections, presented as chapters that articulate key decision and learning points.

**Declaration** 

This thesis is a report of research undertaken between October 2015 and August 2016

as a requirement of the Doctorate in Clinical Psychology at Lancaster University. The work

presented here is my own, except where reference is made. The work has not been submitted

for the award of any higher degree elsewhere.

Graham Simpson-Adkins

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I would like to say an enormous thank you to my mum and dad for the unconditional support and for instilling in me the strength and confidence that got me to this point. And finally, to my wonderful wife, Mags. Thank you for loving me, for taking care of me and for tolerating me! You always believed I could do it and I could not have achieved this without you. x

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# **Chapter 1: Systematic Literature Review**

How Do Children Make Sense of their Parent's Mental Health Difficulties: A Meta-Synthesis

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#### Abstract

Children of parents who experience mental health difficulties (COPE-MHD) consistently demonstrate numerous negative outcomes, including risks of intergenerational continuity of mental health difficulties (MHD). Numerous studies have analysed the experiences and understanding of parents' MHD from the perspective of COPE-MHD. This metasynthesis aims to capture, across available literature, the way in which COPE-MHD make sense of their parent's MHD and how this perception impacts their life. For inclusion in the review, research articles were required to be published in peer-reviewed journals, apply qualitative methods of data collection and analysis and report on the direct accounts of COPE-MHD regarding their understanding or experience of their parents' MHD. Five electronic databases were used; Academic Search Complete, CINAHL, MEDLINE, PsycINFO and Child Development and Adolescent Studies. Fourteen studies were included. Analysis produced three overarching themes. The findings illustrate children's sophisticated biopsychosocial conceptualisation of the cause and process of their parent's MHD. It also highlights how they utilise this understanding to manage the day-to-day concerns associated with their parent's experience of MHD. Clinical implications highlight a need for services working with children, parents and families to more frequently enquire about parents' MHD and to consider the outcomes of such enquiry in the psychological formulation of children and young peoples' mental health and development. Limitations and recommendations for future research are presented.

Keywords: Parents; Children; Mental Health; Biopsychosocial; Qualitative

The World Health Organisation estimated that approximately 450 million people worldwide experience mental health difficulties (MHD) (WHO, 2001). Almost one in every two Australians (Slade, Oakley Browne, Andrews, & Whiteford, 2009), one in five Canadians (Government of Canada, 2006) and one in six British people will experience a MHD in their lifetime, with one in four British adults experiencing at least one MHD in any twelve-month period (Singleton, Bumpstead, O'Brien, Lee, & Meltzer, 2001; McManus, Meltzer, Brugha, Bebbington, & Jenkins, 2007).

People who experience MHD are as likely to be parents as those who do not. In the USA, it has been demonstrated that 67.2% of women and 75.5% of men with severe MHD, such as those with a diagnosis of bipolar disorder or major depressive disorder are parents (Nicholson, Biebel, Katz-Leavy, & Williams, 2002). This means that many children worldwide are likely to have a parent with MHD. Bassani, Padoin, Philipp and Veldhuizen (2009) established that one in every ten Canadian children under 12 lives with a parent experiencing MHD. In England and Wales, it has been estimated that there are over two million children living with parents experiencing MHD (Gould, 2006).

Many empirical studies have highlighted various detrimental effects of a parent's MHD on children. A number of reviews (Rutter & Quinton, 1984; Beardslee, Versage, & Gladstone, 1998) and books discuss this topic (Göpfert, Webster, & Seeman, 2004).

Associated literature consistently indicates that a parent's MHD can have major effects on children, leading to increased risk of behavioural, social, emotional and educational difficulties (Singleton, 2007). One study, based in Sweden, suggested that children from single-parent families, where the caregiver experiences MHD, were at elevated risk in childhood and adulthood of psychological difficulties, substance abuse or death by suicide or substance overdose, compared to those from two-parent families, where only one caregiver

experienced MHD (Weitoft, Hjern, Haglund & Rosen, 2003). This is concerning, given that up to one-in-six COPE-MHD live in single-parent homes (Bassani et al., 2009).

In the Netherlands, COPE-MHD were found to be two to three times more likely to develop MHD compared to their peers (van Doesum & Hosman, 2009). In Australia, Cowling, Luk, Mileshkin and Birleson (2004) also found elevated risk of childhood MHD amongst COPE-MHD. Interestingly, around 60% of parents in this study reported hesitancy in seeking support for their child, citing reasons such as embarrassment, believing they should be able to manage problems alone, not knowing where to go for help, believing nobody could help, concern regarding what others may think and fear concerning the treatment their child may receive (Cowling et al., 2004).

Longitudinal findings from the USA, consistent at 10 and 20-year follow-up, revealed that children of parents with a diagnosis of depression were three times more likely to experience MHD associated with low mood and anxiety compared to their peers, with similarly elevated risk of developing substance dependence (Weissman, Warner, Wickramaratne, Moreau, & Olfson, 1997; Weissman et al., 2006). The necessity for professionals to understand the needs of and risks to COPE-MHD has been reinforced in the UK via a recent inter-agency guide, 'Working Together to Safeguard Children' (Department for Education, 2015). This guide stresses the need to consider the individual situation and needs of each child, as they may be at "risk of harm or be in need of additional help in families where the adults have mental health problems" (pp.58-59).

The development of MHD in COPE-MHD has been associated with numerous risk factors and mechanisms, largely focusing on theories concerning genetic factors (Beardslee, Bemporad, Keller, & Klerman, 1983; Riley, Asherson, & McGuffin, 2003; Weissman et al., 2005). However, research has increasingly emphasised the importance of psychosocial factors (O'Connell, 2008), including attachment relationships, parenting style and ability.

socioeconomic factors and experiencing adverse life events, amongst many others (Fudge, Falkov, Kowalenko, & Robinson, 2004; Royal College of Psychiatrists, 2002). COPE-MHD have been found to be at higher risk of numerous social adversities during childhood (Gladstone, Boydell, Seeman, & McKeever, 2011), such as increased risk of being placed in foster care (Kohl, Jonson-Reid, & Drake, 2011), experiencing mental health associated stigmatisation (Corrigan & Miller, 2004) and experiencing parental suicide, which can all negatively impact child development (Göpfert, Webster, & Seeman, 2004). However, it is important to note that, despite increased risks of poor outcomes, many parents experiencing MHD parent effectively and many COPE-MHD do not experience any adverse effects (Smith, 2004).

Most of the research concerning COPE-MHD has been quantitative. However, qualitative methods enable investigations of vital subjective perspectives of COPE-MHD (Sollberger, 2007), and there have been calls for more qualitative approaches to this topic (Aldridge, 2006). Walsh (2009) suggested that, in order to understand the mechanisms linking parents' MHD to negative outcomes in COPE-MHD, it is valuable to learn how COPE-MHD perceive their parents' mental distress, what this understanding means to the children, and how this perception impacts upon their understanding of mental health. Currently, relatively little is known about what COPE-MHD understand about the MHD of parents. Much of the qualitative literature around the views of COPE-MHD has focussed on retrospective accounts of adult children (Baik & Bowers, 2006; Foster, 2010); reviewed by Murphy, Peters, Jackson and Wilkes (2011). There is a relative paucity of literature concerning the views of COPE-MHD captured during childhood years.

Gladstone et al. (2011) published a review of available literature on children's experience of their parent's MHD. They described numerous negative impacts, including negative effects on familial and peer relationships, difficulties with school, experiencing

community stigma and experiencing the burden of caregiving activities. They also highlighted positive impacts, such as feeling close to the parent. They presented various ways that children appear to cope with these impacts, such as balancing the parent's needs with their own and actively avoiding conflict. They briefly outlined children's understanding of mental health in terms of how they explain their parent's 'problem', highlighting in particular that children rarely used medical terminology, that they feel that MHD are difficult to understand and that they have received little associated teaching. The authors conclude that children's knowledge about their parent's MHD was generally inadequate and/or inaccurate. However, results do not illustrate how children use this seemingly limited knowledge and their daily experiences to make sense of their parent's MHD; the results primarily focus on children's experience in terms of the impacts of their parent's MHD on their daily lives. Furthermore, this review lacked transparency with regards to the search strategy and data analysis. Such transparency is an important characteristic of a qualitative systematic review (Hannes & Macaitis, 2012).

Over recent decades, studies have been published that report on the direct accounts of COPE-MHD regarding their experience and understanding of their parent's MHD. This metasynthesis attempted to review and interpret the available literature, to capture the current understanding, from the child's perspective, about how COPE-MHD make sense of their parent's MHD.

## Method

# **Search Strategy**

A preliminary literature search was conducted to help develop the research question and a comprehensive range of relevant search terms. The research question was defined as; 'how do children understand their parents' MHD?' For this review, MHD was defined as any

mental health difficulty of sufficient clinical severity to receive treatment or support from mental health services. The thesaurus function on Ebscohost was also applied to discover additional search terms and to determine UK and American English alternatives. Where suitable, truncation symbols were also applied. It has been highlighted that search strategies used to strictly identify papers applying qualitative methodologies are complicated by insufficient database indexing. In order to amplify the number of potentially relevant papers returned, a combination of searching strategies, using thesaurus, broad and free-text terms relating to qualitative methods were applied (Harden, 2004; Mays, Pope & Popay, 2005; Shaw et al., 2004).

The search took place on 11<sup>th</sup> November 2015. Five electronic databases were used; Academic Search Complete, CINAHL, MEDLINE, PsycINFO and Child Development and Adolescent Studies (Table 1: Search Terms). Due to large numbers being returned using the search terms alone (>10,000), results were refined by using the age-range functions on Ebsco. The search was run with each applicable age range individually, one at a time; first by Childhood (birth-12 years), which returned 1178 results, then adolescence (13-17 years) which returned 992 results, then school age (6-12 years) which returned 765 results, then adolescence (13-18 years) which returned 400 results, and finally young adulthood (18-29 years) which returned 811 results. These five sets of results were combined and searched together by accessing the search history on Ebsco, selecting each of these searches and then clicking on the "search with AND" function. The search results were restricted to research papers published in peer-reviewed journals, which functioned as pre-determined evidence of quality (Murray & Forshaw, 2012).

#### **Inclusion Criteria**

Any published research article applying qualitative methods of data collection and analysis to study the perceptions of children and young people under 18 years of age regarding their understanding or experience of MHD was considered relevant for inclusion in this review. The upper age limit was selected based on the age limit for most children's services in the UK (Division of Clinical Psychology, 2015). There were no date restrictions. Studies were required to be published in English, due to resource restrictions.

## **Exclusion Criteria**

Studies that did not report qualitative data directly from children under 18 years in the specified age range were excluded, such as parent's perceptions about children's experiences. Retrospective studies of adult children were also excluded. Studies including a broad range of ages were excluded if it was not possible to identify the responses of children under 18 years of age. Studies that analysed multiple perspectives, such as the perceptions of both children and parents were only included if the child-specific data could be identified clearly and independently from non-child data. Similarly, studies applying mixed methods approaches were accepted for inclusion if the qualitative data were reported independently from the quantitative data. An additional exclusion criterion was applied during the reading phase of the review; studies that analysed children's views following interventions aimed at improving the child's understanding of MHD were removed if they did not include the child's perceptions of MHD prior to the intervention. Papers not published in English Language could not be included.

## **Selecting the relevant papers**

The search returned 2,462 papers. EBSCO automatically removed 182 exact duplicates, leaving 2280 remaining results. The titles and hyperlinks for each paper were then copied and pasted electronically from the databases into a Microsoft Excel spreadsheet, to be

sorted alphabetically. This list was then searched manually for duplicates, which removed 50 papers. Titles and abstracts of remaining papers were reviewed, removing a further 2159 papers, based on inclusion and exclusion criteria. Full-text copies of the remaining 71 papers were studied for relevance. A further 62 papers were removed based on inclusion and exclusion criteria, leaving a total of nine relevant papers for inclusion. An additional five relevant papers were retrieved using pearl-growing (see Figure 1: Flow diagram for inclusion of papers for the metasynthesis).

All papers selected for inclusion were published from 1992 to 2013 across six different nations; Canada, UK, Australia, Norway, Sweden, Belgium and USA (Table 2: characteristics of selected papers). The age range of one study, (Griffiths, Norris, Stallard & Matthews, 2012), extended to 19. However, it was decided to include this study as it contained rich data principally within the selected age range for this review. The search results were then scanned for other papers that extended to 19 years; none were found. Two papers used the same sample and data. However, Mordoch (2010) conducted a secondary analysis on data collected by Mordoch and Hall (2008), to reanalyse the data for the purpose of answering a different question and as such, was not excluded.

## Quality appraisal of the selected papers

The Critical Appraisal Skills Programme (CASP) quality research checklist (CASP UK, 2013) was used to evaluate selected papers via the first initial questions; does the paper include a clear statement of aims and does the paper use appropriate qualitative methodology. All papers were then assessed using the remaining CASP checklist questions. To express the strength of explanation of each CASP checklist question reported, a three-point scoring system was utilised to evaluate each paper (Duggleby et al., 2010); weak (1 point), moderate (2 points) and strong (3 points). A score of zero was given if the checklist item was not

present in the paper. The scores ranged from four to 24 (Mean = 15.43, SD = 4.95). However, no papers were excluded based on quality appraisal to avoid papers containing rich, valuable data being discarded based on meticulous use of the CASP (Atkins et al., 2008). Rather, the CASP was used to weigh the data within selected papers, based on methodology, study conduct and the utility and trustworthiness of the findings; higher scoring papers provided more influence on findings (Tong, Flemming, McInnes, Oliver, & Craig, 2012). For example, codes or quotes from papers with low CASP scores were only translated into themes or used to illustrate themes in the results if the content or concept of that code appeared similarly in papers with higher CASP scores.

# Reflection on the author's perspective

Interpretation of qualitative findings can be assisted via transparency of the author's perspective on the topic area (Elliott, Fischer & Rennie, 1999). The main author is a 29-year-old, white British male, studying on the Clinical Psychology Doctorate programme at Lancaster University. Interest in the research area developed via experience on an acute mental health inpatient unit whilst working with adults experiencing MHD, who were parents of dependent children. Interest was gained further via work with children accessing child and adolescent mental health services (CAMHS) who had parents that experienced MHD.

The author identifies with an objective ontological stance within a subjective epistemology; there is a reality independent from human understanding, and knowledge of that reality stems from varying interpretations on that reality (Williams, 2011). The author posits that these varying interpretations are developed via social interactionism, where "people strive and act toward what represents meaning for them", where "meaning arises out of social interaction", and "meaning is being dealt with and modified through interpretive processes" (Handberg, Thorne, Midtgaard, Nielsen, & Lomborg, 2014, p.1023). The

intention of social research from the author's stated position, therefore, is to construct functional explanations that can influence engagement with the social world (Johnson & Duberley, 2000). The aim of this study is to develop an adequate construction of how children understand their parent's MHD, which can offer pragmatic functional clarity for, for instance, professionals working with COPE-MHD or their caregivers (Johnson & Duberley, 2000; Mearns, 2011).

## Synthesis of the selected papers

The selected papers were arranged and read in order of publication date, in order to position the research into a historical context (Noblit & Hare, 1988). Schutz's concept of first, second and third order constructs formed the stages of reading and synthesis, followed by reciprocal translations and line of argument synthesis, outlined by Nobilt & Hare (Atkins et al. 2008; Noblit & Hare, 1988; Schutz, 1962, cited in Reid, Sinclair, Barr, Dobbs & Crealey, 2009). The oldest paper was read first, to begin coding first and second order constructs; verbatim transcriptions of participant responses and subsequent interpretations. With each paper, the author examined and reflected on these codes, beginning the identification of emerging themes, which offered new conceptualisations of synthesised first and second order constructs (Atkins et al. 2008). Akin to a constant comparison approach, the author attempted to continually translate emerging themes, allowing iterative emergence of reciprocal translations across papers (Reid, Sinclair, Barr, Dobbs & Crealey, 2009). All preliminary themes were examined and further reflected upon by the author, based on semantic and latent similarities, to develop preliminary key themes (Reid et al., 2009). Line of argument analysis helped relate and explain the preliminary key themes to develop the final key themes, or third order constructs, which signified the completion of the synthesis. Results were examined by research supervisors to critique the conceptualisation of themes and concepts.

#### Results

Three overarching themes were developed. The first theme represents how children appeared to conceptualise the cause and process of their parent's MHD. The second describes a narrative that portrays how COPE-MHD manage their parents' perceived vulnerability. The final theme illustrates children's' search for positive narratives, whilst managing the day-to-day difficulties presented by their parent's MHD.

Overpowered by the Physiological Consequences of Adversity: "Give us back my old mum"

This overarching theme captures how children seemingly view their parent's MHD as primarily caused by mental distress associated with the parent's experience of adversity, which leads to physical dysfunction and ultimately transforms the parent, if only temporarily. This process can result in a consequential sense of loss of the parent. This theme comprises three subthemes.

Adversity causes mental distress, which leads to physical dysfunction: "someone stuck a fork in, mushed it all up". Over half of the papers reviewed described children's views that MHD is triggered by environmental or psychosocial factors, particularly adverse or stressful life events. Cogan et al. (2005) described how 13 of the 20 interviewed children considered MHD as a consequence of painful or traumatic life events, such as 'getting divorced', 'family arguments', 'grandpa...dying' or 'abuse' (p.56). Children also appeared to put particular emphasis on the effects of childhood adversity as the cause of MHD. For example, Garley et al. (1997) described how one boy associated his mother's MHD to experiencing sexual abuse as a child. Another child was quoted as saying: 'my difficult childhood could lead to me becoming depressed, you know' (Trondsen, 2012, p.180).

It therefore appears that COPE-MHD seem to understand mental distress to be the result of difficult or traumatic experiences in life, suggesting a more psychosocial model of MHD. However, they also appear to view the consequences of such distress to be the development of physical dysfunction. For instance, the majority of the papers highlighted children's frequent use of medicalised language and their views of MHD as an 'illness', associated with a physically malfunctioning body or brain:

I'd describe a healthy brain as a freshly baked blueberry pie. You know everything is in its right place; it is all organized and ready to eat. A brain with a...Mental Illness...is a blueberry pie that somebody stuck a fork in, mushed it all up and everything is mixed up (Mordoch, 2010, p.23).

It was also frequently described that MHD requires treatment via specialist support such as from a medically trained professional, primarily involving medication. Beliefs about the need for medication were depicted well in the following quotes: "You have to take a lot of medicine" (Riebschleger, 2004, p.28), "You won't be able to talk to him if he's not on his medication" (Mordoch & Hall, 2008, p.1131), "There aren't that many drawbacks to it, you know, if they are medicated" (Trondsen, 2012, p.103) and "my dad has to take all these tablets cos he's not well, I think there's something wrong with his brain" (Cogan et al., 2005, p.56). This need for medication was often attributed to their parent somehow malfunctioning or being defective in some way, "the medication, the food, makes parents feel better because something is wrong with them" (Mordoch, 2010, p.23). The perceived need for specialist support was highlighted by Griffiths et al. (2012), "I think the doctor's been the main helpful thing" (p.77), and in Meadus and Johnson (2000), "they have certainly done tremendous work on her because she's doing excellent now" (p.387).

Some of the papers discussed views of mental health as synonymous with physical health problems. For example, Meadus and Johnson (2000) inferred that children "described their parent's illness as just like any other illness" (p.388). This view was also evident in beliefs about the consequences of MHD, "What I know about mental illness is when you get real sick, you have to go to the hospital and then you die" (Riebschleger, 2004, p.29), and in their suggested responses to observing distress "He wouldn't move, couldn't move, couldn't do anything. So we had to call the ambulance" (Garley et al., 1997, p.101).

MHD takes over: "This isn't my mum. She's not acting right". This sub-theme described how children appeared to be aware of MHD primarily via changes in their parents' behaviour and mood. For example, Mordoch (2010) inferred that children understood MHD as "diverse patterns of parental behavioural changes" (p.21). These changes referred to behaviours such as increased length and frequency of sleeping, not working and doing fewer household chores, losing interest in previously enjoyed activities, crying, shouting and unusual or inappropriate behaviours, such as giving money away (Garley et al., 1997; Griffiths et al., 2012; Handley et al., 2001; Mordoch, 2010; Riebschleger, 2004; Trondsen (2012; Van Parys & Rober, 2013). Children also seem to observe or understand there to be changes to their parent in terms of negative felt emotion, such as "getting angry more easily, and being sad" (Van Parys & Rober, 2013, p.334), and negative expressed emotion, such as "My mom starts yelling at me" (Riebschleger, 2004, p.57) and "His face became beet red, his eyes flashed with anger...he almost looked 'evil' ... and then he screamed at us... Sometimes he grabbed us hard" (Trondsen, 2012, p.179). Many studies reported that children described these changes in behaviour and mood as unstable and unpredictable, "sometimes he'll get angry and sometimes he'll be very nice. Like different...one minute later" (Garley et al., 1997, p.101) and "she can be the nicest person you can talk to and then she can just change so quickly... she will just sit and cry" (Cogan et al., 2005, p.55).

Most studies highlighted a view amongst children that their parent was separate from their MHD, with an understanding that their extreme and unpredictable changes in behaviour or mood were the result of the MHD and not a fundamental characteristic of the parent. For instance, Webster (1992) described how one child illustrated a sense that their mother was no longer the same person when she experienced MHD:

when she got ill we just wanted to get away. We didn't want to know. She wasn't our mum then. ... I used to cry every night, you know. I used to pray to God at night and say, "Give us back my old mum. I don't want this person. This isn't my mum. I don't want this person. This isn't my mum. She's not acting right (p.323).

