Walking on Eggshells: Having a Parent Who Has Obsessive Compulsive Disorder

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A thesis submitted in partial fulfillment of the requirements for the degree of Master of Psychology (Counselling)

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## Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Index of Tables</td>
<td>iv</td>
</tr>
<tr>
<td>List of Appendices</td>
<td>v</td>
</tr>
<tr>
<td>Declaration of Originality</td>
<td>vi</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>vii</td>
</tr>
<tr>
<td>Abstract</td>
<td>viii</td>
</tr>
<tr>
<td><strong>Introduction</strong></td>
<td>9</td>
</tr>
<tr>
<td>Prevalence and Negative Impact of Parental Mental Illness</td>
<td>9</td>
</tr>
<tr>
<td>Nature and Prevalence of OCD</td>
<td>12</td>
</tr>
<tr>
<td>Stigmatisation</td>
<td>13</td>
</tr>
<tr>
<td>Family Accommodation</td>
<td>14</td>
</tr>
<tr>
<td>Research Focusing on The Experiences of Children Living with a Parent</td>
<td>15</td>
</tr>
<tr>
<td>with OCD</td>
<td>18</td>
</tr>
<tr>
<td>Research Aim</td>
<td></td>
</tr>
<tr>
<td><strong>Method</strong></td>
<td>18</td>
</tr>
<tr>
<td>Participants</td>
<td>19</td>
</tr>
<tr>
<td>Recruitment Procedure</td>
<td>21</td>
</tr>
<tr>
<td>Interview Procedure</td>
<td>22</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>22</td>
</tr>
<tr>
<td><strong>Results</strong></td>
<td>23</td>
</tr>
<tr>
<td>Impact on Children</td>
<td>24</td>
</tr>
<tr>
<td>Highly controlled home environment- ‘a lot of arguments’</td>
<td>24</td>
</tr>
<tr>
<td>Effect on schooling</td>
<td>25</td>
</tr>
<tr>
<td>Social isolation</td>
<td>26</td>
</tr>
<tr>
<td>Parentification of children</td>
<td>27</td>
</tr>
<tr>
<td>‘Followed all of the rules’</td>
<td>27</td>
</tr>
<tr>
<td>Positive impact- ‘it makes you more open-minded’</td>
<td>28</td>
</tr>
<tr>
<td>Participant’s Perception of Parental Rearing</td>
<td>28</td>
</tr>
<tr>
<td>‘It would override what she wanted to do’</td>
<td>29</td>
</tr>
<tr>
<td>Relationship with their parent- ‘it was really difficult’</td>
<td>29</td>
</tr>
<tr>
<td>Empathy for their parent- ‘it’s not your parent’s fault’</td>
<td>30</td>
</tr>
<tr>
<td>Distancing oneself and negotiating boundaries</td>
<td>30</td>
</tr>
<tr>
<td>Secrecy</td>
<td>31</td>
</tr>
</tbody>
</table>
Index of Tables

Table 1. Participant Demographics 20
Table 2. Identified Themes 24
List of Appendices

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix A.</td>
<td>Schedule for the Adult Semi-structured Interviews</td>
<td>55</td>
</tr>
<tr>
<td>Appendix