The authors inferred from this that COPE-MHD appear to view MHD as having an almost possession-like subjugation of their parent, where the essence of the parent they knew before MHD, or at least when MHD are less pronounced, still fundamentally exists, but is not present when under the influence of MHD. This change in presence was captured well by two comments in Mordoch and Hall (2008), "it's just his illness, it's not him talking." (p.1134) and "It's scary 'cause it's not your dad. It's just the illness." (p.1140). When they consider that MHD has taken over, they appear to suggest that it thus transforms their parent's personality and behaviour, making them somewhat unrecognisable or presents a distorted version of their parent. A comment in Tronsden (2012) illustrates this distortion: "The problem is that I see the man, but not my father" (p.181)

A sense of loss: "It was as though she did not exist". All but one study (Van Parys & Rober, 2013), described a sense of loss for the children as a result of their parent being overcome by MHD. For example, there was a sense of emotional absence or unavailability of the parent, "She can't be there emotionally for me" (Meadus & Johnson, 2000, p.386). There was also a sense of physical absence, "When she was ill she used to stay upstairs...she would

live upstairs and we would live down here...It was as though she did not exist" (p.320). Handley et al. (2001) portrayed how one child felt that MHD had "ripped" their parent from them (p.225). Trondsen (2012) described a loss of parental interaction with the child, "I lack a mother...A mother who says something enthusiastically over the dinner table or asks and offers opinions, not just sits there and stares stone-faced into space." (p.181). Again, a quote in Trondsen (2012) highlighted the sense of loss and longing for the parent, despite them still being alive and present, "I often miss my dad so much that it hurts, even though he lives with me and I see him almost every day" (p.181).

# Vulnerability, Protection and Secrecy: "always treading on eggshells"

The second overarching theme describes a consistent narrative across all papers that portrayed children's attempts to alter their life in an attempt to protect their parent, themselves and life as they knew or desire it to be. This theme consisted of three subthemes.

MHD are a persistent cause for angst: "I worry just in case". All but one study (Maybery et al., 2005) described a sense of children feeling fearful and anxious about the effects of MHD on their parent and themselves. For instance, "My father's illness mostly makes me scared. I hate being scared, but that is probably the feeling I've felt most during the last 12 years" (Trondsen, 2012, p.179). Many of these concerns related to a fear of losing the parent. For example, Riebschleger (2004) described how one child was so worried about "being put in foster care" as a result of their parent experiencing MHD that they insisted on using a pseudonym during the interview (p.27).

Many children reported fears of losing their parent to hospitalisation or suicide (Riebschleger, 2004; Östman, 2008). Mordoch and Hall (2008) reported a comment that illustrated a sense of fearful apprehension, "I don't think he'd [father] commit suicide. I don't think he'd actually go to that level but sometimes I just worry just in case." (p.1135).

Trondsen (2012) described how awareness of negative stereotypes can increase such fears, "I've heard many times lately about people with mental problems who have killed family members. My mom isn't that bad now, but you never know" (p.180).

Mordoch (2010) suggested how worries appear to increase due to the unpredictability and instability of changes in their parent's behaviour and mood. Accordingly, children learned to monitor their parent for signs of change, as this enabled them to identify patterns of behaviour that symbolised MHD, "We always eat dinner together, she's sleeping at 11 o'clock and that's not her" (Mordoch & Hall, 2008, p.1131). Others described anxiously thinking about or checking on their parent due to a fear of self-harm or suicide, "when she was in the bathtub or if she had a razor or whatever. You just wanted to ask, Mom are you okay in there, or with whatever she was doing" (Meadus & Johnson, 2000, p.386). Van Parys and Rober (2013) deduced that, due to an awareness or apprehension of parental suicide or harm, children can begin to interpret everyday behaviours, such as sleeping, as risky.

Another identified instigator of worry was that the parent and others attempt to keep information about MHD from the child, as a method of protection (Van Parys & Rober, 2013). A quote from Cogan et al. (2005) illustrates this protection, "my da (father) stays in his room when he's depressed, he doesn't want us seeing him when he's like that" (p.54). However, Trondsen (2012) illustrated how this protection of children can exacerbate rather than alleviate the child's anxiety, "our imagination and thoughts are running wild, and constantly wondering, constantly trying to figure things out ourselves, can be much worse than dealing with the truth." (p.179). Mordoch (2010) portrayed similar views, "I don't think parents realize, it causes more stress not to know what's going on...You're lost as to what's happening" (p.21). Garley et al. (1997) illustrated how anxieties can be further exacerbated when the child eventually becomes aware of their parent's distress, as they are unaware of

what is happening or how to help, "sometimes she'd cry or something. That was hard for me to understand cause I didn't know what she was crying about" (p.100).

Finally, many studies described how children worried about MHD being transmitted to them, biologically or otherwise: "first when she was ill in hospital I was wondering if it was hereditary then, because if I felt down or something or the other, then I was worrying, well am I going to be like that too." (Meadus & Johnson, 2000, p.387). Trondsen (2012) described how some children can begin to monitor their own behaviour, as they do their parents, and associate emotions such as sadness as a sign of developing MHD. A quote in Riebschleger (2004) also illustrated this concern, "Mom says that worrying is how it (a psychiatric disability) started...and now I'm worrying about things all the time too." (p.28).

Subjugate own needs for the parent's: "Sometimes it's more like I'm the one who's the parent". All but four of the papers described children attempting to adjust their behaviour or life, poignantly described as "like always treading on eggshells" (Griffiths et al., 2012). This was done to avoid upsetting or burdening their parent, suggesting that the parent is viewed as "vulnerable" (Webster, 1992, p.321). Riebschleger (2004) exemplified such a response, "I try not to talk to her so that she doesn't get upset and get worse. I try not to tell her things that would get her upset" (p. 27). Maybery et al. (2005) stated that children described needing to "be quiet when their parent was unwell" (p. 6). Other attempts not to burden or upset the parent included doing housework, caring for siblings, avoiding provocation, not bringing friends home, getting out of the house or generally staying away from the parent (Mordoch & Hall, 2008; Mordoch, 2010; Venkataraman, 2011; Trondsen, 2012; Griffiths et al., 2012). It was also found that children hide their worries from their parents and reassure them that they were not affected by their parent's distress (Van Parys & Rober, 2013).

Children appear to view their parent as in regular need of help, support and comfort as a result of MHD. For example, many of the papers described children increasing their responsibilities in order to support their parent, "I do all the washing and ironing. I just help out really wherever it needs...if she's ill I'll do the whole house" (Griffiths et al., 2012, p.74). A perception that the parent needs to be taken care of and comforted was depicted in Venkataraman (2011), "Parents need help and children can talk to them, try and understand what is wrong: Sometimes you have to take care of your parent" (p.23), and again in Van Parys and Rober (2013), "when Mommy is very sad she cannot comfort herself, can she?" (p.338).

Some of the studies also referred to children recognising a change to their role in the family, particularly taking on more of a typically parental role. For instance, in Meadus and Johnson (2000) it was illustrated how children can transition to a caregiver role, "it's difficult for her to be [Pause] the caregiver, and I tend to be more of the caregiver" (p.386). This was also demonstrated in Trondsen (2012), "Sometimes it's more like I'm the one who is the parent, and he is the child. I feel like he's my responsibility, and that I have to take care of him" (p.181).

A family secret: "I'm afraid to tell anyone", "It's not something we talk about". The title of this theme describes how children seem to hold a belief that, as a result of MHD, their parent or family is not "normal" (Östman, 2008, p. 357). They are also acutely aware that, socially, the subject of mental health is often taboo, meaning MHD are often treated as a "family secret" (Riebschleger, 2004, p.28), due in part to an apparent awareness of risk of or actual stigmatisation from others. For instance, Östman (2008) described how children recognised that others, including neighbours or distant relatives, sometimes perceived their family as different from "normal" families.

Many of the papers described how children appeared to be aware of "other people's reactions" (Meadus & Johnson, 2000, p.388). For instance, "I'm afraid to tell anybody that my mum has got problems like that cos some folk (other young people) can start slaggin' (ridiculing) you and things like that" (Cogan et al., 2005, p.56). Furthermore, in Riebschleger (2004), "I think it...is something that other people think bad about...Lots of people get teased" (p.28). Children also appear to be aware that discussing MHD is often met with reluctance from relatives, teachers and mental health professionals, suggesting that MHD is not something that is talked about (Handley et al., 2001; Trondsen, 2012). In Riebschleger (2004), two of the children portrayed being treated differently by proxy after being taken into care, "They (foster parents) treated me like I was some kind of delinquent or something. I didn't do anything wrong." (p.25). This fear of stigma by proxy was further evident in Cogan et al. (2005), "cos of my mum and that a [sic] don't want to invite them (friends) back...cos a [sic] think 'I'm no inviting them back they'll think that I'm a weirdo!'" (p.57). There appeared to be a desire not to reveal the family secret, "it's just like a problem that's in the home. You don't want to let it out" (Griffiths et al., 2012, p.75). This message sometimes appears to be encouraged by parents, "My parents tell me to keep it hush-hush." (Mordoch & Hall, 2008, p.1134), "I'm banned (from talking about OCD to others) because my mother doesn't like to mention it' (Griffiths et al., 2012, p.75). Three papers drew attention to comments from children reporting that they experience a sense of embarrassment due to their parent's MHD, inferred as another reason why it is kept as a family secret (Handley et al., 2001; Griffiths et al., 2012; Webster, 1992).

Searching for a Needle of Hope in a Haystack of Adversity: "You don't know what's going on and it's hard to be happy"

The final overarching theme illustrates a struggle by COPE-MHD to develop alternative, positive narratives about their parent, family life and their own ability to cope

whilst experiencing the direct and indirect adverse psychological impacts of their parent's MHD. This theme consisted of two subthemes.

The impact of persistent uncertainty: "I hide myself in my room, and feel deeply sad". All papers depicted practical and psychological difficulties experienced by COPE-MHD as a result of exposure to and attempts to manage the unpredictability of their parent's MHD. One child in Garley et al. (1997) generalised these impacts by reporting, "my life has changed altogether" (p.100).

Negative impacts were often associated with a sense of overwhelming burden faced by children, due to increased responsibilities when the parent is experiencing MHD:

I will stay at the house all day because I don't want anyone to walk in or anything and I can't lock the door because my sister is already gone and she doesn't have her key. It doesn't really bother me, just feel like I have lot of responsibilities sometimes...I think that I would like to have responsibilities because I feel like needed but sometimes it is just like wow! (p.101).

Östman (2008) inferred that "children experience great suffering in taking responsibility when no one else does" (p.356). Van Parys and Rober (2013) suggested that children reflect on the impact of MHD on their lives and can consequently feel down or become more easily angered. Trondsen (2012) further exemplified this negative emotional impact on children:

It is really hard coming home after school and unexpectedly finding my mum [mother] sitting in her chair, depressive, unkempt and tousle-headed, staring expressionless at the television, but without attention, and not saying a word...I hide myself in my room, and feel deeply sad (p.179).

Mordoch and Hall (2008) further exemplified the impact on children's mental health, "I actually remember questioning what I was doing in my life. I wonder if I should kill myself. Everything was like a blur. You don't know what's going on and it's hard to be happy." (p.1141). Others, such as Maybery et al. (2005) describe how these impacts negatively affect education, reporting for example, that one interviewee described feeling lethargic and depressed due to the effects of their parent's MHD and consequently found it difficult to attend school.

Some studies referred to a sense of isolation for children. Meadus and Johnson (2000) reported that children in their study described feeling lonely and helpless. This appeared to be associated, at least in part, with a reluctance to invite friends to their home (Trondsen, 2012). Alternatively, difficulties relating to their peers regarding personal experiences of home life and MHD was also cited as a cause for isolation:

Some of my best friends say that I can talk to them when I need to, and that is certainly a good thing, but regardless of how much I tell them, they will never really understand. I feel very alone in the middle of all this (Trondsen, 2012, p.180).

The search for a silver lining: Its "not all bad, you know". Despite difficult experiences, children also described feeling "used to it" and that "She's had it for so long I don't know what it's like without living with it" (Griffiths et al. 2012, p.76). It was unclear whether there was a sense of hopelessness or acceptance in relation to these comments, but their experiences were described as "just part of my life" (Meadus & Johnson, 2000, p.387) and inferred by Riebschleger (2004) as "merely a part of a number of concerns in their lives" (p.28).

Cogan et al. (2005) suggested that COPE-MHD were less likely to express stigmatising opinions of people with MHD generally, due to their personal experience of

living with MHD. However, it appeared from some of the comments that children were actively attempting to develop alternative, positive narratives about their parent and the meaning they attribute to the impact of the parent's MHD. For instance, Mordoch (2010) explained how their lived experiences helped children to understand that MHD is "not 24/7", and "not all bad, you know." (p.23). Griffiths et al. (2012) described one child's attempt to develop an alternative narrative, by suggesting that experiencing their parent's MHD had helped them to learn helpful ways to manage their own mental health, "I know I'll always have [the worries] but I'm going to learn ways just like my mum does of handling them" (p.76).

Some children described positive attitudes towards mental health as a consequence of living with their parent's MHD. For example, in Venkataraman (2011), when asked about the possibility of developing MHD themselves, one child reported, "'Actually, I am not concerned because it makes me who I am and it makes me a unique kind of person" (p.103)

#### **Discussion**

This metasynthesis is an attempt to combine and analyse qualitative data from 14 studies, with the aim of providing a functional conceptualisation regarding the sense children make of their parent's MHD. It was not clear from this analysis whether there was a direct relationship between these themes. However, the author hypothesises a possible circular process (Figure 2: Thematic Map). Results suggest that children appear to cite environmental or psychosocial factors, primarily traumatic experiences and particularly those occurring in childhood, as the main causes of their parent's MHD. However, they largely seem to view that the mental distress stemming from these adversities triggers an illness involving physical dysfunction. They appear to believe that this illness then takes over the parent, but maintain that any changes to the parent's behaviour or mood are a consequence of the MHD, and not a

fundamental characteristic of the parent. Viewing MHD as an illness coincides with a view that the parent therefore requires specialist support, particularly medical support and chiefly medication. This need for specialist support and the perceived behavioural and emotional 'abduction' of the parent by MHD is understood to mean that the parent is 'abnormal' and highly vulnerable. Children consequently make numerous lifestyle alterations to protect this vulnerability, namely via a dominant and perpetual worrying, burdensome parentification and the harbouring of the family secret to fend off stigmatisation. The consequence of these alterations seemingly results in detrimental psychological impacts on COPE-MHD, despite their efforts to develop alternative, preferred narratives that paint their parent and their ability to cope in a positive light. It is hypothesised that this search for alternative narratives reinforces and is reinforced by the belief that the parent is out of control when under the influence of MHD. This conceptualisation and theorised process will require further investigation to confirm its clinical functionality.

## **Theoretical and Clinical Implications**

There was some consensus found in this review that the cause of MHD are understood to be chiefly environmental or social. This supports international findings that the public designate psychosocial factors, such as poverty, loss, family conflict and traumatic childhoods far more frequently than biological or genetic factors when asked the cause of MHD (Read & Haslam, 2004; Read, Haslam, Sayce, & Davies, 2006). Children's explanation of MHD as an 'illness' and their awareness of a proposed genetic heritability suggests that their understanding of MHD relates to a biopsychosocial model of mental health.

This concept of MHD as physical dysfunction, resulting from psychosocial adversity, which consequently requires specialist support, may have implications for how COPE-MHD make sense of their own responses to adversity and the subsequent support they may seek.

For instance, as in Meadus and Johnson (2000), findings suggested that COPE-MHD selfmonitor and subsequently associate their experiences, such as feeling sad, as a sign of developing MHD, based on their experience of their parent and their understanding of MHD. It was also found that children experience intense psychological distress in terms of frequent worries about their parent. Negative inferences about MHD, such as the parent being vulnerable and socially unusual, may support the development of problematic assumptions, or schemata, regarding mental health generally. Schemas are "relatively stable representations of knowledge stored in memory structures", that once activated, "influence information processing, shape the interpretation of experience, and affect behaviour" (Wells, 2013, p.3). Schema development has been previously associated with cognitive risk factors for the intergenerational continuity of MHD in COPE-MHD (Koenen, Moffitt, Poulton, Martin, & Caspi, 2007; Yehuda & Bierer, 2008). This finding demonstrates a need to continue and expand on efforts to raise public understanding of mental health, particularly for children and young people, via, for instance, anti-stigma campaigns, such as Time to Change (Henderson & Thornicroft, 2009) and the provision of mental health-awareness training, such as Mental Health First Aid (Kitchener, Jorm, & Kelly, 2013; Hadlaczky, Hökby, Mkrtchian, Carli, & Wasserman, 2014).

These psychological impacts may also be of particular interest to researchers exploring mediating and moderating factors for the development of MHD for COPE-MHD. Findings may support attempts to conceptualise intergenerational MHD (Goodman & Gotlib, 1999; Hosman, van Doesum, & van Santvoort, 2009), which propose multiple biopsychosocial systems of influence for both risk and protective factors. This review may add value to such models by providing an insight into possible cognitive processes involved, resulting from the way COPE-MHD make sense of mental health via experience of their parent's MHD.

The awareness of social stigma supports previous research suggesting that relatives experience associative or courtesy stigma (Angermeyer, Schulze, & Dietrich, 2003; Carroll & Tuason, 2015; Chang & Horrocks, 2006; Goffman, 1963; Koschade & Lynd-Stevenson, 2011). This review also highlighted that COPE-MHD experience shame and isolation resulting from their awareness of courtesy stigma, initiated in part by familial requests for secrecy, which also supports previous findings (Pitman & Matthey, 2004; Polkki, Ervast, & Huupponen, 2004). In response, children consequently avoid inviting friends home, experience embarrassment and feel unable to communicate their experience to others for fear of humiliation. COPE-MHD experience or fear indirect social stigmatisation as a consequence of their relationship to their stigmatised parent, which has a subsequent disabling effect on self-expression and certain social behaviours. It appears, therefore, that COPE-MHD may experience a form of secondary psycho-emotional disablism (PED) (D. Reeve, personal communication, April 18, 2016) as a result of courtesy stigma, which may indicate another possible mechanism of intergenerational continuity. PED is a form of social oppression operating at the private level, enacted via, for instance, restrictions on ways of being resulting from the stigmatising messages of others or the internalisation of such messages, resulting in internalised oppression (Reeve, 2015; Thomas, 2007). PED can destabilise one's sense of self and self-esteem (Reeve, 2008; Reeve, 2015), the psychological impacts of which have been compared to that of emotional abuse (Reeve, 2006). This possible phenomenon may have implications for the development of MHD for COPE-MHD and requires further investigation.

Walsh (2009) proposed that children who consider MHD as external to their representation of their parent may be more likely to have better outcomes than those that embed MHD, particularly the negative aspects, within their mental representation of their parent. The ability to externalise MHD from the parent or self has been associated with

greater resilience in COPE-MHD (Beardslee et al., 2003; Walsh, 2009). The discovery from this review that children appear to externalise MHD from the parent, may suggest the utility of narrative therapy approaches with COPE-MHD, in order to support this process (Daniel & Wren, 2005; Focht & Beardslee, 1996; Pluznick & Kis-Sines, 2014). Furthermore, this review supports findings that personal exposure to MHD can promote positive attitudes towards people with MHD (Angermeyer & Matschinger, 1996; Read & Harre, 2001). A narrative therapy approach may also support COPE-MHD to capitalise on these positive attitudes and help to move them from problem saturated understandings of mental health, to more preferred stories (White & Epston, 1990), which may encourage the development of helpful, adaptive schemas.

The experience of reported psychological distress by COPE-MHD found in this review may encourage those caring for or supporting a child to consider their parents' mental health as a systemic contributing factor in child presentations of anxiety or low mood. Alan Carr's (2010) handbook of child and adolescent clinical psychology suggests consideration of exposure to a parents' MHD when formulating child presentations; this review may provide some context to the effect of such exposure, which may guide further exploration of impacts. However, it has been suggested that COPE-MHD may not demonstrate observable behavioural difficulties during episodes of increased parental distress and are thus unlikely to be known to services (Cooklin, 2010). The desire not to burden the parent, also identified by this review, may mean that their distress goes unnoticed or undisclosed until more severe. Weir and Douglas (1999) suggested that COPE-MHD can often appear superficially fine until ensuing disclosure highlights experiences of adversity. Furthermore, retrospective accounts of adult COPE-MHD highlight a desire to receive more information about MHD, alongside professional support for themselves during childhood (Knutsson-Medin, Edlund, & Ramklint, 2007). This may highlight a need to develop procedures for routine enquiry, such as that

described by McGee et al. (2015), which encourages enquiry about various adverse childhood experiences, of which having a parent that experiences MHD is a well-recognised item (Chapman et al. 2004; Felliti et al., 1998).

#### Limitations.

The above discussion should be considered within the typical limitations of qualitative reviews. For example, the analytic quality of the review is dependent in part on study quality. However, as described above, papers were not excluded based on quality appraisal to reduce the risk of excluding valuable interpretive data that could obstruct the development of new conceptualisations. Moreover, the search strategy was restricted only to papers published in peer-reviewed journals, excluding alternative sources, such as grey literature. The intention of this decision was to support the systematic quality and transparency of the search and to increase the ease of replication, as well as to ensure a minimum standard of research included. It is however acknowledged that additional relevant qualitative research may therefore have been excluded, which may have effected findings. Another limitation is that third order constructs presented are dependent on the reliability and rigor with which first and second order constructs were developed by the authors in the reviewed papers (Duggleby et al., 2012). However, in agreement with Murray and Forshaw (2013), these findings could nevertheless be considered robust, as the presented themes were developed across literature that varies in terms of context, sample characteristics, publication date and study setting.

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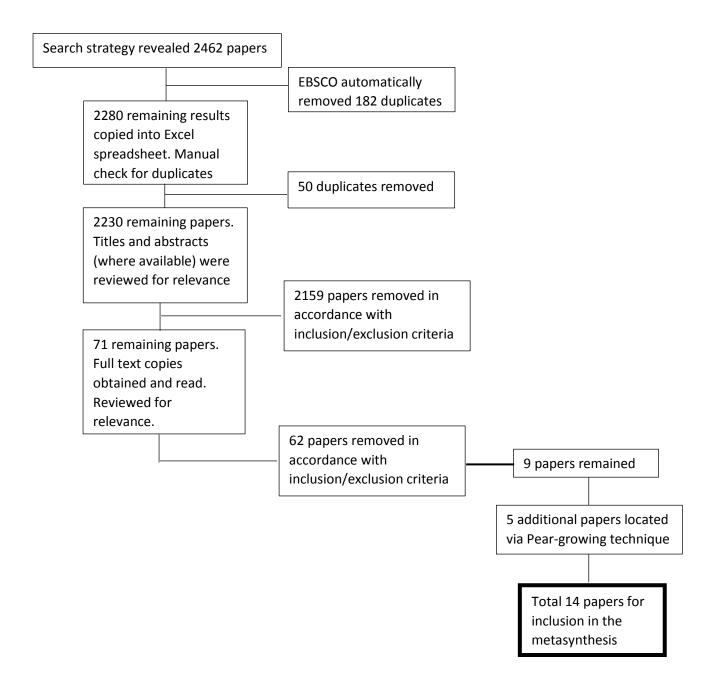
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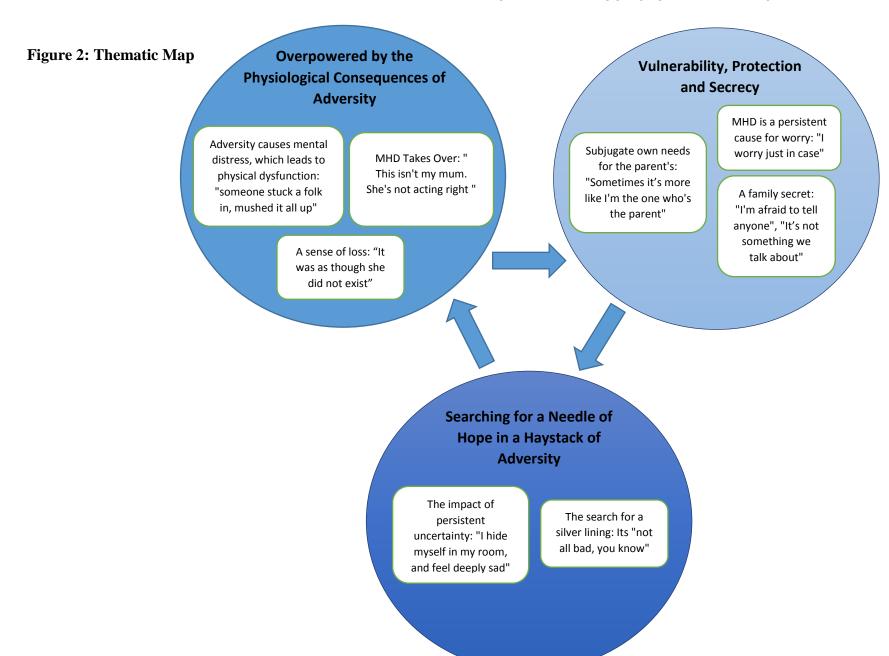
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# **Tables and Figures**

Figure 1: Flow diagram for inclusion of papers for the metasynthesis





**Table 1: Search Terms** 

		Search terms		
	AND	AND	AND	AND
"Qualitative" OR "theme" OR "thematic" OR "phenomenolog*" OR "IPA" OR "content analysis" OR "Narrative" OR "discourse" OR "grounded theory" OR "focus group*" OR "constant comparative" OR "hermeneutic"	"mentally ill" OR "mental illness" OR "mood disorder*" OR "mental disorder*" OR "mental health"	"parent" OR "parents" OR "parental" OR "mother*" OR "father*"	"understand*" OR "view" OR "comprehend" OR "construct*" OR "think" OR "perspective" OR "perceive" OR "perception*" OR "meaning" OR DE "Adolescent Attitudes" OR DE "Child Attitudes" OR "Label*" OR "Concepts" OR "Schema" OR "belief*" OR "belief*" OR "experience*" OR "knowledge" OR "aware*" OR "opinion*"	AND "child*" OR "adolescen*" OR "young people*" OR "young person*" OR "youth*"

<sup>\*</sup>Truncation symbol used to search databases for word variants.

**Table 2: Characteristics of Selected Papers** 

Authors	Aim	Qualitative Method	Sample	Setting	
Webster (1992)	Assess the burden experienced by children of parents with a diagnosis of schizophrenia	Interviews, analysis not stated	20 children between 8-18 years (10 males, 10 females) of parents with a diagnosis of schizophrenia	Depot Injection Clinic. Manchester, UK	
Garley, Gallop, Johnston & Pipitone (1997)	Explore the subjective needs, cognitions and perceptions of asymptomatic children of parents with a mood disorder, to guide the development of a group intervention	Ethnographic approach, semi- structured focus groups, thematic analysis	6 children between 11-15 years (3 males, 3 females) of parent with a diagnosed mood disorder (depression and manic depression)	University-affiliated psychiatric facility. Toronto, Canada	
Meadus & Johnson (2000)	Describe the experiences of adolescent children living with a parent who has a mood disorder	Unstructured interviews, Giorgi's (1985) Descriptive Phenomenological method	3 female children aged 17 years living with a parent with a parent with a mood disorder	Psychiatric facility and volunteer organisation. Toronto, Canada	
Handley et al. (2001)	(1) To identify the number of children of parents/carers with mental illness, (2) to identify the types of supports needed by parents, children and service Providers (3) identify level of support available	Small groups and individual interviews	4 female children of parents with diagnosis of affective disorder, aged 11-15 years	Government Mental Health Services in the southern region of Tasmania, Australia	
Riebschleger (2004)	Explore a child's eye view of living day to day in a family that included a parent with a psychiatric disability.	Secondary analysis of Data from individual interviews and focus groups, Grounded Theory	22 children between 5-17 years (mean age = 9.36, 11 males, 11 females) of parents with a psychiatric disability	Prevention programs located in three community mental health agencies in northeast, southwest, and central Michigan, USA.	
Maybery, Ling, Szakacs & Reupert (2005)	Determine differences in perspective on issues facing children whose parents have a mental illness	Interpretative paradigm, separate child and parent focus group interviews, analysis not stated	12 children between 6-16 years of parents with mood disorder, personality disorder and psychotic disorder	North east Victoria, Australia.	
Cogan, Riddell & Mayes (2005)	Explore the understanding and experiences of children affected by parental mental health problems	Semi-structured interviews, analysed using interactive model of Huberman and Miles (1994)	20 children between 12-17 years (10 males, 10 females) of parents with IDC-10 diagnosis of an affective illness and 20 children between 13-17 years (10 males,	Recruited via family support workers. Glasgow, Scotland.	

## CHILDREN MAKING SENSE OF THEIR PARENT'S MENTAL HEALTH DIFFICULTIES

Authors	Aim	Qualitative Method	Sample	Setting	
			10 females) of 'well' parents.		
Östman (2008)	Investigate experiences of children of parents with a severe mental illness	Thematic analysis	8 children between 10-18 years (3 males, 5 females) of parents with psychiatric diagnosis	Psychiatric unit. South of Sweden	
Mordoch & Hall (2008)	Explore how children manage their experiences of living with a parent with a mental illness	Interviews, participant observation and drawings. Constant comparative grounded theory	22 children between 6-16 years living part of full-time with a parent with depression, schizophrenia or bipolar diagnoses.	Midwestern Canadian city	
Mordoch (2010)	Explore how children understand mental illness and what they want to tell other children living with parental mental illness	secondary grounded theory analysis of data from Mordoch and Hall (2008), focussed on investigation of a component of the 'Monitoring' category from the primary analysis	22 children between 6-16 years living part of full-time with a parent with depression, schizophrenia or bipolar diagnoses.	Midwestern Canadian city	
Venkataraman (2011)	Explore children's perspectives on the parenting of mothers with a diagnosis of bipolar disorder	Initial semi-structured interview and follow-up interview. Constant comparative grounded theory	4 children between 10-15 years with mothers that had a diagnosis of bipolar disorder	Community mental health centres and support groups. Un-named town Midwest USA	
Griffiths, Norris, Stallard & Matthews (2012)	Explore the experiences of young people with a parent with obsessive compulsive disorder (OCD)	Semi-structured interviews. Inductive thematic analysis	10 children between 13-19 years (5 males, 5 females) with a parent with OCD	Mental health services and voluntary organisations, UK	
Trondsen (2012)	Provide insight into the perspectives and experiences of children and adolescents living with a mentally ill parent	Action-oriented study of online self-help group for 2 years. Issue focussed analysis (Weiss, 1994)	16 adolescents between 15-18 years (1 male, 15 females) of parents with a mental illness using an online self-help group	Norwegian hospital-run self-help group	
Van Parys & Rober (2013)	Explore how children experience parental depression and how they experience their own caregiving in the family	Family interviews. Thematic analysis	14 children between 7-14 years (5 males, 9 females) of parents hospitalised for depression	Psychiatric unit for affective disorders at University, Belgium	

**Table 3: CASP Checklist Results** 

	Research Design	Recruitment strategy	Data collection	Reflexivity	Ethical issues	Rigorous data analysis	Clear statement of findings	Valuableness of the research	Total score
Webster (1992)	0	1	1	0	0	0	1	1	4
Garley, Gallop, Johnston & Pipitone (1997)	3	3	3	2	2	1	2	2	18
Meadus & Johnson (2000)	3	3	2	1	3	2	3	2	19
Handley et al. (2001)	2	3	3	0	2	1	3	3	17
Riebschleger (2004)	2	3	3	1	0	2	3	2	16
Maybery, Ling, Szakacs & Reupert (2005)	1	2	2	0	1	1	1	2	10
Cogan, Riddell & Mayes (2005)	2	3	3	1	3	3	3	3	21
Östman (2008)	2	3	2	1	3	2	2	2	17
Mordoch & Hall (2008)	3	3	3	1	3	3	3	3	21
Mordoch (2010)	3	2	1	1	0	2	3	3	15
Venkataraman (2011)	2	3	3	1	2	2	2	2	16
Griffiths, Norris, Stallard & Matthews (2012)	1	2	1	3	1	3	3	3	17
Trondsen (2012)	3	3	3	3	3	3	3	3	24
Van Parys & Rober (2013)	3	3	3	1	2	3	2	3	20

## **Appendices**

## **Appendix A: Journal Instructions**

Journal of Child and Family Studies

#### General

In general, the journal follows the recommendations of the 2010 Publication Manual of the American Psychological Association (Sixth Edition), and it is suggested that contributors refer to this publication. The research described in the manuscripts should be consistent with generally accepted standards of ethical practice. The anonymity of subjects and participants must be protected and identifying information omitted from the manuscript.

## **Manuscript Submission**

The Journal uses Editorial Manager<sup>TM</sup> as its submission and peer review tracking system. All authors are required to register as a new user with Editorial Manager the first time they login in to the system. Straightforward login, registration procedures and step-by-step instructions for submitting manuscripts can be found on the website. Authors can use the Editorial Manager to track the review of their manuscripts in real time.

All authors should submit their manuscripts online. Manuscript submissions to the Journal should be prepared electronically and submitted in a standard word processing format. Microsoft Word® is preferred. Electronic submission substantially reduces the editorial processing and reviewing times, and shortens overall publication times. Please connect directly to the site: http://jcfs.edmgr.com and upload all of your manuscript files following the instructions given on the screen.

## Suggested Reviewers

Authors of research and review papers, excluding editorial and book review submissions, are allowed to provide the names and contact information for, maximum, 4 to 6 possible reviewers of their paper. When uploading a paper to the Editorial Manager site, authors must provide complete contact information for each recommended reviewer, along with a specific reason for your suggestion in the comments box for each person. The journal will consider reviewers recommended by the authors only if the reviewers' institutional email is provided. A minimum of two suggested reviewers should be from a university or research institute in the United States. You may not suggest the Editor or Associate Editors of the journal as potential reviewers. Although there is no guarantee that the editorial office will use your suggested reviewers, your help is appreciated and may speed up the selection of appropriate reviewers.

Authors should note that it is inappropriate to list as preferred reviewers researchers from the same institution as any of the authors, collaborators and co-authors from the past five years as well as anyone whose relationship with one of the authors may present a conflict of interest. The journal will not tolerate this practice and reserves the right to reject submissions on this basis.

•http://jcfs.edmgr.com

### **Publication Policies**

The Journal considers manuscripts for publication with the understanding that they represent original material and have not been published, submitted or accepted elsewhere, either in whole or in any substantial part. Each manuscript should report sufficient new data that makes a significant contribution to its field of research; thus, the submission of small amounts of data from a larger study or research project for divided publications would be inappropriate. A statement transferring copyright from the authors (or their employers, if they hold the copyright) to Springer Science+Business Media, Inc. will be required before the manuscript can be accepted for publication. Such a written transfer of copyright, which previously was assumed to be implicit in the act of submitting a manuscript, is necessary under the U.S. Copyright Law in order for the publisher to carry through the dissemination of research results and reviews as widely and effectively as possible.

Authors can expect a decision usually within 8 to 10 weeks. Reviewers comments are sent with the decision. Accepted papers are subject to editorial revisions and copyediting. However, the contents of the paper remain the responsibility of the author.

### Double-Blind Peer Review

All submissions are subject to double-blind peer review. In general, experimental/research studies are judged in terms of the following criteria: originality, contribution to the existing research literature, methodological soundness, and readability.

When you are ready to submit a manuscript to JCFS, please be sure to upload these 2 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

A title page with no running head, manuscript title, and complete author information. Followed by the Abstract page with keywords and the corresponding author e-mail information.

The blinded manuscript containing no author information (no name, no affiliation, and so forth).

## Manuscript Style

All manuscripts should be formatted to print out double-spaced at standard 8" x 11" paper dimensions, using a 10 pt. font size and a default typeface (recommended fonts are Times, Times New Roman, Calibri and Arial). Set all margins at one inch, and do not justify the right margin. Double-space the entire manuscript, including title page, abstract, list of references, tables, and figure captions. After the title page, number pages consecutively throughout including the reference pages, tables, and figure legends. The average article length is approximately 30 manuscript pages. For manuscripts exceeding the standard 30 pages, authors should contact the Editor in Chief, Nirbhay N. Singh directly at nirbsingh52@aol.com.

The Journal encourages the publication of research that is virtually jargon-free and easy to read. Thus, a personalized manuscript, written in active tense, is preferred. For example, "This study examined . . ." could be stated as, "We examined . . ." The Journal encourages a conversational rather than an impersonal tone in the manuscripts. Hypotheses should be written as a part of the last paragraph of the Introduction and not in bullet form. All reference

to the study being reported should be consolidated in the last (or, if necessary, the last and penultimate) paragraph of the Introduction and not scattered throughout the introductory section.

## Title Page

A title page is to be provided and should include: (1) the title (maximum of 15 words); (2) full names of the authors (without degree), with a bullet between the names of the authors; (3) brief running head; and, at the bottom of the title page, (4) the corresponding author's initials and last name (without degree), affiliation, mailing address, and e-mail address. The initials and last name of all authors should be listed as well. All authors from the same institution should be listed together, with a bullet separating the names. For all, but the corresponding author, list the affiliation, city and state only.

#### Abstract

The abstract should be between 200 and 250 words. It should be concise and complete in itself without reference to the body of the paper. In addition to a general statement about the field of research as the first sentence, abstracts of experimental/research papers should contain a brief summary of the paper's purpose, method (design of the study, main outcome measures, and age range of subjects), results (major findings), and clinical significance. Abstracts of review papers should include a general statement about research area being reviewed as the first sentence, it should contain a brief summary of the review's purpose, method (data sources, study selection process), results (methods of data synthesis and key findings), and conclusions (summary statement of what is known, including potential applications and research needs). Do not use sub-headings and do not cite data or references in the abstract.

## **Key Words**

A list of 5 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.

## Text

Text should begin on the second numbered page. Authors are advised to spell out all abbreviations (other than units of measure) the first time they are used. Do not use footnotes to the text. When using direct quotations from another publication, cite the page number for the quotation in the text, immediately after the quotation. When reporting statistically significant results, include the statistical test used, the value of the test statistic, degrees of freedom, and p values. In the discussion include an evaluation of implications (clinical, policy, training or otherwise) of the study when appropriate. Also, discuss limitations in study design or execution that may limit interpretation of the data and generalizability of the findings. Do not use any sub-headings in the Introduction or Discussion sections.

#### **Footnotes**

No footnotes are to be used.

References Cited Within the Text

Cite references in alphabetical order within the text.

### References

The accuracy of the references is the responsibility of the authors.

List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. References should include (in this order):

• last names and initials of all authors,

year published (in brackets)

title of article

name of publication

volume number

and inclusive pages

Do not include issue numbers of journals unless each issue begins with page 1. For book chapters, include volume number (if applicable) and page numbers, as shown below.

Consult the Publication Manual of the American Psychological Association, 6th Edition (Chapter 7) for formatting references. The style and punctuation of the references should conform to strict APA style – illustrated by the following examples:

## • Journal Article:

Roelofs, J., Meesters, C., & Muris, P. (2008). Correlates of self-reported attachment (in)security in children: The role of parental romantic attachment status and rearing behaviors. Journal of Child and Family Studies, 17, 555-566.

## Book:

McBee, L. (2008). Mindfulness-based elder care: A CAM model for frail elders and their caregivers. New York: Springer.

## Book Chapter:

Singh, N.N., Winton, A.S.W., Singh, J., McAleavey, K., Wahler, R.G., & Sabaawi, M. (2006). Mindfulness-based caregiving and support. In J.K. Luiselli (Ed.), Antecedent assessment and intervention: Supporting children and adults with developmental disabilities in community settings (pp. 269-290). Baltimore, MD: Paul H. Brookes.

#### **Tables**

Tables follow the Reference section. Create tables using the table creation and editing feature of your word processing software (e.g., Word) instead of spreadsheet programs. Tables that are a single column are actually lists and should be included in the text as such. Number tables consecutively using Arabic numerals in order of appearance in the text. Cite each table in the text and note approximately where it should be placed. Type each table on a separate page with the title and legend included. Double-space the table and any footnotes to it. Set each separate entry in a single table cell. Do not use underlining. Properly align numbers, both horizontally and vertically. Use brief headings for columns. If abbreviations are

necessary, define them in a key at the bottom of the table. Keep footnotes to a minimum; if necessary, use superscript letters to denote them.

# Figures

Figures follow the tables. Figures must be submitted in electronic form. Figures and illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of Arabic numerals.

# **Chapter 2: Research Paper**

Exploring the Impact of Enquiring About the Adverse Childhood Experiences of Parents

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### **Abstract**

Due to identified public health risks, there have been calls to develop methods of early detection in child and family services to interrupt the widespread impacts and intergenerational continuity of Adverse Childhood Experiences (ACE). Routine Enquiry about Adversity in Childhood (REACh) is a model that supports health professionals to consistently and appropriately ask service-users about ACEs in clinical practice. This study aimed to understand how parents, who had experienced at least one ACE, experienced being asked about their own ACEs and what, if any, subsequent impact occurred. Eleven semi-structured interviews were conducted across seven participants, analysed using thematic analysis. Three themes were developed. The first relates to a five-stage chronological model of ACE enquiry. The second raises issues of disproportionate social power in the enquirer-discloser relationship. The final themes illustrate a process of post-disclosure behaviour change, seemingly initiated by ACE enquiry. These findings provide a theoretical contribution to disclosure literature and provide clinical recommendations to support engagement of parents in discussions regarding the impact of trauma histories.

Keywords: Routine enquiry; adverse childhood experiences; trauma; parents; children

Although 'trauma' and 'traumatic impact' are terms in common academic and clinical usage, they remain difficult to adequately define. Efforts to clarify what is meant by these terms have focussed on providing or critiquing clinical definitions for the diagnostic criteria of post-traumatic stress disorder (PTSD) (American Psychiatric Association; APA, 2013; Division of Clinical Psychology; DCP, 2013; World Health Organisation; WHO 1990). These definitions have been widely criticised for their narrow focus, which excludes many experiences that may invoke a trauma response, but do not adequately meet the objective diagnostic criterion (Scott & Stradling, 1994). Diagnostic definitions also do not sufficiently acknowledge the subjective nature of traumatic experiences and response (see Bovin & Marx, 2011; May & Wisco, 2016; Weathers & Keane, 2007). Conversely, it has been suggested that it is the subjective cognitive appraisal of events, rather than an objective measure of stressor severity that determines the psycho-biological stress response (Allen, 2005; Olff, Langeland, & Gersons, 2005). Therefore, one's internal processing of any event may determine whether it is deemed traumatic. For this study, psychological trauma is defined as the psychobiological consequence of "an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being" (Substance Abuse and Mental Health Services Administration, 2012, p. 2).

There is general unanimity of opinion regarding the traumatic nature of particular types of events, such as sexual assault and involvement in or being witness to natural disaster (Saunders & Adams, 2014). Consequently, much of the literature, including childhood trauma, has focused on such experiences (Rossiter et al., 2015). However, between the 1980's and the turn of the century, there was an increased deliberation regarding the subjective interpretation of experiences deemed traumatic (Copeland, Keeler, Angold, & Costello,

2007). For instance, research identified that the incarceration of a child's parent or a parent disclosing a historic suicide attempt was as likely as sexual assault to result in that child experiencing diagnostic classifications of post-traumatic stress (Giaconia et al., 1995). Other childhood experiences have subsequently been recognised as having a potentially traumatic impact, and have been frequently associated with increased risk of experiencing mental health difficulties and reduced health-related quality of life in adulthood (Benjet, Borges, Méndez, Fleiz, & Medina-Mora, 2011; Draper et al., 2008; Huang, Schwandt, Ramchandani, George, & Heilig, 2012).

An important development over recent years in exploring the link between childhood trauma and detrimental adult outcomes, is research on Adverse Childhood Experiences (ACEs) (Centers for Disease Control and Prevention; CDC, 2013; Felitti et al., 1998). The original ACE study evolved as a method of assessing, amongst adults, the prevalence of exposure to different types of adverse events experienced during the first 18 years of life (Felitti et al., 1998). Numerous ACE studies have consistently demonstrated associations between ten categories of experiences with increased risk of health and social difficulties, increased health care costs, and reduced life expectancy (Felitti & Anda, 2014).

The ten categories of ACE have been separated into three theoretical subsets. The first, household dysfunction, consists of living with a parent who experiences mental health difficulties, living with a parent who misuses alcohol or drugs, separation from a parent of carer via divorce or imprisonment, and witnessing domestic violence. The second relates to personal experience of abuse; physical, sexual and emotional. The final subset incorporates personal experiences of both physical and emotional neglect (Felitti et al., 1998). These categories provide an ACE score, giving a measure of cumulative stress experienced during childhood. This is achieved by assigning a score of one to each ACE category, totalling ten (Murphy et al., 2014).

Some have questioned the reliability and validity of self-report methods of assessing the impact of childhood trauma, such as ACEs. For instance, although Dube, Williamson, Thompson, Felitti and Anda, (2004) reported high test-retest consistency for ACEs, this has been criticised. Widom, Raphael and DuMont (2004) highlighted potential influence of variables such as the age and physical or psychological health status of participants in the Dube et al. (2004) study; referring to the likelihood of greater negative bias or false negatives for older participants and those in poorer health. However, a number of international studies have indicated reliable and valid internal consistency of the ACE questionnaire (Bruskas & Tessin, 2013; Kazeem, 2015; Pinto, Correia, & Maia, 2014). In a review of literature regarding validity, Hardt and Rutter (2004) concluded that retrospective assessment of ACEs can be considered "sufficiently valid...to warrant its use in case-control studies even though there is significant under-reporting and probably some bias" (p.270). Others have highlighted cultural issues in defining ACE categories and have begun to research additional ACEs, such as peer rejection, peer victimisation and exposure to community violence (Finkelhor, Shattuck, Turner, & Hamby, 2013). However, these currently require further validation and therefore, when discussing ACEs within this study, we refer only to the validated ten.

Despite difficulties in establishing accurate international prevalence rates, estimates from American (Dube et al., 2003a; Felliti et al., 1998), UK (Bellis et al., 2013; Bellis et al., 2014b), cross-European (Bellis et al., 2014a) and cross-continental studies (Kessler et al., 2010) have suggested that around half to two-thirds of the population report experiencing at least one ACE. Of particular relevance to these prevalence findings is the dose-response relationship; higher ACE scores equate to greater numbers and severity of the aforementioned health and social outcomes in adulthood (Dube et al., 2003b; Edwards, Holden, Felitti, & Anda, 2003). However, the temporal relationship between ACE exposure and health outcomes could not be accurately verified, so it is not possible to know with certainty

whether onset of health or social difficulties occurred pre or post-ACE exposure (Dube et al., 2003).

Of particular interest to the current study is the intergenerational continuity of ACEs; children of parents that experienced ACEs are at greater risk of experiencing ACEs themselves (Narayan et al., 2016; University College London (UCL) Institute of Health Equity, 2015). Rates of maltreatment continuity have been shown to vary (Berlin, Appleyard, & Dodge, 2011) and Ertem, Leventhal and Dobbs (2000) outlined the methodological shortcomings of research that claims evidence of continuity. However, numerous studies have indicated a greater risk of abuse among children of parents that experienced abuse (Dixon, Hamilton-Giachritsis, & Browne, 2005; Egeland, Bosquet, & Chung, 2002; Ertem et al., 2000; Kaufman & Zigler, 1993; Pears & Capaldi, 2001), of which Egeland, Jacobvitz, and Sroufe (1988) has been described as providing strong, methodologically sound evidence (Ertem et al., 2000). Mediation analyses have highlighted the multifactorial nature of continuity (Dixon, Hamilton-Giachritsis, & Browne, 2005) and, given the high prevalence rates of ACEs, it is therefore important to consider what may constitute such risks.

Attachment theory (Bowlby, 1951; 1982; 1988) provides one psychological framework for understanding intergenerational continuity of ACEs. Attachment theory posits that the parent-child relationship shapes the development of internal working models of the self and others. One internalises, via experience of a parent or carer, a model of oneself as a parent or carer, encompassing one's assumptions and expectations of parental and child behaviour (George, 1996; Morton & Browne 1998; Steele et al., 2016). These internal working models of the self as a parent, particularly when experiencing high levels of stress, may determine one's choice of parenting behaviour (Bowlby, 1982; Busch & Lieberman, 2010).

Higher numbers of ACEs have also been found to predict higher levels of parenting distress, which has been linked to problematic parenting (Steele et al., 2016). Parents who experience childhood maltreatment have demonstrated difficulties in displaying particular beneficial parenting behaviours and attitudes, such as sensitivity, responsiveness and parental reflective functioning (Slade, 2005; van IJzendoorn, 1995) and greater levels of unhelpful behaviours, like hostility, intrusiveness and aggression (Conger, Schofield, Neppl, & Merrick, 2013; Lyons-Ruth & Jacobvitz, 2008; Newcomb & Locke, 2001).

There has long been debate regarding what constitutes "good enough" vs. "not good enough" parenting, yet clarity has been hampered by attempts to account for prevailing economic, social and political contexts in which family systems function (see Taylor, Spencer & Baldwin, 2000). However, unhelpful parenting behaviours, such as those listed, have, in particular contexts, demonstrated negative associations with elements of child development (Gershoff, 2002; Newman, Harrison, Dashiff, & Davies, 2008). Such behaviours, attitudes and stressful conditions have also been found to increase the risk of child maltreatment (Montes, de Paúl, & Milner, 2001). Social learning models suggest that children who experience ACEs are more likely to display intergenerational continuity of harmful parenting behaviours, such as physical punishment, by modelling the parenting they experienced as children (Muller, Hunter, & Stollak, 1995; UCL Institute of Health Equity, 2015).

Given the repeatedly demonstrated impacts and intergenerational continuity of ACEs, there is a widespread public health need to interrupt this cycle of adversity (Murphy et al., 2014; Shonkoff, Richter, van der Gaag, & Bhutta, 2012). There have been requests to develop methods of early detection in child and family services to support the identification of clinical need, develop and provide targeted support, and to prevent poor outcomes (Munro, 2011; Read, Hammersley & Rudegeair, 2007; Steele et al., 2016). However, one difficulty in attempts to develop such methods has been that survivors of childhood trauma can often be

reluctant to voluntarily disclose (Anderson, Martin, Mullen, Romans and Herbison, 1993; Frenken & Van Stolk, 1990; Read, McGregor, Coggan & Thomas, 2006).

Survivors have described shame and guilt in relation to their experience, and anxiety about sharing their story as primary barriers to disclosure (Alaggia, 2004; Dohary & Clearwater, 2012). Some have described avoiding disclosure due to uncertainty about the legitimacy (Dohary & Clearwater, 2012) or the severity of their experiences (Crowley & Seery, 2001). Others have expressed concern about potential consequences (Sorsoli et al., 2008), such as their story being shared further without their permission (Del Castillo & Wright, 2009; Tener & Murphy, 2015). Difficulties in predicting the impact of a disclosure has been suggested to result in increased distress, which can be further exacerbated by negative responses from the listener (Glover et al., 2010).

Little is known about the decision to disclose childhood trauma in adulthood, or the process of disclosure (Tener & Murphy, 2015). Draucker and Martsolf (2008) proposed a series of stages for adult disclosure of childhood trauma. These stages involve initial consideration of the method and completeness of their potential disclosure, including evaluations of the listener and assessment of potential consequences. This is followed by the purposeful decision to begin disclosure, during which the listener's response is evaluated and, if appraised as positive, will lead to sharing in greater detail. However, as with much of the literature on disclosure, this model refers specifically to disclosure of sexual abuse and it is unclear whether this staged model would be applicable to disclosure of other or multiple forms of childhood trauma, such as ACEs.

Whether elicited by enquiry or voluntarily shared, disclosures involve deliberation and calculated decisions about how, what and with whom to share (Del Castillo & Wright, 2009). The quality of relationship between discloser and listener, particularly concerning trust

(Draucker & Martsolf, 2008; Hunter, 2011; Sorsoli et al., 2008) is important to ensure the survivor feels comfortable (Del Castillo & Wright, 2009) and that the listener is able to provide a positive, unconditional and non-judgmental response (McGregor, Glover, Gautam, & Ju¨lich, 2010; Sorsoli et al., 2008). However, practitioners have historically cited discomfort with, and an apparent reluctance to enquire about trauma (Read et al., 2006; Read et al., 2007; Read & Fraser, 1998). Young, Read, Barker-Collo, and Harrison (2001) investigated the motives underlying professionals' enquiry-avoidance. They discovered that professionals experienced anxiety about distressing the service-user or themselves and feared encouraging false memories. However, disclosure has been repeatedly demonstrated as having positive influences on recovery and psychological healing, resulting in greater resilience, more positive perceptions of self and reduced experience of distress (Frattaroli, 2006; Hemenover, 2003; Marriott, Lewis, & Gobin, 2016).

Research has also found that disclosure can encourage post-traumatic growth (Slavin-Spenny, Cohen, Oberleitner, & Lumley, 2011; Smyth, Hockemeyer, & Tulloch, 2008); a phenomenon in which people experience cognitive benefits following trauma, including; meaning making; re-evaluation of personal priorities; increased self-awareness; increased reflection; and appreciation of life (Tedeschi & Calhoun, 2004). However, whilst disclosure has been found to provide short-term relief, others have found no long-term positive impact on emotional functioning (Zech & Rime, 2005). Furthermore, research has shown that the effects of disclosure depend, in part, on the response of the listener, with negatively appraised responses resulting in negative impacts (Tener & Murphy, 2015). Consequently, principles and guidance on 'why, when and how to ask about childhood abuse' have been proposed (Read et al., 2007). Encouraging safe disclosure, with an appropriately trained listener, may offer one method of detecting, providing support for and preventing ACEs.

Routine enquiry has been applied as an effective method of assessing other healthrelated societal issues, such as domestic violence, with clinicians describing it as an important clinical duty (Price, Baird, & Salmon, 2007). Service-users also expressed an expectation to be asked and that by asking, cultural discourses around the appropriateness of disclosure are altered and public awareness is increased (Salmon, Baird, & White, 2015). In 2013, Lancashire Care Foundation Trust (LCFT) developed a model for Routine Enquiry about Adversity in Childhood (REACh); a programme designed to assist health professionals in developing the skills and confidence to detect ACEs in a clinical population, and to formulate targeted support. However, little is known about how people disclose childhood trauma and less is known about how people experience being asked about ACEs. Formal evidence does not currently exist regarding parents' experiences of ACE enquiry and "whether asking about ACEs makes a difference in their healing processes or in their parenting decisions" (R. J. Gillespie, personal communication, May 17, 2016). This has been described as "a gap" in the disclosure and ACE literature (H. Larkin, personal communication, May 3, 2016). Due to limited documented knowledge, the primary research questions were intentionally broad; 'How do parents experience being asked about their own ACEs?' and 'What is the impact on parents who are asked about their ACEs?'.

### Method

## **Participants**

The criteria for participation attempted to be as inclusive as possible, as prior to investigation, little was known regarding which factors may influence a parent's response to routine enquiry about adversity. All participants had parental responsibility for at least one child and must have identified at least one ACE during REACh. Participants were required to be competent in English, due to resource restrictions, but no restrictions were placed on any

demographic information for either participants or their children. Participants were excluded if they were currently receiving support for post-traumatic stress, to preclude risk of eliciting trauma-responses.

Recruitment services were third sector and local authority family support services. Professionals were family support workers or family wellbeing practitioners trained in REACh and working with parents. These services accept referrals via professionals in education, housing, health, social care or police and youth justice services or self-referral. The services provide advice and guidance on a range of childcare, learning and family support needs. All parents accessing these services are offered REACh at the initial assessment stage, as per guidance from Read et al. (2007). Consent is obtained from parents to complete REACh and parents are advised that they may decline to answer any questions during assessment (see McGee et al., 2013).

The author attended service meetings to introduce and discuss the project with professionals. Professionals were asked to identify parents on their caseload that met the inclusion criteria and share with them a participant information sheet (PIS) (Appendix A). Participants were asked to contact the author or to provide verbal consent for the author to contact them.

Seven participants were recruited in total. All participants were invited to be reinterviewed for the purpose of checking the accuracy of and further developing the interpretation of parents' individual and collective accounts. Four agreed to be reinterviewed; data was analysed across eleven interviews from seven participants. Six participants were female and all identified as white British. ACE scores ranged from two to eight, with an average of 4.3.

## The Author's Perspective

To support the reader's interpretation of qualitative findings, it is important to clarify the author's affiliation with the topic and their epistemological and ontological stance (Elliott, Fischer & Rennie, 1999; Braun & Clarke, 2006; Braun & Clarke, 2013). It is acknowledged that the author is a trainee clinical psychologist, with prior clinical experience as an assistant clinical psychologist and psychological play and parenting specialist, working directly with parents, children and families in mental health services. The author also spent their final year placement of clinical psychology doctoral training working on the development of REACh and other methods of routine enquiry. However, the author had no involvement in the training of services that supported recruitment, which occurred prior to their association with REACh. The need to conduct this study arose following receipt of anecdotal reports from REACh trained practitioners, that parents frequently described the REACh enquiry as helpful. However, there had been no investigation of this effect from parents' perspectives, within these services locally or reported within available literature.

Due to the interpretive nature of qualitative analysis, incorporating and demonstrating methodological trustworthiness and rigour is valuable and, as such, a number of steps were taken in attempt to exhibit procedural credibility (Kidd, et al., 2016; Shenton, 2004; Yardley, 2008). Firstly, reflections on the research process were logged and shared with research supervisors. Coding and theme development were also submitted to multiple rounds of review by supervisors to identify and challenge bias. Finally, participants were invited to comment on the analysis to encourage the trustworthiness of conceptual interpretations of participant accounts (Kidd, et al., 2016).

This study was conducted from an objectivist ontological position (Barrett, Barrett, & Zhang, 2015); a reality exists independent of the author's knowledge, in that an experience

occurs and a response is actioned by parents following REACh. However, a subjective epistemological stance is taken to this position (Johnson & Duberley, 2000), in that it is held only possible to know about any reality via social interactionism; developing meaning through interpretive processes by engaging critically in social interaction with, for this study, parents (Handberg, Thorne, Midtgaard, Nielsen, & Lomborg, 2014). From this position, the intention of this research is thus to pragmatically construct knowledge that provides a useful understanding for, for instance, services working with parents. It is hoped that this pragmatic conceptualisation can influence an understanding of and engagement with parents' experiences in relation to REACh and encourage further discussion.

### **Data Collection**

Data were gathered via individual, face-to-face and telephone interviews and followed a semi-structured format, consisting primarily of open-ended questions. Initial interviews lasted an average of 49 minutes, ranging from 30 to 69 minutes. Follow-up interviews lasted an average of 29 minutes, ranging from 21 to 45 minutes. The aim was to facilitate exploratory conversations and rich accounts of participant's views regarding their experience of being asked about ACEs during REACh. An interview topic guide was used to scaffold the questions included in the interviews, whilst allowing for exploration of each participant's individual experiences (see Appendix C). The topic guide continually evolved during collection to include additional questions relating to concepts or emerging issues. This was done to ensure that the research questions were sufficiently addressed and to permit consideration of participants' experiences and understanding.

The approach to follow-up interviews allowed clarification of the meaning of participants' experiences and permitted investigation of additional content stimulated by the initial interview (Knox & Burkard, 2009). Participants were read a narrative description of

their individual account, on which they were asked open-ended questions regarding the accuracy of the description. This process was repeated with a narrative description of the collective accounts, alongside further meta-discussion regarding their experience of the interview.

An electronic dictation device was used to record qualitative data provided during interviews. All audio data were transcribed by the author. Participants were given pseudonyms to protect anonymity.

## **Data Analysis**

As this study attempted to address a gap in the literature, it was felt the research design should enable the identification of themes across participant accounts and should subsequently highlight recommendations for future empirical direction (Fielden & Sillence, 2011). Consequently, data were analysed using inductive thematic analysis at both the semantic and latent level, following the phased approach outlined by Braun and Clarke (2006). This approach encouraged procedural replicability, whilst maintaining epistemological flexibility (Fielden & Sillence, 2011). The aim of analysis was to distinguish patterns of meaning across participant accounts embedded within the data (Braun & Clarke, 2013).

Audio recordings were listened to individually, prior to transcription, to commence a process of immersion with the data, making note of reflections on both the content and manner of delivery in participant accounts (Braun & Clarke, 2006; Braun & Clarke, 2013; Hammersley, 2010). To establish meaning within the data set, a critical frame was applied to encouraging analytic reading of data (Braun & Clarke, 2013). Codes were generated using the comments function in Microsoft Word to create semantic and conceptual notations on lines of data (Appendix D). Coded lines of text were transferred into a spreadsheet using

Microsoft Excel, along with their corresponding code and any notations. This enabled sideby-side examination for similarities between codes, in terms of content or hypothesised meaning.

Initial candidate themes were developed by grouping and giving similar codes provisional descriptive titles, based on quotes that captured the central organising concept. Groups of candidate themes were then arranged within discrete sheets within the spreadsheet to begin identification of overarching concepts. During this stage, a chronological order was identified across themes. Themes were initially organised as stages across this order; each stage formed a preliminary overarching concept. However, on further analysis of each stage or the order, there appeared to be two detailed overarching concepts captured within and across the chronological stages. Themes were then arranged via three central organising concepts; a chronological staged-order, issue of power in the enquirer-discloser relationship, and a post-enquiry behaviour change process.

Codes and scarcely populated candidate themes not grouped thematically were categorised as miscellaneous and stored in a separate sheet. This allowed continual reference with new developing themes until the completion of the analysis, upon which miscellaneous themes were discarded.

To encourage an inductive approach, the conceptual meaning of themes were appraised against the content and context of participant accounts by re-reading them against original transcripts. This approach aimed to ensure themes adequately represented the experiences portrayed. The analysis was then organised into a coherent structure, comprising final overarching themes and subthemes, with individual, descriptive narratives that depicted the conceptual meaning of, and associations between each theme (Table 1). All follow-up interviews indicated that final themes and their narrative descriptions accurately reflected

participant experiences. A thematic map was produced to present the proposed structure of the final analysis (Figure 1).

#### **Ethical Considerations**

The study was reviewed by Lancaster University's Faculty of Health and Medicine Research Ethics Committee and approved by the University Research Ethics Committee prior to commencement. To manage potential distress following interviews, risk management plans were devised. The PIS provided information regarding confidentiality, withdrawal procedures, and details of organisations offering support (Appendix A). Participants provided informed written consent prior to participation (Appendix B). Please refer to the Ethics section for more details.

## **Findings**

Three themes were developed from participant accounts. The first represents a proposed five-stage chronological model of ACE enquiry. The second and third themes illustrate a number of psychological processes functioning within this model, pertaining to issues associated with power in the enquirer-discloser relationship and the process of post-disclosure behaviour change, respectively.

### A Chronological Staged Model of Parents' Responses to ACE Enquiry

Analysis revealed a chronological pattern to parents' responses to REACh, the order of which was confirmed as accurate by the four re-interviewed participants. This theme comprises five subthemes, each describing a separate stage.

Stage 1 - Deciding how much to disclose: "I might say something to you that you might use against us, so I better not". The first stage of enquiry relates to the process of decision-making upon being asked permission to talk about ACEs; the pre-enquiry phase.

The decisions concern, primarily, how to and how much to disclose about their childhood, following an almost unanimous feeling of discomfort regarding the enquiry.

Over two thirds of parents reported experiencing initial negative cognitive or emotional responses when asked permission to discuss ACEs. For example, parents described feeling "awkward" (P6), "weird" (P3) and "a bit nervous" (P4). One parent described feeling so overwhelmed that they seemingly experienced a flight-freeze style response: "I just wanted to walk out, erm, but I didn't. I sat there, kept quiet" (P2). This supports Alaggia (2004) and Dohary and Clearwater (2012), who described anxiety as a key barrier to disclosure. The rationale for such responses primarily related to fear of judgement and potential consequences, also supporting previous findings on barriers to disclosure (Alaggia, 2004; Del Castillo &Wright, 2009; Dorahy & Clearwater, 2012; Draucker & Martsolf, 2008). Parents described concern about possible ulterior motives behind REACh. For instance, P4 described considering whether the professional was secretly judging her as a parent: "I was thinking, well, what does she want to know about my childhood for, you know. Is it, am I a bad mum? Is that why she's asking these questions?". P3 also described a general distrust of professionals as a concern for disclosure, "at the start it was like, 'she's a professional, be careful what you say'".

There were also clear factors that helped parents to feel more comfortable discussing their childhood. For instance, concerns were partially settled when professionals explained clearly the rationale and process of REACh, including available support: "she told me why she was asking, she explained it all first and I think that helped" (P1). Informing parents that they do not have to answer the questions was similarly supportive, "I had the choice, so I thought, no I don't mind" (P4). The skills or personal qualities of the professional was also cited as a relief to discomfort: "You know, she doesn't push, she doesn't direct me or anything" (P6). In fact, the most frequently referenced factor that supported parents to feel

comfortable disclosing more detailed information was the relationship with the professional, particularly concerning trust. This substantiates previous findings that cite a trusting, accepting, non-judgemental relationship and response as supportive of decisions to disclose (Del Castillo & Wright, 2009; Draucker & Martsolf, 2008; Hunter, 2011; McGregor et al., 2010; Sorsoli et al., 2008).

Prior to responding, it appeared that parents rapidly weighed up factors that made them feel more or less comfortable, before making a decision regarding the legitimacy and comprehensiveness of their impending disclosure. This appears to marry with the considerable internal debate cited in Draucker and Martsolf's model (2008). However, despite overwhelming discomfort, all chose to disclose something, with over half explicitly describing a sense of acquiescence; parents felt the need to provide some form of answer. For instance, P4 illustrated a lack of protest, despite feeling uncomfortable: "I just felt a bit took aback, a bit, but I said, yeh".

Stage 2 - Disclosure is an Emotional Rollercoaster: "I was practically crying inside". The second stage entails numerous emotional responses during the process of disclosure. Over two thirds of participants described a range of emotions experienced between starting and finishing their disclosure.

Chiefly, emotions felt on commencing disclosure were associated with discomfort. For example, P1 described experiencing numerous negative emotions, stating "it made me feel a little angry and a little resentful" and "it made me feel guilty as well, because of some of the things that I've done similar to my parents that I didn't want to do". Whereas P2 described a more constant state of distress, "I was practically crying inside". Draucker and Martsolf (2008) also described how the telling process can be highly emotive for some.

Such strong emotions appeared to be in relation to a process of remembering: "it made me think about some things I hadn't thought about for a long time" (P1). Conversely, P5 described the process of disclosure as less emotional than others, stating, "it felt alright...it was just normal" (P5). However, she qualified this statement by saying "it was alright, cos I had a good childhood". This may suggest that emotionality during disclosure may be somewhat determined by the way one cognitively appraises one's childhood, despite ACEs, which supports theories that stipulate the role of subjective interpretation in determining trauma responses (Allen, 2005; Olff et al., 2005).

All but two described a sense of relief following disclosure, regardless of distress experienced, which supports the short-term relief found by Zech and Rime (2005). For instance, P6 described the act of disclosure as "getting it all out of my system! So, I'm not gonna lie, I did feel better after getting it off my chest!". P7 described a sense of relieving pressure, "it was like a weight off my shoulders!... I felt happier that I'd told somebody the truth! Instead of...bottling it all up!"

Stage 3 – The cognitive aftermath: "I went over the conversation in my head, over and over and over again all night!". The third stage observed what appeared to be a cognitive and emotional aftermath of disclosure for all parents following the end of the appointment, primarily involving rumination and paranoia.

All but one parent described experiencing incessant rumination once they left the appointment, lasting from "a few days" (P1) to "months" (P7). A couple of parents described ruminating about memories of their own childhood. However, parents more frequently described ruminating on the act of disclosure. For example, P3 described how the conversation kept "coming back all night long". P6 illustrated how these thoughts penetrated

multiple areas of her life: "I could be out having a walk; it would be on my mind. On my mind at work...thinking about my mum".

Parents went on to experience persistent paranoid thoughts about the possible consequences of their disclosure. It was inferred by the author that many quotes appeared to depict how, following brief relief immediately post-disclosure, parents experienced anxiety and paranoia relating to relinquished control over whether or how the information would be shared: "anything could happen now, they could say anything, do anything and twist anything" (P3). These distressing thoughts and loss of control after revealing their story supports Glover et al., (2010), who concluded that an inability to predict the consequences of disclosures can invoke psychological distress (Tener & Murphy, 2015). Perhaps this is one reason for the erosion of relief observed by Zech and Rime (2005), who found that post-disclosure relief was time-limited.

Stage 4 – Reflection results in heightened awareness, which leads to (re)evaluations of self and others: "I think it opened my eyes a bit more". The fourth stage portrays how the experience of persistent rumination and paranoia appeared to encourage increased reflection about their own childhood, their parents and their current situation. For instance, P6 described reflecting on and beginning to re-story the way she remembered feeling as a child: "I've never thought about it before and I know it was always there, but I realised that I was unloved!". Parents described reflecting on the way they were parented and beginning to make connections to their own parenting choices: "I've just thought more about how my mum was with me growing up, really, and linking that to my parenting" (P3). This may support social learning models of ACE continuity; parenting choices are developed via parent modelling (Muller, Hunter, & Stollak, 1995).

Reflection guided (re)evaluation. For instance, P7 described cognitively re-appraising her childhood, "after I'd told her everything I thought, yeh, I must have had a bad childhood!". P6 described re-evaluating her parents, "I worshiped the ground my dad walked on, and then I stopped seeing my dad for a while, erm, and if I'm honest I actually felt a bit...angry towards my dad!". Whilst others re-evaluated their sense of self as a parent, "it made me think, really, that I hadn't been as good a parent as what I thought!" (P6).

However, not all (re)evaluations were negative. P5 reported that, "it made me feel grateful", and "when I realised that I'd done what my mum used to do, it made me feel like I was doing something right!". Increased reflection also appeared to help some parents to feel empathic towards their own parents: "it's sort of helped me to understand her a bit more…put myself in her shoes" (P3). This process of (re)evaluation may indicate a process of post-traumatic growth, resulting in (re)evaluation of personal priorities and increased self-awareness (Tedeschi & Calhoun, 2004).

Stage 5 - Motivation to be a better parent: "it actually did make me stop and think, I want her brought up better!". The final stage depicts what appeared to be an either transitory or enduring surge in motivation towards newly pledged parenting goals and subsequent attempts to initiate parenting-based behavioural changes, driven by (re)evaluations.

All described experiencing an increased desire to be a "better parent" (P7), particularly motivated by providing a better upbringing for their child than they experienced. For instance, P7 stated, "It made me think…I don't want (child)…being brought up the same way. It actually did make me stop and think, I want her brought up better!". Parents described experiencing this as a sudden realisation, "I think it was a wakeup call…I thought, you're gonna have to change your life around!… I kept thinking to myself 'no, you're not gonna be

like my mum" (P4). They seemingly held these motivating thoughts in mind, "I thought about it for so long after we had that conversation, thinking, 'I'm gonna change this!" (P1). Such thinking also appeared to drive modification of parenting goals and the reconceptualisation of their role as a parent:

it did make me look at it a little bit more and just want to make sure that he's got everything that I didn't feel. And it's not just about what you do, as a parent, it's about time, predominately time! And how you make a person feel is very, very important. I see that now.

Consequently, many of the parents described experiencing an increased motivation to engage in, what they considered to be, positive parenting activities, "I just wanted to do more with them, do more reading, play more games with them...to create more good memories for them" (P3). P1 also described this increased desire to act out their understanding of positive parenting: "I felt I just needed to do more. So I doubled the amount of housework that I normally do, erm, you know, bought the kids some new clothes".

Acting on this increased drive to parent, all described conscious attempts to alter their behaviour during the weeks following enquiry. Some of these attempts involved noticeable behaviour changes, such as "spending all my time with her" (P7), "Me and my kids have like a movie day or a movie night now" (P5), and "I started reading more books with them, playing more games with them, trying to focus my mind on them" (P3). For some parents, this occasionally involved overcompensation: "For those few days where I was feeling unsettled, if they asked me for something they got a yes. I was very much a push over for those few days" (P1). However, other changes were more discrete and cognisant, described as parenting "maybe a bit more mindful really" (P6). For instance, P1 clarified how, during a discussion with her daughter, she responding more reflectively than she typically would have:

"My initial gut reaction was 'NO', but I didn't say it...I said...in my head, 'that's what your dad would have done'...instead of going with my gut reaction...I'm thinking about it more". Increased reflection following elicited disclosure seemingly improved parental reflective functioning, a quality associated with 'beneficial' parenting (Slade, 2005).

Power in the Enquirer-Discloser Relationship: "I Felt Like, If I Didn't Work with Her, That Would Go Against Me"

This theme describes issues associated with inherent power imbalances in the clinical encounter that permeated all stages. Here, power refers to an act of influence between professionals and service-users during the enquiry process, which originates from the dominant social status of professionals (Carter, Swank & Brown, 2014; Zur, 2009). Through the operation of their socially defined statuses, service-users are often positioned within a submissive role in relation to professionals, unbalancing the relationship. Service-users can consequently experience undue pressure to conform to the perceived wishes of professionals, often in fear of perceived consequences or of upsetting the professional (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012; Joseph-Williams, Edwards, & Elwyn, 2014; Kettunen, Poskiparta, & Gerlander, 2002).

Disproportionate power appeared to influence parents' decision to disclose, particularly those who acquiesced. For instance, rationales underpinning acquiescence included feeling obliged to answer, "I felt like I should" (P2) and fearing possible unspoken consequences of declining, "I felt like, if I didn't work with her, that would go against me" (P2). Parents seemingly recognised professionals' power to judge and, more importantly, act on such judgements, such as referring to social services, "They could do something or say something, you know, that could trigger social care" (P4). They consequently experienced an implicit pressure to conform.

Trust in the professional and the quality of their interpersonal relationship appeared to partially eliminate fear of consequences and therefore lessened professionals' power to apply such consequences: "I...got to know her and knew that she wouldn't tell anybody, unless I was at risk or my daughter was at risk" (P7). However, for some, there appeared to be an active or implicit attempt to contest power imbalances by acting to increase their own power. Although all answered, some withheld detailed information: "I didn't go into detail" (P3). P7 described fabricating parts of the story to avoid talking about genuine experiences, "I just didn't want to answer them, so I made up a lie". A person gains a power advantage when they acquire knowledge of another's personal information and therefore knowledge-power lies with those holding information (Zur, 2014). Withholding information or fabrication may, thus, be seen as a method of avoiding vulnerability, or maintaining or acquiring power. Power also appeared to be redistributed somewhat when professionals informed parents of their choice over engagement: "she told me I didn't have to answer them...so if I didn't want to...I knew it wasn't going to be a problem" (P1).

# The Post-Enquiry Behaviour Change Process: "Seeing Changes...It Was Making the Kids Happier"

The final theme relates to an apparent process of change observed across the chronological model, particularly concerning parenting. This process appears to map onto the readiness stages outlined in the stages of change (SOC) model; pre-contemplation, contemplation, preparation, action and maintenance (Heimlich and Ardoin 2008; Prochaska & DiClemente, 1983).

In stage one, invitation to discuss ACEs appeared to move a person from precontemplation, where the person was unaware of any issues or where intention to change was low, "I've never thought about it before" (P6), to contemplation, where awareness of issues increased and change was considered, "it's just made me more aware of myself and how I parent [pause] I want it to be different now" (P1). These could be described as 'cues to action' (Janz, Champion, & Strecher, 2002), provided externally, by the enquiry in stage one, and internally, via the remembering and reflective processes in stage two, three and four; all of which seemingly construct the contemplation phase.

Contemplation was dominated by a fear of consequences and increased awareness of subjective norms, resulting in reflections about the perceptions of others regarding their parenting: "I even said to (husband), 'she's going to think we can't cope...and probably try and take our three kids" (P3). Reflections also highlighted elements of their parenting that participants disapproved of, altering their attitude towards these behaviours, "I was so determined not to be a parent like mine, but in some ways I still am...I hate that" (P1). The theory of planned behaviour (TPB) (Ajzen 1985, 1991; Ajzen & Madden 1986) suggests that intentions, based on attitudes towards a behaviour, the propensity to abide by subjective norms, and perceived efficacy over successful performance, predict behaviours. Post-enquiry reflection appeared to alter parents' intentions regarding their parenting choices.

Parents also seemed to evaluate risks to their own, but more notably their child's wellbeing as a result of their parenting choices. Based on their own childhood experiences, parents appeared to view the susceptibility and severity of intergenerational risk as high. Consequently, it appeared that parents considered changing their behaviour to avoid risking their child experiencing a similarly negative childhood. According to the health belief model (HBM) (Becker, 1974), motivation to change depends on threats to wellbeing, which require appraisals of the susceptibility and severity of risk, and a perception that "taking action is likely to either prevent or reduce the risk at an acceptable cost with few barriers" (Nisbet & Gick, 2008, p.297). Parents can engage in this process on behalf of their children (Redmond, Spoth, Shin, & Hill, 2004), such as by taking preventive action when they perceive elevated

risk to their child (Spoth, Redmond, Kahn, & Shin, 1997), influenced by internal and external cues to action (Janz, Champion, & Strecher, 2002). P3 described preventative motivations, portraying a desire "to create more good memories for them, so…they can say they had a good childhood". Consequently, parents experienced an upsurge in motivation to parent differently by stage five, which can be seen as movement towards preparation, where self-efficacy improves and they commit to action.

Maintenance also seems to occur in stage five. Some described success in maintaining changes, reinforced primarily by noticeable positive impacts on their child and themselves, "It was making the kids happier. We're happier. So we want to keep things going and moving forward" (P3). However, not all changes were maintained. P1 explained that she fell "back into our old routines, I think it was more like it tapered off". P2 also suggested that more support and continued conversation on this topic would have been beneficial.

### **Conclusions**

In response to the limited documented knowledge concerning parents' experience of ACE enquiry, the present study aimed to explore these experiences and establish any subsequent impact. Thematic analysis established three themes. The first represents a proposed five-stage chronological model of ACE enquiry. Following an almost unanimous negative perception of ACE enquiry, driven primarily by anxiety about disclosing their story and a fear of judgement and consequences, all parents chose to disclose information, with many describing a sense of acquiescence. The process of disclosure was highly emotive.

Post-enquiry impacts involved initial rumination, leading to paranoia, increased reflection on self and others and eventually a process of (re)evaluating one's parental goals, roles and priorities. Evaluations appeared to drive the final stage. All parents experienced increased

motivation and ensuing attempts to parent differently, propelled by the desire to give their child a better start in life.

The second theme illustrated the complex influence of and occasional struggle for power in the enquirer-discloser relationship, which appeared to impact the process from preto post-enquiry. The final theme demonstrated the process of post-disclosure behaviour change occurring across the chronological staged model, which seemingly maps onto the SOC model (Prochaska & DiClemente, 1983). These themes and the points at which they relate to the chronological staged model are depicted in Figure 1.

To the authors knowledge, this study provides the first attempt to understand, from service-users' perspectives, the experience and impact of being routinely asked about ACEs in clinical practice. These results add to our current theoretical understanding in this area. For instance, new insights are offered regarding barriers and facilitators to elicited disclosure, alongside improved understanding of cognitions and affects involved in the decision to and the process of disclosure, including specific predictors of positive and negative service-user experiences of disclosures, such as the effects of enquirer-discloser power dynamics.

Furthermore, the analysis highlights possible impacts of disclosures on parents, such as increased mentalizing capacity and experiences comparable to post-traumatic growth. These findings highlight areas of further qualitative and quantitative investigation and indicate numerous clinical implications.

### **Clinical Implications**

Trust appeared to be highly influential in supporting decisions to disclose and in limiting distress during and post-enquiry. Guidance on enquiry about childhood adversity suggests that enquiries should be conducted early to reduce the risk of professional avoidance (Read et al., 2007). However, all parents believed that developing trust over time is essential to encourage engagement and reduce anxiety. The therapeutic relationship is a widely

accepted predictor of outcomes in clinical encounters (Roth & Fonagy, 2013), and therefore current guidance may require review regarding the most appropriate enquiry-point in care pathways.

The preamble also appeared valuable in improving engagement and comfort with enquiry, whilst a lack of transparency about intentions to share information following the clinical encounter had detrimental effects on these factors. More detailed information preenquiry, alongside a clear statement of intentions of whether information will or will not be shared immediately post-enquiry, may improve engagement and reduce negative post-enquiry effects. Furthermore, Draucker and Martsolf (2008) described decisions to disclose as purposeful and carefully planned. Such deliberation does seemingly occur prior to REACh. However, the author considers whether there is sufficient time available for service-users to fully consider their options directly following the request for permission to enquire. Another clinical implication would be to consider introducing REACh during an appointment prior to the one in which enquiry is planned. This may enable service-users to make a more considered and informed choice about disclosure.

However, any attempts to address these difficulties may need to be evaluated alongside careful consideration of power. Service-users' pre-existing interpretations of professionals' social status produces imbalanced power that appears to influence disclosure. Professionals' power may implicitly coerce engagement, which raises questions about service-users' ability to provide genuine consent. The influence of professionals' power also seemingly continues beyond the end of the appointment, due to continued fear of consequences concerning their disclosure. "In so many ways, the power differential and...vulnerability persist, regardless of the termination of...sessions." (Gabbard, 1989, p. 122). This mental representation and the continued influence of professional power and judgement may unintentionally contribute to behaviour change seen in stage five, indicating

implicit ethical issues of such assessments. Research has suggested that professionals should acknowledge the imbalance of power in clinical encounters and seek instead to maintain a neutral position and pursue egalitarian collaboration with service-users to reduce inherent influence over choice (Marecek, J., & Kravetz, 1998; Zur, 2009). Collaboration and empowered involvement in decision-making can stimulate motivation to wilfully engage and promote emotional well-being (Fitzsimons & Fuller, 2002). However, engagement is sometimes defined in relation to compliance (Dawson & Berry, 2002) and it is therefore important for professionals to consider not only their power, but their intentions when attempting to 'engage' service-users. Moreover, parents did not specify factors that contributed to issues of power. Further research may assist exploration of power dynamics surrounding enquiry and disclosure.

A final area of implication involves the apparent fit between the stages of ACE enquiry proposed and the SOC model. Parents seemingly progressed through each stage without professional assistance; none informed the professional of the experiences they described across all stages. This finding highlights an opportunity for professionals to support parents' transitions through stages.

Transitions are typically motivated by two factors; self-efficacy and the outcomes of decisions based on factors associated with HBM and TPB (Armitage & Conner, 200; Ajzen & Madden, 1986; Becker, 1974). Randolph, Fincham and Radey (2009) suggest that professionals should provide external and promote internal cues to action at various points throughout parent engagement. For instance, professionals could provide detailed information about the risks of intergenerational continuity of ACEs, allowing parents to assess the severity of child-related risk, and help parents to identify benefits and barriers, perhaps through motivational interviewing (Miller & Rollnick, 2012). This may improve engagement

and provide a means of preventing continuity of ACEs. Further research is required to establish the chronological staged model and to evaluate the impact of intervention.

#### Limitations

Firstly, participation was limited to those proficient in English, which limits the generalisability of findings, beyond that by which qualitative research is typically criticised (Myers, 2000). Although no further restrictions were placed on participant demographics, lack of participant gender and ethnic diversity should be taken into account when interpreting these findings. The size of the sample should also be acknowledged as a limitation.

In terms of information about ACEs, only the score was collected. It was not possible to determine whether specific ACE categories or combination had any impact on parents' experience of enquiry, or their subsequent response. Additionally, although all professionals were trained in REACh, which provides guidance on questions and appropriate methods of disclosure-response, it is not known exactly what questions participants were asked during ACE enquiry, and whether or not this experience was therefore equally comparable across participants.

Finally, data collection relied entirely on retrospective narratives. It could be argued that these results rely, therefore, on the accuracy of accounts, which cannot be guaranteed. However, in alignment with the author's epistemological position, reality is understood subjectively. Analysis relies on the author's subjective interpretation of the participants' subjective interpretations of their experience, and thus does not claim to provide an objective account of participants' experiences. However, re-interviewing participants was intended to regulate the impact of this limitation.

Nonetheless, these findings contribute to our understanding of ACE enquiry and highlight implications for service delivery, provision and development. It is hoped that these

findings begin plugging the previously indicated gap in the literature and provide the first of many attempts to understand service-user experiences and the impact of being routinely asked about ACEs in clinical practice.

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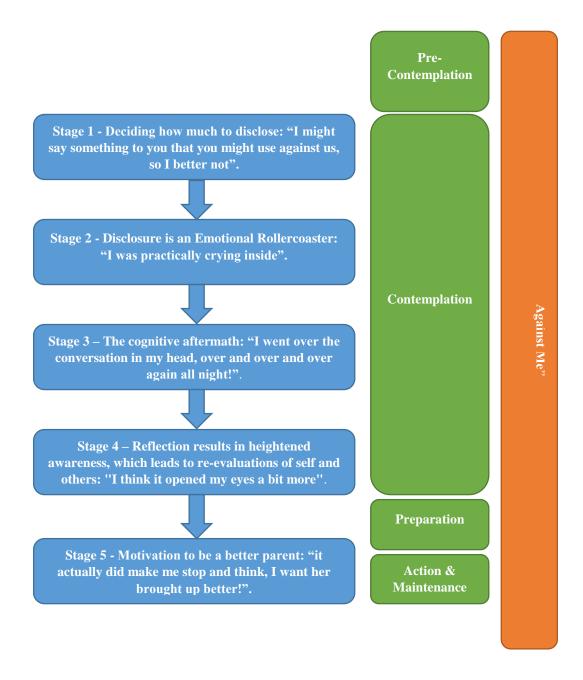
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# **Tables and Figures**

Figure 1: Thematic Map



**Table 1: Example of Codes and Themes** 

Theme	Subtheme	Narrative descriptions	Example codes
A Chronological Staged Model of Parents' Responses to ACE Enquiry	Stage 3 – The cognitive aftermath: "I went over the conversation in my head, over and over and over again all night!".	Parents experienced incessant rumination post-enquiry	as soon as I went to bed I, the conversation would go around in my head again. It was like "should I have said that like that" and replay the entire conversation again "should I have said that, should I have said that" and then "oh maybe I should have said that instead" or then I would remember something that I didn't say (P1)
			it was on my mind quite strongly. Even, whatever I was doing, making tea, I could be out having a walk, it would be on my mind. On my mind at work, on my mind, thinking about my mum (P6)
		Parents experience paranoid thoughts, primarily concerned with a fear of possible consequences post-enquiry	I might have been in the shower and I would think "she's spying on me her!", but I were thinking "no, I'm getting paranoid" (P4)
			I was thinking about it, what had been said, thinking, how is she going to twist that and turn it against us, sort of thing. I even said to (husband) "she's going to think we can't cope, we can't cope with (children), we wouldn't cope with (child) and probably try and take our three kids, put them up for adoption" and everything like that. Some horrible things were going through my mind (P3)
			I was just expecting to get the phone call off social workers, you know, more than anything (P7)

## **Appendices**

## **Appendix A: Participant Information Sheet**



## **Participant Information Sheet**

## Exploring the Impact of Enquiring About the Adverse Childhood Experiences of Parents

My name is Graham Simpson-Adkins and I am conducting this research as a trainee on the Clinical Psychology doctoral programme at Lancaster University, Lancaster, United Kingdom.

#### What is the study about?

The aim of this study is to develop a better understanding about how parents experience being asked about their experiences of adversity in childhood. This information may help us to understanding more about the impact that enquiry has on parents. It may also help us to understand what support parents may want following these conversations in services.

## Why have I been approached?

You have been asked to take part because you are a parent, because you have completed a routine enquiry about adversity in childhood and because you identified at least one adverse childhood experience during that enquiry. Adverse Childhood Experiences (ACEs) are potentially traumatic events that occur during the first 18 years that can have a negative impact on some people, but not everyone.

#### Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Taking part will have no negative repercussions in terms of the service you receive. Your participation is voluntary and you are free to withdraw at any time without giving any reason. It might not be possible for your data to be withdrawn once your name and any other identifiable information has been removed. However, every

attempt will be made to remove your data, up to the point of submission of the final report to Lancaster University examination board.

#### Are there any benefits to taking part?

You will be invited to take part in a prize draw to win a £50 Amazon voucher. To do this, you will be asked to provide your email or postal address on the consent form before taking part in the interview. The voucher will be sent to the winning participant via email or post, depending on your preference, after all interviews have taken place. There are no other direct benefits.

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

If you decide you would like to take part, you would be asked to contact the researcher, Graham Simpson-Adkins, to let him know. You will be asked to provide Graham with telephone or email contact details, which will only be used to contact you to arrange the initial or follow-up interviews. Graham will then contact you to arrange a date, time and

place to complete an interview. Interviews are expected to take place at the centre that you were recruited from (i.e. children's centre) or alternatively at Lancaster University Campus. If you need to travel, then you will be able to claim back travel expenses up to the amount of £20. It is also possible to complete interviews via telephone. Interviews will last between 45-60 minutes and will be recorded for later transcription and analysis. During interviews, you will be asked a number of questions about your experience of being asked about ACEs. We would really like to hear your thoughts and about your experience of this. However, you do not have to answer any questions that you do not want to. You might be asked if you can be contacted again after your initial interview to talk more about certain topics or clarify information from the first interview. However, you are free to decline any further contact following the first interview, if you chose to.

## Will my data be confidential?

When you meet with the researcher he will ask you to talk about you and your thoughts, feelings and experiences of being asked about ACEs. Confidentiality means that what we say during the interviews is mostly private and will stay between you and the researcher.

There are some limits to confidentiality. If what is said in the interview makes the researcher think that you, or someone else, is at significant risk of harm, they may have to share this information. If the researcher thinks that there is a risk, either to yourself or to others, the researcher will share this with their supervisor. However, if confidentiality needs to be broken then, wherever possible, the researcher will attempt to discuss this with you and will explain what will be done with that information.

Also, sometimes the researcher will talk to their supervisor and they might listen to the audio recording together or read the transcript of what was said. This is to check that the researcher is doing things correctly and what they are saying is appropriate. However, when this happens, information such as your name will be removed so that it will remain anonymous.

All information you provide will be kept anonymous. The information collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed or deleted after the final project report has been submitted for examination to Lancaster University.
- The file containing the typed version of your interview on the computer will be encrypted. Nobody other than the researcher will be able to access them and the computer itself will be password protected.
- At the end of the study, hard copies of questionnaires will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- o The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

## What will happen to the results?

The results will be submitted as an academic assignment as part of the Clinical Psychology doctoral programme at Lancaster University. The results may also be submitted for publication in an academic or professional journal. The findings of this research will also be shared with professionals and other students via a short presentation. Care will be taken to

ensure that the confidentiality of participants will be preserved when sharing the results, by ensuring that data is anonymised.

## Are there any risks?

You will be asked to talk about your personal experience of being asked about ACEs. The intention of the interview is not specifically to talk about sad or upsetting things. However, we understand that it is possible that for some people, talking about their experiences might make them think about difficult or distressing things. If this does happen during the interview, the researcher will ask you if you would like continue, take a break or end the interview. You will not be made to continue talking if you do not want to and you will not be asked to talk about anything that you do not want to. After the interview the researcher will ask you if you would like to talk about what it was like to do the interview.

## Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University 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:

Main researcher: Graham Simpson-Adkins

Trainee Clinical Psychologist Division of Health Research

C16 Furness Building Lancaster University

Lancaster LA1 4YG

Email: <a href="mailto:simpson1@exchange.lancs.ac.uk">simpson1@exchange.lancs.ac.uk</a>

Tel:

Research supervisor: Prof Bill Sellwood

Programme Director

Division of Health Research

Furness Building, Lancaster University

Lancaster, LA1 4YG

Email: <u>b.sellwood@lancaster.a</u>c.uk

Tel: 01524 593998

Field supervisor: Dr Warren Larkin

Director, Children & Families Network Lancashire Care NHS Foundation Trust Sceptre Point, Sceptre Way, Walton Summit

Preston PR5 6AW

Email: warren.larkin@lancashirecare.nhs.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:

Prof Bill Sellwood Programme Director Division of Health Research Furness Building, Lancaster University Lancaster, LA1 4YG

Email: b.sellwood@lancaster.ac.uk

Tel: 01524 592858

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

Professor Roger Pickup Tel: (01524) 593746

Associate Dean for Research Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster LA1 4YD

Thank you for taking the time to read this information sheet.

## **Resources in the event of distress**

Should you feel distressed at any point, before, during or after taking part, you can access support for your concerns by contacting your GP. You may also access support or advice from the following agencies:

## Samaritans

Samaritans volunteers listen in confidence to anyone in any type of emotional distress, without judging or telling people what to do.

Tel: **08457 90 90 90** (24 hrs 7 days a week)

www.samaritans.org

## **ASSIST**

ASSIST Trauma Care is a specialist Third Sector (Not-for-Profit) Organisation offering therapeutic help to adults and children, individuals and families, affected by a wide range of traumatic occurrences.

Helpline: 01788 560800 www.assisttraumacare.org.uk

#### The Survivors Trust

A UK-wide national umbrella agency for 141 specialist organisations for support for the impact of rape, sexual violence and childhood sexual abuse throughout the UK and Ireland.

Tel: 01788 550554

www.thesurvivorstrust.org

**Appendix B: Consent Form** 



## **Consent Form for Participants**

We are asking if you would like to take part in a research project that will aim to explore

Study Title: Exploring the Impact of Enquiring About the Adverse Childhood Experiences of Parents

your views on being asked about your experience of adversity in your childhood. Before you consent to participating in the study, we ask that you read the participant information sheet and mark each box below with your initials if you agree. By providing your signature on this consent form you are confirming that you consent to participate in this study. If you have any questions or queries before signing the consent form, please speak to the researcher, Graham Simpson-Adkins. 1. I confirm that I have read the participant information sheet and fully understand what is expected of me within this study 2. I confirm that I have had the opportunity to ask any questions and to have them answered. 3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. 4. I understand that audio recordings will be kept until the research project has been submitted for examination to Lancaster University. 5. I understand that I might be contacted again after my initial interview to talk more about certain topics, and that I can decline this if I choose to. 6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. 7. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of submission of the final report to Lancaster University examination board. 8. I understand that the information from my interview will be combined with other participants' responses, anonymised and may be published 9. I consent to anonymised information and quotations from my interview being used in reports, conferences, publications and training events. 10. I understand that any information I give will remain anonymous, unless it is thought that there is a risk of harm to myself or others. Should a situation arise in which the researcher suspects that there is a potential risk, either to myself or to others, the researcher will share this information with their Supervisor, who will also keep this information private. I understand that wherever possible and

appropriate, I will be made aware that confidentiality is being broken.

11. I understand that the information I provide will be discussed and shared

with the researcher's supervisors, who will also keep this information private.				
<ul> <li>12. I consent to Lancaster University keeping written and electronic copies of written transcriptions of the interview for 10 years after the study has finished. I understand that my information will be destroyed after this period.</li> <li>13. I consent to take part in the above study.</li> </ul>				
Name of Participant	_ Signature	_ Date		
Name of Researcher	Signature	_ Date		
If you would like to take part in a prize	draw to win a £50 Amazon y	voucher, please provide		
your email or postal address below.	araw to will a 250 /illia2011	rodener, prease provide		
Email:				
Postal Address:				
The voucher will be sent to the winning participant via email after all interviews have taken place.				

## **Appendix C: Sample Interview Topic Guide**



# Sample Interview Topic Guide (may change during research process)

Topic	Possible questions	Follow-up questions	
Enquiry	Can you tell me about your experience	What were you thinking when they asked that?	
	of being asked about experiences in childhood?	What did it feel like? How did it make you feel?	
	How did you respond when they asked you those questions?	Can you tell me more about that?	
		What do you mean by that?	
Following enquiry	Can you tell me about what happened after you were asked?	What were you thinking about?	
	What happened when you left the appointment?	What did you do? Why do you think you did that?	
	What happened when you were with your child/family?		
	How did you feel (behave/communicate) with (towards)	Who did you speak to about this? What happened?	
	your child/family after this conversation?	Can you give me an example?	
Impact	Was this conversation helpful? If so, can you describe how?		
	Can you tell me what impact this experience has had on you/your child/your family?	Can you tell me more about	
	Do you do anything differently after having this conversation?	that? What do you mean by that?	
	How did this conversation make you think about your role as a parent? Could you tell me more about this/give me an example?		
Support	What support, if any, did you want after having this conversation?	Can you tell me more	
	What would have been most/least helpful?		

# **Appendix D: Example of Transcripts and Initial Notations**

Interviewer: ok, so if we go back to when (support worker) actually asked you those questions, what was that	M	Graham Simpson-Adkins Negative first response
like? P3: It felt awkward at first. It felt a little bit awkward talking about my grandmother, because I don't really talk	· - 1	Graham Simpson-Adkins A topic not often talked about
about her a lot, because it brings back a lot of bad memories. A lot of good ones as well and that's where it gets me a little bit, and that's why it felt a little bit awkward, but afterwards it felt alright. And after she left		Graham Simpson-Adkins Negative response because it brought up old
(husband) asked me if I was alright and that night we sat down and I told him all about (information about  ACEs not transcribed) and I broke down in tears that night and I told him about it. But he understands why I		memories
got upset and why I felt a bit awkward, so, that's alright.		Graham Simpson-Adkins Need to confide in someone close
Interviewer: how did you manage that awkwardness during the session?  P3: erm, think it was more we were there to try and prove to social services we could change the people we		Graham Simpson-Adkins Felt obliged to answer
were because (husband) was fighting for his little girl at that point and so I just focussed on trying to help		
(husband) the best I could, because obviously he was fighting with social services, but he lost that, but he has carried on fighting now though.		
Interviewer: so when she asked you the questions, what was going through your head, what were you thinking about? When she first asked you the questions	M	Graham Simpson-Adkins Initial space to reflect before disclosure
P3: paused for a few seconds, thought about my childhood and then my grandma came to mind straight away, that was the first thing that came to mind, because that was the biggest thing, yeh and then	·	Graham Simpson-Adkins Thoughts in sequence by severity
(information about other ACEs not transcribed). It were a crazy few years.	ı	
Interviewer: what was it like telling her those things?  P3: didn't go into detail about (information about specific ACEs not transcribed) I just said (information about		Graham Simpson-Adkins Deciding how much to tell the practitioner – not in
specific ACEs not transcribed). I didn't get told the truth straight away but (details about ACE not transcribed), I		detail

## **Appendix D: Research Protocol**

# Exploring the Impact of Enquiring About the Adverse Childhood Experiences of Parents

Exposure to ACEs is associated with numerous negative physical, emotional and mental health outcomes that can persist into adulthood (Chapman et al., 2004; Felitti et al., 1998). ACEs have also been found to be highly prevalent across the world, with estimates demonstrating up to 50% of people experiencing at least one ACE in the UK, which is comparable to international findings (Bellis et al., 2014).

Research has suggested that a parent's early childhood experiences may indirectly impact parenting behaviour, namely, sensitivity and responsiveness (Slade, 2005). Higher numbers of ACEs have been found to significantly predicted higher levels of parenting distress, which has been linked to problematic parenting (Steele et al., 2016).

Recent research has identified the intergenerational continuity of ACEs in children of parents that have experienced ACEs (Narayan et al., 2016). Consequently, there has been a call to develop methods of screening for ACEs in children and family services to help identify risk factors for problematic parenting and enable targeted support to reduce the intergenerational continuity of ACEs (Steele et al., 2016).

To support this, Lancashire Care NHS Foundation Trust (LCFT) developed and piloted a Routine Enquiry about Adversity in Childhood (REACh) training package to support health professionals to enquire about ACEs during their assessment processes with service users. This training has been evaluated in terms of staff responses, which demonstrated positive results. However, little is known about how parents respond to enquiry and what impact this has on them.

Understanding more about the impact that enquiry has on parents may help us to understand how parents respond to enquiry, what impact it has on them as a parent or on their perception of the parent-child relationship. It may also help us to understand what support parents may want following enquiry.

#### Name of applicant/supervisors/affiliations/version number

- > Graham Simpson-Adkins, Trainee Clinical Psychologist, Lancaster University
- Prof. Bill Sellwood, Programme Director, Doctorate in Clinical Psychology,
   Lancaster University
- ➤ Dr. Warren Larkin, Director, Children & Families Network, Lancashire Care NHS
  Foundation Trust
- Dr. Anna Daiches, Clinical Director, Doctorate in Clinical Psychology, Lancaster University

## Method

## **Participants**

The minimum sample size will be five for the study to be viable, but the target sample size is between 10 and 20 participants. All participants will be parents that highlighted at least one ACE when asked by professionals at participating recruitment services as part of a routine enquiry during the service assessment procedures. Inclusion criteria are that participants must be a parent of at least one child. Participants can be any form of biological or non-biological parent of the child/children. Parents must have identified at least one adverse childhood experience during routine enquiry. In terms of exclusion criteria, no restrictions have been placed on any demographic information, such as age or gender for either the parent or their child/children. However, parents who are currently receiving

treatment for PTSD will be excluded, given the possibility for triggering a trauma-response. The inclusion criteria are as inclusive as possible, as we do not currently understand what factors may influence a parent's response to routine enquiry about adversity. Participants are required to be competent in English, due to resource restrictions. Participants will be recruited via identification by professionals in participating services. The researcher will make contact with the service site person, who will advertise the project amongst the teams. Alternatively, where appropriate, the researcher will attend the service to introduce and discuss the project with the service. The service professionals will be asked to firstly identify parents that may meet the inclusion criteria and then provide them with a participant information sheet and discuss the study with them. If the parent agrees to take part, they will either be asked to provide verbal consent to the service professional to share their contact details with the researcher, who will then contact the parent (contact details will be stored in a password protected file on an encrypted computer and will be destroyed upon completion of data analysis), or the parent will be asked to make contact with the researcher themselves via contact details provided on the flyer. Parents will also be informed that they can contact the researcher to discuss the research study further, if required. Participants will then be provided with a Consent Form.

#### **Design**

This research will employ a qualitative design. Data will be gathered via one-to-one semi-structured interviews. Interviews will last approximately one hour. The aim of interviews will be to facilitate an exploratory conversation, using open ended questions that focus on the participant's views regarding how they experienced being asked about ACEs during a routine enquiry. Participants will be informed via the participant information sheet and consent form that they may, if necessary be contacted again after their initial interview to clarify or elaborate on gathered information. An interview topic guide will be used to scaffold the

questions included in the interviews, whilst allowing for exploration of each participant's individual experiences. The researcher will analyse the data using a form of inductive thematic analysis. Audit trails will be documented to illustrate each stage of analysis and the emergence of themes. A reflective journal will be completed by the researcher to provide transparency in relation to the research process, which will be shared with the research supervisors to support the identification of any bias that may influence the interpretation of data. Emerging themes and the process by which they have emerged will be checked by the research supervisors.

#### **Materials**

An interview topic guide will be used to scaffold the questions included in the interviews.

This is an example guide that may change during the research process, allowing for exploration of each participant's individual experiences. Additional materials in the form of a Participant Information Sheet and Consent Form will also be required for each participant.

## Procedure

Participants will be recruited via local authority family support services in and and organisation. Participants will be identified by professionals in these services. The researcher will make contact with these organisations to arrange an opportunity to visit and discuss the research project with their teams and to share the participant information sheets. If a parent has identified at least one ACE during routine enquiry, the professionals will be asked to share the participant information sheet with the parent and explain the study. If they agree to, parents will be asked to take the Participant information sheet and will be asked to provide consent for the professional to share their contact details with the researcher via the consent to contact form, so that the researcher can contact the parent to discuss the study. The contact details will be

stored in a password protected file on an encrypted computer and will be destroyed upon completion of data analysis. Alternatively, the parent will be informed by the professional that they can get in contact with the researcher via the details provided on the information sheet if they would like to take part or to discuss the study. Parents and patients will be provided with detailed information regarding the study via the Participant Information Sheet.

When participants have registered their interest in taking part, an appointment will be offered to their parents to take part in the researcher interview. Participants will be asked that the interview take place either at the service building from which they were recruited or at Lancaster University Campus, which can be booked via the clinical psychology programme administrative team. Where it is not possible or convenient for participants or parents to travel to Lancaster University or the service from which they were recruited, telephone calls will be offered to conduct interviews. Where home visits or alternative locations are requested, the researcher will adhere to Lancaster University lone worker guidance, as outlined in the University's document Guidance on safety in fieldwork (<a href="http://www.lancaster.ac.uk/depts/safety/files/Fieldwork.pdf">http://www.lancaster.ac.uk/depts/safety/files/Fieldwork.pdf</a>) and appropriate risk assessments conducted (see section 16).

Participants will be asked to provide written consent to participate in the study via the completion of Consent Form, provided at the start of the interview. It is anticipated that interviews will take approximately 1 hour for each participant. All interviews, face-to-face and telephone will be recorded audibly using an electronic dictation device. Participants will be informed via the participant information sheet and consent form that they may, if necessary be contacted again after their initial interview to clarify or elaborate on gathered information. The data will then be transcribed and anonymised as soon as possible following interviews. These audio recordings will be uploaded to a password protected file on the Lancaster University network server. Original recordings will then be deleted off the

Network server upon submission of the completed thesis to the University for examination.

Transcripts of interviews will be made anonymous and stored in an encrypted file on a password protected computer which will only be accessible by the researcher. These files will be deleted following the completion of data analysis. Following analysis, anonymised interview transcripts, coded data produced during analysis and paper consent forms will be scanned and stored electronically, encrypted and transferred securely to the Research Coordinator using Box file transfer software. The research coordinator will save the files in password-protected file space on the university server. Encrypted files will be stored by the research coordinator for 10 years after the end of study. At the end of the storage period, the data will be deleted by the Doctorate in Clinical Psychology Research team.

## **Proposed analysis**

It is proposed that the data, in the form of verbatim transcripts of first person accounts, will be analysed using a form of inductive thematic analysis. A reflective research journal will be used alongside supervision in order to facilitate the process of analysis. The research supervisor will be given access to audio recordings and written transcripts to aid supervision and provide guidance regarding the collection and analysis of data.

## Practical issues (e.g., costs/logistics)

Interviews will be arranged at a mutually convenient time and location. This may require travel and lone working for the researcher. Where lone working is required to attend interviews, the researcher will abide by the Lancashire Care NHS Lone Working Policy. In accordance, the Field Supervisor will be informed of the date, time and location of interviews. As the researcher is able to travel to participant's place of work, travel expenses will not be offered to participants, where possible. However, where participants are required

to travel, expenses will be covered by Lancaster University. Recording equipment and devices used to aid transcription will be provided by Lancaster University.

Where lone working is required, the Lancashire Care NHS Trust lone worker guidance will be implemented. The researcher will not enter a situation where there is obvious potential risk. To encourage the researcher's safety, risk assessment will be carried out on the room in which interviews will take place in order to ensure that the researcher is aware of a safe exit from the area. The researcher will ensure to sit next to door, when appropriate, to allow safe exit, if

required. Interviews will only be conducted during standard office hours (9am-5pm). The researcher will ensure that supervisors are informed of the location of interviews and the predicted arrival and departure times, in accordance with Lancashire Care NHS Trust lone worker guidance. On completion of interviews and exit from the venue, the researcher will contact the field supervisor or a member of the Doctorate in Clinical Psychology administration team via the research mobile phone provided by the university, to inform them that the interview has ended. Anna Daiches (research supervisor) has agreed to be the contact person. As per the lone worker policy, Anna will be provided, prior to interviews taking place, with the full address of where the interview will take place, telephone numbers for myself and the centre, and indications of how long the interview is expected to last at those locations (both arrival and departure times). Where there is genuine concern for the researcher, as a result of not attending a visit within an agreed time or not making contact with Anna at the agreed time following the interview, Anna will use the information provided to her to help track the Lone Worker. Depending on the circumstances and whether contact through normal means (mobile phone, pager and so on) can or cannot be made, the manager or colleague should involve the police if necessary. If police involvement is needed, they should be given full access to information held and personnel who may hold it, if that

information contains data that might help trace the Lone Worker and provide a fuller assessment of any risks they may be facing.

#### **Ethical concerns**

Ethical approval will be sought from the FHMREC. Participants will be asked about their personal experience of being asked about ACEs. It is acknowledged that this may relate to distress experienced during or after this process. Should distress be experienced by the participant during the interview, the researcher will acknowledge the level of distress and ask the participant if they wish to continue and any concerns about a participant at any point due to perceived discomfort or distress will be shared with the research supervisors. This information will be included on the Participant Information Sheet and participants will be reminded of this issue verbally immediately prior to the start of the interview. In order to ensure the wellbeing of participants, the Participant Information Sheet will also provide details of organisations that can offer support, such as Samaritans.

## **Timescale**

- March 2016 Submit thesis proposal form
- March 2016 Submit thesis feedback form, finalise supervisors and choice of research strategy, method and measures. Agree research timetable with supervisors, submit UREC application. Finalise method, develop strategy for coding, decide journal for research paper/literature review
- April 2016 Hand n final draft of Literature review. Write first draft of introduction
   & method section of research paper.
- April June 2016 Data collection. Commence data analysis, write draft abstract/results/discussion. Submit draft intro/method.

• **June – September 2016 –** Submit final versions of paper and literature review, submit draft and final critical appraisal

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38. doi:10.1037/cbs0000034

## **Appendix E: Journal Instructions**

#### The International Journal of Child Abuse and Neglect

## **Types of contributions**

- 1. **Reports of Empirical Research**: Child Abuse and Neglect publishes reports of quantitative, qualitative, and mixed-method research. However, research methods must be appropriate, of course, for the questions posed, and all empirical reports are subject to peer review in relation to the scientific adequacy of the methods and the interpretations of results. Include a clear introductory statement of purpose; historical review when desirable; description of method and scope of observations; full presentation of the results; brief comment/discussion on the significance of the findings and any correlation with others in the literature; section on speculation and relevance or implications; summary in brief which may include discussion. Abstracts for these manuscripts should follow conventional APA style. The journal does not ordinarily publish articles focused exclusively on instrumentation.
- 2. **Reviews**: Plans for proposed review or discussion articles are invited to first submit a draft outline to the Editor-in-Chief. Please send review or discussion proposals to <a href="mailto:chiabu@elsevier.com">chiabu@elsevier.com</a>. The editors will commission reviews on specific topics. Reviews submitted without invitation or prior approval will be returned.
- 3. **Theoretical and Policy Analyses**: Such articles must present a creative integration of empirical research and/or normative (legal, philosophical, and/or theological) analyses. The coherence of the argument, the strength of its foundation, and the tightness of the logic will be major factors in evaluation of such manuscripts. Abstracts for these manuscripts should follow conventional APA style.

#### **Contact details for submission**

All correspondence, including notification of the Editor-in-Chief's decision and requests for revision, takes place by e-mail and via the Author's homepage, removing the need for a hard-copy paper trail.

For those authors unable to utilize the EES system, or with questions about submissions, please contact the Editorial Office (chiabu@elsevier.com) for assistance.

## **Ethics in publishing**

Please see our information pages on <u>Ethics in publishing</u> and <u>Ethical guidelines for journal publication</u>.

## **Human and animal rights**

If the work involves the use of human subjects, the author should ensure that the work described has been carried out in accordance with <u>The Code of Ethics of the World Medical Association</u> (Declaration of Helsinki) for experiments involving humans; <u>Uniform Requirements for manuscripts submitted to Biomedical journals</u>. Authors should include a statement in the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects must always be observed.

All animal experiments should comply with the <u>ARRIVE guidelines</u> and should be carried out in accordance with the U.K. Animals (Scientific Procedures) Act, 1986 and associated guidelines, <u>EU Directive 2010/63/EU for animal experiments</u>, or the National Institutes of Health guide for the care and use of Laboratory animals (NIH Publications No. 8023, revised 1978) and the authors should clearly indicate in the manuscript that such guidelines have been followed.

#### **Declaration of interest**

All authors are requested to disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. More information.

#### **Submission declaration**

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## Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the <u>Guide to Publishing with Elsevier</u>). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

#### Length and Style of Manuscripts

Full-length manuscripts should not exceed 35 pages total (including abstract, text, references, tables, and figures), with margins of at least 1 inch on all sides and a standard font (e.g., Times New Roman) of 12 points (no smaller).

Instructions on preparing tables, figures, references, metrics, and abstracts appear in the Publication Manual of the American Psychological Association (6th edition).

For helpful tips on APA style, click here.

#### **Article structure**

## Subdivision

Divide your article into clearly defined sections. Three levels of headings are permitted.

Level one and level two headings should appear on its own separate line; level three headings should include punctuation and run in with the first line of the paragraph.

#### Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

## **Essential title page information**

- *Title*. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
- Author names and affiliations. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
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#### Abstract

Abstracts should follow APA style (see 6th ed., pages 25-27 for detailed instructions and page 41 for an example). Abstracts should be 150-250 words.

## **Keywords**

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

#### Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, please include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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Table footnotes Indicate each footnote in a table with a superscript lowercase letter.

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# You are urged to visit this site; some excerpts from the detailed information are given here.

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Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

#### References

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Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

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## **Chapter 3: Critical Appraisal**

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## Abstract

This critical appraisal firstly provides a brief outline of the research findings, followed by personal reflections on key aspects of the research process. These reflections primarily concern the personal difficulties experienced in selecting, getting to grips with and eventually decision to change the project. Reflections are presented as chapters that capture crucial decisions points along this process and outline the consequential learning. A summary of key reflections is also presented.

## **Research Findings**

Chapter one presents findings from a meta-synthesis of qualitative literature concerning the sense children make of their parent's mental health difficulties (MHD).

Results suggest that children view their parent's MHD as an outcome of environmental or psychosocial factors, which corresponds to research on public perceptions of MHD. Children appeared to believe that these factors lead to the development of an illness related to a physically dysfunctional brain, which they associate with the need for specialist, primarily medical support, positioning the parent as unusual. Attention is drawn to possible implications of such beliefs, particularly in terms of children's learnt response to personal experiences of psychological distress. Results also highlight the impact of such beliefs on the child, namely persistent anxiety. Implications include the need to enquire more readily about parents' MHD and to consider this as a factor in the psychological formulation of children and young peoples' mental health.

Chapter two explored the impact of asking parents about adverse childhood experiences (ACEs). Findings demonstrate similarities with trauma disclosure literature and a set of possible stages, specific to routine enquiry about adversity in childhood (REACh) are proposed. Parents appeared to give purposeful consideration to the process of disclosure, particularly the content and delivery. However, all parents interestingly acquiesced to professionals' invitation to discuss ACEs, despite considerable discomfort, which raises potential issues regarding subjectively disproportionate social power. Results also highlight the high emotionality involved for parents in talking about their own experiences of adversity. However, almost all participants described a sense of relief following disclosure, highlighting disclosure as an emotionally laborious, but potentially rewarding process. Postenquiry effects were also polarised. For instance, parents experienced constant distressing rumination and paranoia regarding expected consequences of their disclosure. However, this

appeared to lead to useful reflections and re-evaluation of aspects of life that guided subsequent positive behaviour change, which appears to indicate possible aspects of post-traumatic growth. These findings also appeared to demonstrate a process of change across the chronological staged model, particularly impacting on parenting behaviours and their perception of role, which seemingly imitates existing models of behaviour change.

The findings of both papers provide both clinical and theoretical implications that can support service delivery, provision and development in relation to support of parents, children and families who are personally or systemically affected by MHD and ACEs.

## If at First You Don't Succeed: The Challenges of Starting Again.

The empirical paper presented in chapter two was not the original thesis topic. There were, consequently, a number of difficult decisions and undesirable conditions throughout this research process. Presented under this subheading is the thesis timeline, structured under seven chapters. These chapters refer to important dates and personal reflections on crucial decisions along this process, concluded with a summary of key learning points.

## October - November 2014: Losing sight of what matters.

On 30th October 2014, I discussed with research supervisors a proposal for a thesis project, which aimed to qualitatively explore foster parents' concerns when caring for looked after child with a confirmed or suspected history of sexual abuse. This idea developed from personal experience of offering psychological input to a looked after children's team. A number of parents raised particular concerns and questions related to this topic, complaining of a lack of associated support and guidance. I held discussions with this service, who were willing to support the research. As an alternative option, should the initial proposal be rejected, I had chosen a project from an approved list of thesis proposals put forward by external supervisors; a qualitative exploration of the experiences of mood fluctuation in children of parents who experience recurrent mood disturbances, associated with a bi-polar

spectrum conditions. The only element of this project I was drawn to was the focus on young people, as my primary area of clinical interest at that time was children's mental health and parenting. There were few other options for child-related topics on the approved list.

Various members of the research team were suggested as possible supervisors upon discussion of both proposal options. However, none were available. Almost all supervisors had already agreed to supervise the projects of others and consequently had no more capacity. I was advised by the research team, via email, that at Lancaster University, "In choosing a project you need to think about how it might fit (or be adapted to fit) with the research competence / interest of someone from the team". I was thus provided with options for contacts regarding available supervisors within the research team with interests in at least one of my proposed projects. However, due to staff absence, I repeatedly did not receive a response to correspondence, which left me with further limited options regarding availability of supervisors. On 17<sup>th</sup> November 2014, a final alternative supervisor was offered to me, who had a particular interest in one of the research proposals put forward; my alternative option. Following discussion of both proposals, it was decided that it would be most suitable for my allocated supervisor to support the bi-polar disorder-related proposal, due to the superior fit with their research interest.

This was the first major decision point; choosing to acquiesce. On reflection, I feel that this was an unhelpful decision. I had little knowledge or experience of the subject area and, if honest, little personal interest in the topic, alongside an incongruent position on diagnoses and mental health related language. In hindsight, I feel strongly that many of the issues that followed would not have occurred should I have chosen to stand by my own interest area and persist with my original topic idea.

I feel there were issues relating to power in the supervisor-supervisee relationship, and even more so between the course and my position as a trainee. Others have highlighted

power struggles following conflict or disagreement over thesis topic choice, citing ruptures in supervisory relationships and demonstrations of passive aggression or feelings of disempowerment by the supervisee (Osborne, 1998), the latter of which I feel certainly applied. I feel that in my position as a trainee, I felt unable to maintain the challenge over the thesis topic with members of the course who, in my opinion, held considerable power over my progression through the course. I therefore felt it necessary to acquiesce and continue with the alternative topic.

## December 2014 – June 2015: Finding a moral footing.

Given my limited exposure to this topic area, prior to the project, I began familiarising myself with research related to children of parents with a diagnosis of a bi-polar spectrum conditions. One difficulty that arose for me during this process was the frequent use of diagnostic and medicalised terminology within related literature. In particular, the reference to 'children of bi-polar parents', 'bi-polar offspring', or the general use of the diagnosis 'Bipolar Disorder', challenged my stance on such constructs in relation to the epistemological position described in chapters one and two.

It has been suggested that the use of diagnostic and medicalised language in relation to MHD can have detrimental impacts on one's sense of identity and self-esteem (Barham & Hayward, 1995; Division of Clinical Psychology; DCP, 2013; Honos-Webb & Leitner, 2001). Mental health diagnoses have been considered dehumanising (Martinez, Piff, Mendoza-Denton, & Hinshaw, 2011), as people assigned such labels can experience community devaluation and rejection, which can have a greater psychosocial impact than the actual experience of MHD (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). Many have also questioned the use of functional psychiatric diagnoses, such as bipolar disorder, due to issues of reliability and validity of the research unpinning its development and use (Barker, 2011; Bentall, 2004; Berger, 2013; Bracken et al., 2012; British Psychological Society; BPS,

2011; DCP, 2000, 2011, 2013). Furthermore, as part of my preparatory learning for the topic area, I met with the Spectrum Centre service-user advisory group to discuss research design, all members of which had some level of experience with this label. They informed me that some who meet diagnostic criteria for bipolar disorder choose to reject the label due, somewhat, to issues described above.

I was aware that it is generally acknowledged that the current classification systems for psychiatric diagnoses have and continue to dominate most mental health related research and theory (DCP, 2013). However, following discussions about my position with both academic and field supervisors, I felt it was necessary that the language I engaged with in relation to this study, including the title and recruitment materials, was congruent with my position on the use of language in relation to MHD.

Jones, Lobban and Cooke (2010), whilst choosing to use the term 'bipolar disorder' in their guidance document, emphasise that experiences of those diagnosed with bipolar disorder are described as 'mood states', rather than 'symptoms'. DCP (2015) guidelines on language in relation to functional psychiatric diagnoses also suggest alternative descriptions of bipolar disorder, including mood swings, severe mood swings, severe changes in mood states and extreme mood states. In line with these guidelines, I decided not to use the label 'bipolar disorder' in my research materials or title, choosing instead to use these alternative descriptions.

# October 2015 – December 2016: Where is everyone?

Ethical approval was granted on 8<sup>th</sup> October 2015 and recruitment commenced immediately. Recruitment involved contact and advertisement with a mixture of national and local non-NHS organisations and support groups, such as the Spectrum Centre and Bipolar UK, and social media, such as Twitter.

There were complications on commencement of recruitment. Prior to ethical approval, I was informed that Bipolar UK would support this research, by allowing me to attend support groups to present the research as a means of recruitment. It was anticipated by my research and field supervisors that this method would be the most successful method of recruitment for this research. However, when I contacted them upon gaining ethical approval, they explained recently changing their policy on research activity; access to support groups was strictly by invitation only and direct contact with groups was prohibited. I requested that my research flyer be shared with the group, but I was never offered an invitation. I contacted a number of alternative national and regional organisations associated with supporting people who may have met inclusion criteria, but was only invited to attend one small region group, which contained no eligible participants.

Social media recruitment was also unsuccessful. I posted regularly on social media and these posts were frequently shared. Nevertheless, I received no responses. I have since wondered whether this poor response was, if only in part, a consequence of my decision regarding the use of language for the study. On reflection, I feel that, due to the dominance of medical discourse concerning MHD in western societies, by attempting to respect diversity and the subjectivity of related language, with the aim of enhancing inclusivity, the choice of language may have actually been excluding. Many potential participants may not have associated their experience with the language used in the advert, as the diagnostic label, 'bipolar disorder' may be the language they typically use or hear in relation to their MHD.

### December 2015 – January 2016: Pulling out all the stops.

Due to limited interest in the study, I commenced discussions with supervisors about altering the design in order to broaden the sample pool. The first option was to reconsider the age range of the sample; lowering the lower age limit. The lower age limit was originally set at 13 years. Research has suggested that, by the age of 9 or 10 years, children begin to

associate MHD with brain function and cognition (Spitzer & Cameron, 1995), can understand the complex nature of MHD by age 11 year (Roose & John, 2003) and can accurately describe MHD between 9-13 years (Roberts, Beidleman & Wurtele, 1981). Consequently, I decided that lowering the age limit from 13 years to 11 years would be appropriate and may increase the sample pool. An amendment to ethics was submitted and approved on 8<sup>th</sup> January 2016. The other option was to gain ethical approval to recruit within NHS services. It was agreed with supervisors that this may increase access to larger numbers of potential participants. An application for NHS ethical approval was commenced on 12<sup>th</sup> December 2015 and formally submitted on 9<sup>th</sup> February 2016.

## February 2016 – March 2016: Biting the bullet.

The application to NHS ethics was reviewed on 26<sup>th</sup> February 2016, with the formal decision of an unfavourable opinion delivered on 8<sup>th</sup> March 2016. However, it was clear at the review meeting that this would be the likely outcome, due to the types of issues raised. I therefore began reflecting on the possible impact of these issues on 26<sup>th</sup> February, rather than waiting for the decision.

One issue in particular stood out amongst the rest. At the meeting, which I attended in person, I was informed by the panel that children under 16 years may feel intimidated by the idea or experience of being alone in a room with an adult male. They also drew specific attention to the possibility of a child, particularly a female child, reporting post-interview that something inappropriate may have occurred during the interview and that I and the child would therefore be at risk. The committee suggested that the only option to overcome this would be to conduct interviews only via a two-way mirror, at the University, with a witness observing and it would not be safe to conduct the study otherwise. All members of the panel seemed to condone these, what I considered to be, gender-based discriminatory comments. I was shocked by the chair's comments about the possible detrimental impact of my gender on

participants, but more by the general consensus amongst or lack of challenge from other panel members. It was therefore unclear whether this was the view of the chair or an institutionalised opinion regarding male researchers. When I challenged their comment, requesting clarification, they did not provide any clear evidence for this assumption. My initial internal response was anger, although, conforming to social norms and the evident positional and reward power differential (Zur, 2014), I supressed my desire to express this emotion. The psychological consequence of their comment, and my subsequent suppression of emotion, was further feelings of disempowerment.

This issue raised difficulties for me in deciding whether to continue with this project, or to abandon it and devise a new project. Alongside these gender-based comments, suggested changes included developing multiple participant information sheets and consent forms for very discreet age brackets, each containing different age-specific language, despite the existing forms being designed to be comprehensible to the youngest age range and therefore suitable for all. There were also requests that the method of screening for eligibility be altered.

Given that the deadline for submission of the thesis was 13<sup>th</sup> May 2016, less than seven weeks away by that time, I felt I needed to consider whether time spent altering the study design and procedures would be beneficial or detrimental. Firstly, I needed to decide whether changes would be achievable, and secondly whether such changes, particularly the inclusion of interviewing via two-way mirror, would further restrict recruitment opportunities and therefore jeopardise data collection.

I immediately contacted academic and field supervisors and my clinical tutor to request advice via email. I spent that weekend, in anticipation of their response, compiling ideas for alternative projects. Upon discussion with supervisors and tutors, due to receiving no recruitment interest in the project for five months, despite my continual efforts to advertise

the project and subsequently broaden the sample pool, it was agreed that it would be more time efficient to design and commence a new project, with greater recruitment opportunities.

#### March 2016 - May 2016: A new hope.

I spent my final year on a service development focussed placement, working specifically on REACh projects described in chapter two. Prior to my involvement with these projects, the team had trialled the approach with family support workers in a local authority family support team and regional charitable organisations offering family-based support. These teams had been trained in the REACh approach to initiate discussion and specifically ask about ACEs with parents. This project had already been evaluated in terms of feasibility (McGee et al., 2013) and the experiences of professionals had been qualitatively analysed by another Trainee Clinical Psychologist on the Lancaster University Doctoral programme. The evaluation of professional experiences of enquiry revealed anecdotal evidence that parents begin to question their experiences as children following enquiry and subsequently consider the impact these experiences have had on their parenting. However, when searching the literature on this topic, I could not find research into the experience of enquiry about ACEs from a parent's perspective, nor from any service-user's perspective.

I contacted Dr Vincent Felitti, one of the founders of ACE research, and Prof. Heather Larkin, a leading ACE researcher. I asked whether they were aware of or had conducted any formal or informal research on parent perspectives of ACE enquiry; they were not and had not. Prof. Larkin added in her email that this type of research will be, "filling a gap" in the ACE literature (H. Larkin, personal communication, May 3, 2016). As such, I discussed with my placement supervisor the possibility of qualitatively analysing the perspectives of parents regarding their experiences of REACh; this was agreed. I also contacted these services to enquire as to whether they would support recruitment; they agreed. I promptly developed a

new research proposal and submitted this for review by the clinical psychology research team at Lancaster University on 29<sup>th</sup> February 2016, which was approved on 2<sup>nd</sup> March 2016.

Having learnt lessons from the previous project regarding the need to consider the intricacies of research design, I started by reflecting on all those that were issues in the first study, such as potential issues with specific sample characteristics, interview location and the language used to describe the study. I also invited service-user consultation from the Lancaster University Public Involvement Network (LUPIN) to ensure the appropriateness of research materials and language during the design phase.

An application to the Faculty of Health and Medicine Research Ethics Committee was completed on 15<sup>th</sup> March 2016 and I received confirmation of ethical approval on 9<sup>th</sup> May 2016; four days prior to the original submission deadline. I agreed with my supervisors to extend the deadline to 31<sup>st</sup> August 2016; giving me just under four months for recruitment, data collection, analysis and write up.

### May 2016 - August 2016: Don't rush, be judicious.

Given the short timeframe for completion, there was a need to plan and act perspicaciously with regards to project management. Continuing with the reflective practice approach, I learnt from my experience with the previous project. I took the time to develop good relationships with the recruitment service. I arranged, prior to ethical approval, opportunities to meet formally with the support workers to gain their buy-in, so to encourage strong engagement from them with the study. This helped me to develop a good rapport and maintain regular contact with the team and its members, which developed strong channels of communication throughout the project, particularly regarding the state of recruitment.

I also felt it necessary to be judicious with regards to decision making about recruitment and data collection. The first participant was interviewed on 27<sup>th</sup> May 2016.

There were clear patterns emerging by participant three, interviewed on 2<sup>nd</sup> June 2016, and I

became aware that very little new information was being collected in terms of codes by the fifth interview, conducted on 20<sup>th</sup> June 2016. After the seventh participant, the services explained that there were no other eligible participants currently within the service or that wanted to take part. Given the great deal of similarity between participant accounts, I decided to request the opportunity to re-interview participants to clarify the accuracy of my understanding of their accounts and to enquire further about particular emerging themes. All participants were invited and four agreed. Again, very little new information was being collected in terms of novel codes and it appeared data had reached a point of data 'sufficiency' (Dey, 1999); new data did not necessitate adaptation of themes. I thus decided to cease recruitment on the 14<sup>th</sup> July 2016.

# A summary of key reflections.

The experience of completing this thesis has enlightened me to a number of pertinent issues for myself as researcher, which may have relevance to others. Firstly, I learned a number of practical lessons, such a developing close relationships and ensuring regular, reliant channels of communication with recruitment streams and to engage those involved prior to and as part of the research design. I also learnt to assess, where possible, whether there are any planned changes to services or procedures involved in recruitment streams, to avoid preventable disruptions to recruitment.

Towards the end of the thesis process I discussed with the academic supervisors my reflections on the lack of available support from the course to peruse the project of primary interest at the start of the thesis process. We also discussed the consequent feelings of disempowerment that resulted in my acquiescence to choosing the project that was eventually stopped. This discussion has led to debate within the course regarding the support of trainees in choosing a topic area and the necessity, or not, of matching supervisor-supervisee research interests in the future.

Similar to the issues of power raised in chapter two regarding the enquirer-discloser relationship, I believe it is important to address the issues of power between supervisor and supervisee. In response to course staff, by nature of their socially defined status on the course as evaluators to trainee progression, I felt that I, like service-users in the ACE study, adopted a submissive position when deciding on the thesis topic, due, in part, by a perceived pressure to conform to the stated 'expectation' of trainee conduct in relation to thesis topic choice. This relationship is considerably imbalanced. I feel a similar solution to that suggested for clinical encounters in chapter two is required. Trainee clinical psychologists and doctoral courses should more readily and explicitly acknowledge issues of power in supervisory relationships, from the start and throughout the research process, with the aim of fostering trainee empowerment and autonomy. I feel this will enable richer professional development within the profession, particularly regarding research competence.

Finally, I discuss the difficulties experienced during recruitment by deciding not to engage with mental health terminology related to current diagnostic classification systems. There has been a call within the field of clinical psychology for a "paradigm shift" with regards to the use of mental health diagnoses, which demands "an approach that is multifactorial, contextualises distress and behaviour, and acknowledges the complexity of the interactions involved in all human experience" (DCP, 2013, p.5). However, issues such as those experienced in my attempt to avoid such language may restrict recruitment, which risks impacting the validity of and learning from eventual findings. This highlights a key dilemma in conducting mental health research more broadly. The dominant medical discourse concerning MHD, particularly in western societies, demands the use of such language to support research recruitment, due to its more widely recognised status. However, continuing to employ diagnostic language in research, for this reason, perpetuates this issue.

Due to time restrictions enforced for successful completion of doctoral training, I was not able persist with my approach. However, I believe that to achieve this paradigm shift, clinical psychology as profession has a responsibility to search for and mobilise alternative language. This may involve attempts to conduct research that disengages from these medicalised systems of language and strives instead to use language that directly reflects service-user identities and their multi-factorial experiences. Just as Deegan (1993) describes receiving diagnoses as a "radically devaluing and dehumanizing transformation from being a person to being an illness", I believe that we need to produce a movement within mental health literature and beyond, employing service-user led language that provides a radically re-valuing and re-humanising transformation from having an 'illness', to being a person experiencing contextualised distress.

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# **Chapter 4: Ethics**

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# **Ethics Application Form**

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

# Application for Ethical Approval for Research

1. Title of Project:
Exploring the Impact of Enquiring About the Adverse Childhood Experiences of Parents
2. If this is a student project, please indicate what type of project by ticking the relevant
box:
□ PG Diploma □Masters dissertation □MRes □MSc □ DClinPsy
SRP
□ PhD Thesis □ PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being □ MD X
DClinPsy Thesis
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Applicant information
4. Name of applicant/researcher: Graham Simpson-Adkins
5. Appointment/position held by applicant and Division within FHM
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6. Contact information for applicant:
o. Contact information for applicant.
E-mail: <a href="mailto:simpson1@exchange.lancs.ac.uk">simpson1@exchange.lancs.ac.uk</a> Telephone: 07852518411
Address: 44 St Asaph Drive, Callands, Warrington, WA5 9RP
7. Project supervisor(s), if different from applicant:
To job object the state of the
Name(s): Prof. Bill Sellwood (Thesis Academic Supervisor)
b.sellwood@lancaster.ac.uk
Dr Anna Daiches (Second Academic Supervisor) a.daiches@lancaster.ac.uk
Dr Warren Larkin (Thesis Field supervisor)
warren.larkin@lancashirecare.nhs.uk
8. Appointment held by supervisor(s) and institution(s) where based (if applicable):
Prof. Bill Sellwood, Programme Director, Doctorate in Clinical Psychology, Lancaster University
Dr Warren Larkin, Director, Children & Family Services, LCFT
,,
Dr Anna Daiches, Clinical Director, Doctorate in Clinical Psychology, Lancaster University

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

Graham Simpson-Adkins (Trainee Clinical Psychologist), Neuropsychology BSc (University of Central Lancashire)

### The Project

**NOTE**: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. Summary of research protocol in lay terms (maximum length 150 words).

The study I propose aims to gather qualitative data from parents regarding their experience of being asked by professionals about their own adverse childhood experiences (ACE). Individual semi-structured interviews will be used to facilitate exploratory conversations with parents about their experience of this routine enquiry. Participants will be parents that highlighted at least one ACE during enquiry by one of the professionals at participating recruitment services. Participants will be recruited via Local Authority and Charitable organisations. A minimum number of 5 participants is required, but the study will aim to recruit up to 20 participants. Data will be analysed using a form of inductive thematic analysis.

### 11. Anticipated project dates

Start date: April 2016 End date: September 2016

12. Please describe the sample of participants to be studied (including number, age, gender):

The term 'Participant' will refer to parents that highlighted at least one ACE when asked by professionals at participating recruitment services as part of a routine enquiry during assessment. Inclusion criteria are that participants must be a parent of at least one child. Participants can be any form of biological or non-biological parent of the child/children. Parents must have identified at least one adverse childhood experience during routine enquiry. In terms of exclusion criteria, no restrictions have been placed on any demographic information, such as age or gender for either the parent or their child/children. However, parents who are currently receiving treatment for PTSD will be excluded, given the possibility for triggering a trauma-response. The inclusion criteria are as inclusive as possible, as we do not currently understand what factors may influence a parent's response to routine enquiry about adversity.

A minimum number of 5 participants is required to ensure the study will be viable, however, the study will aim to recruit up to 20 participants. Participants are required to be

competent in English, due to resource restrictions. No restrictions will be placed on gender, age or any other demographic information.

13. How will participants be recruited and from where? Be as specific as possible.

Participants will be recruited via local authority family support services in and organisation. Participants will be identified by professionals in these services. The researcher will make contact with these organisations to arrange an opportunity to visit and discuss the research project with their teams and to share the participant information sheets. If a parent has identified at least one ACE during routine enquiry, the professionals will be asked to share the participant information sheet with the parent and explain the study. If they agree to, parents will be asked to take the Participant information sheet and will be asked to provide consent for the professional to share their contact details with the researcher via the consent to contact form, so that the researcher can contact the parent to discuss the study. The contact details will be stored in a password protected file on an encrypted computer and will be destroyed upon completion of data analysis. Alternatively, the parent will be informed by the professional that they can get in contact with the researcher via the details provided on the information sheet if they would like to take part or to discuss the study.

### 14. What procedure is proposed for obtaining consent?

Potential participants will be provided with full details of the study from the Participant Information Sheet. Participants will have opportunity to discuss the project with the researcher, who will explain any information that is not clear and/or provide more information where necessary. Participants will be informed of the data collection and analysis method. Participants will be required to provide written consent, which will be captured and recorded via signature on the Consent Form prior to the start of interviews. It will be explained that participants are welcome to withdraw from the study at any time before or during the interview and up to the completion of transcription.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

Participants will be asked about their personal experience being asked about adverse childhood experiences (ACEs). They will not be asked to discuss these ACEs, only the experience of the routine enquiry and the impact this had on them. However, it is acknowledged that this may relate to adverse or distressing experiences in itself. Should distress occur during the interview, the researcher will acknowledge the level of distress and ask the participant if they wish to continue or discontinue; participants will be provided with the option to (a) continue, (b) to terminate the interview and withdraw their participation from the study, (c) to terminate the interview but permit the researcher to use any data gathered to that point, or (d) to pause the interview and continue after a break or

to rearrange another interview date. Debriefing will be offered to participants following completion of their interview or alternatively, a time will be offered for a single debrief phone call during the day following the interview, if required. The researcher will provide information regarding appropriate sources of support, such as Samaritans, which can be found on the participant information sheet. Should the researcher develop concerns about a participant at any point due to perceived discomfort or distress, the researcher will share this information with the research supervisors. This procedure will be explained to all participants as part of informed consent and will be described on the participant information sheet. Subsequent to reporting to supervisors, action plans and risk assessments for future interviews will be discussed in supervision to minimise the risk of a reoccurrence of any distressing or harmful events during interviews. Should action be required regarding risk of harm to others, such as safeguarding referrals, an appropriate action plan will be developed and carried out, with regular contact with the research supervisor to encourage effective completion of necessary actions.

Should the interviewee experience a trauma-response, such as a flashback during interviews, they will be asked if they want to take a break or to discontinue the interview, as above. The researcher will allow time to ensure the interviewee feels safe to leave before ending the interview and will enquire as to whether the interviewee would like to make contact with services, access any form of support or contact someone they know. The interviewee will be provided with a list of support agencies via the participant information sheet. Should the interviewee require emergency attention, the researcher will contact emergency services, follow safeguarding procedures and inform the research supervisors.

Participants will be informed via the participant information sheet and consent form that they may, if necessary be contacted again after their initial interview to clarify or elaborate on gathered information. It will not be necessary to gain secondary consent to be re-contacted, as they will have provided consent for this on the consent form for the initial interview. Participants will also be informed via the consent form that they can decline the request to be re-contacted after their initial interview if they choose to.

Participants will be informed via the consent form and prior to commencing the interview that they will be able to request to withdraw their data from the study at any time until the start of data analysis, after which it will not be possible to withdraw data.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

The potential for harm or distress to the researchers is minimal. However, to safeguard the safety of the researcher, policy and guidelines will be adhered to. Should distress be experienced by the research, the researcher will contact the research and/or field supervisor to discuss personal distress. Time will be allocated to reflect on any experience

of personal distress before continuing with the study, with consideration given to possible effects on participants or the impact on data collected. Any and all issues that occur will be discussed with the research/field supervisors. By default, interviews will take place at the service building that they were recruited from, which is anticipated to be the children's centre that they are registered with and receiving support from. I have agreement from the children's centre managers that it is ok to hold interviews in the children's centres. Alternatively, interviews will take place on the Lancaster University Campus. The researcher will not enter a situation where there is obvious potential risk and necessary risk assessments will be performed, where appropriate. To encourage the researcher's safety, risk assessment will be carried out on the room in which interviews will take place in order to ensure that the researcher is aware of a safe exit from the area. The researcher will ensure to sit next to door, when appropriate, to allow safe exit, if required. Interviews will only be conducted during standard office hours (9am-5pm). Where lone working is required, the Lancashire Care NHS Trust lone worker guidance will be implemented. The researcher will ensure that supervisors are informed of the location of interviews and the predicted arrival and departure times, in accordance with Lancashire Care NHS Trust lone worker guidance. On completion of interviews and exit from the venue, the researcher will contact the field supervisor or a member of the Doctorate in Clinical Psychology administration team via the research mobile phone provided by the university, to inform them that the interview has ended. Anna Daiches (research supervisor) has agreed to be the contact person. As per the lone worker policy, Anna will be provided, prior to interviews taking place, with the full address of where the interview will take place, telephone numbers for myself and the centre, and indications of how long the interview is expected to last at those locations (both arrival and departure times). Where there is genuine concern for the researcher, as a result of not attending a visit within an agreed time or not making contact with Anna at the agreed time following the interview, Anna will use the information provided to her to help track the Lone Worker. Depending on the circumstances and whether contact through normal means (mobile phone, pager and so on) can or cannot be made, the manager or colleague should involve the police if necessary. If police involvement is needed, they should be given full access to information held and personnel who may hold it, if that information contains data that might help trace the Lone Worker and provide a fuller assessment of any risks they may be facing.

Should the researcher become distressed during or after interviews, clinical supervision will be sought from Supervisors. Only the university email address of the researcher will be given to participants, as well as the research mobile phone number.

17. 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.

It is hoped that the resulting findings will contribute to research relating to parenting and parent-child interactions and to mental health related research more generally, which may be particularly relevant to participants and their families.

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

Participants will be invited to take part in a prize draw to win a £50 Amazon voucher. This incentive will be paid for by the Researcher, Graham Simpson-Adkins. To enter the prize draw, participants will be asked to provide their email addresses (or a postal address) on the consent form, indicating that they wish to be entered in to the draw. The voucher will be sent to the winning participant via email (or post where participants do not have an email account and would prefer it to be sent to a postal address) after all interviews have taken place. In the event that the winning participant is no longer contactable, the researcher will choose another participant at random.

It is expected that, wherever possible, participants will not be required to travel. However, wherever a participant is required to travel, they will be reimbursed up to the amount of £20 in accordance with Lancaster University Clinical Psychology Doctoral programme guidance on research expenses.

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

Data will be gathered via one-to-one, semi-structured interviews lasting approximately one hour. The aim of interviews will be to facilitate an exploratory conversation, using open ended questions that focus on the participant's views regarding how they experienced being asked about adverse childhood experiences. Participants will be informed via the participant information sheet and consent form that they may, if necessary be contacted again after their initial interview to clarify or elaborate on gathered information. With the participant's permission, the interviews will be recorded on an audio recording device and the data collected will be transcribed by the researcher and analysed using a form of inductive thematic analysis. Data collected during any follow up conversations will also be audio recorded and transcribed in the same way as the first interview.

Participants will be asked that the interview take place either at the service building from which they were recruited or at Lancaster University Campus, which can be booked via the clinical psychology programme administrative team. Where it is not possible or convenient for participants or parents to travel to Lancaster University or the service from which they were recruited, telephone calls will be offered to conduct interviews. Where

home visits or alternative locations are requested, the researcher will adhere to Lancaster University lone worker guidance, as outlined in the University's document Guidance on safety in fieldwork (<a href="http://www.lancaster.ac.uk/depts/safety/files/Fieldwork.pdf">http://www.lancaster.ac.uk/depts/safety/files/Fieldwork.pdf</a>) and appropriate risk assessments conducted (see section 16). The researcher will contact the field or academic supervisor or the clinical psychology administrative team prior to the interview taking place, and on its completion. Interviews will be carried out between 9am – 5pm to ensure that allocated people can be contacted before and after the interview.

All participants will be asked if they wish for a chaperone to be present during interviews. The researcher will ensure that interviews take place in a safe environment by conducting appropriate risk assessment (see section 16). All participants will be informed that they are free to take breaks during interviews at any time. The researcher will also ensure to check in with the participant throughout interviews to assess for any distress, using skills developed via training in clinical psychology. If concerns are raised at any point, information will be shared with relevant safeguarding organisations. If there is concern regarding immediate and significant risk of harm, information will be shared with the police.

The researcher is DBS checked.

Limits to confidentiality will be explained on the consent form and prior to interviews. It will be explained that if what is said during the interview makes the researcher think that the participant, or someone else, is at risk of harm, the researcher may have to share this information. If the researcher thinks that there is a risk, either to the participant or to others, this will be shared with the researcher's supervisor and other appropriate agencies. However, if confidentiality needs to be broken then, wherever possible, the researcher will attempt to discuss this with the participant and will explain what will be done with that information. It will also be explained that sometimes the researcher will talk to their supervisor and listen to the audio recordings together or read the transcript of what was said. This is to check that the researcher is doing things correctly and what they are saying is appropriate. However, when this happens, information such as the participants name will be removed to maintain confidentiality.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

The researcher will make contact with The Lancaster University Public Involvement Network (LUPIN) to present the proposed project and to consult with expert-by-experience. The aim of these consultations will be to discuss research design and the wording of research documents, such as the participant information sheet and potential research questions. Any suggested changes will be reviewed by the researcher and research supervisors and amendments will be made, where appropriate.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

Data stored on portable devices, such as laptops will be encrypted where possible and identifiable data, including recordings of participant interviews, will be stored securely and deleted as soon as the data has been transferred to the university server via the Virtual Private Network (VPN). The researcher will transcribe all interviews. Transcripts of interviews will be anonymised and stored as an encrypted file on a password protected computer. Personal details will be kept separately from data, in a separate file on the password encrypted server and will be deleted once the thesis has been assessed. These files will only be accessible by the researcher and the research supervisors for quality assurance. Files with audio recordings and written transcripts will be securely transferred to the research supervisor via Lancaster University's Box file transfer software. Following data analysis, anonymised interview transcripts, coded data produced and paper consent forms will be scanned and stored electronically, encrypted and transferred securely to the University Research Coordinator using Box file transfer software. Files will be saved by the research coordinator on a password protected file space on the university server. Encrypted files will be stored by the research coordinator for 10 years after the end of study. At the end of the storage period, the data will be deleted by the Doctorate in Clinical Psychology Research team.

22. Will audio or video recording take place?  $\Box$  no X audio  $\Box$  video If yes, 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 uploaded to a password protected file on the Lancaster University network. The original recordings will then be deleted off the recording device used. The reason for earliest possible upload of audio recordings is that it is not possible to encrypt the portable devices. Prior to deletion of recordings, the recorder will be stored securely in a locked draw. Audio recordings will be deleted from the Lancaster University network upon submission of thesis report to the University.

## 23. What are the plans for dissemination of findings from the research?

The findings of this research will be disseminated via the resulting Thesis report. This document will be submitted as an assignment as part of the Clinical Psychology doctoral programme. It is also anticipated that the findings of this research will be disseminated to other professionals and students, via a short presentation as part of course requirements and may be presented at future conferences. If appropriate, the research will be submitted for publication. Care will be taken to ensure that the confidentiality of participants will be preserved during the dissemination process by ensuring that data is anonymised and is not

attributable to any participants identifying information.

24. What particular ethical problems, 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 advice from the FHMREC?

The personal email and postal addresses that participants provide if they wish to enter the prize draw following completion of the study will be recorded on the consent form, which will be stored securely in a password-protected file on the University's secure server. Any emails to participants will be sent by the researcher from the researcher's university account. All files not stored securely will be deleted.

The researcher will contact their supervisors to seek advice should an ethical issue occur or if the researcher becomes or is made aware of ethical issues not already considered, and/or if the researcher feels unable to respond to any issues without advice.

### **Appendices**

## **Appendix A: Ethical Approval Letter**



Applicant: Graham Simpson-Adkins

Supervisor: Bill Sellwood Department: Health Research FHMREC Reference: FHMREC15064

09 May 2016

Dear Graham,

Re: Exploring the Impact of Enquiring About the Adverse Childhood Experiences of Parents

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 University Research Ethics Committee (UREC), 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 requirements in 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 (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Diane Hopkins (01542 592838 <a href="mailto:fhmresearchsupport@lancaster.ac.uk">fhmresearchsupport@lancaster.ac.uk</a>) if you have any queries or require further information.

Yours sincerely,

Dr Diane Hopkins

Research Development Officer

CC Ethics@Lancaster; Professor Roger Pickup (Chair, FHMREC)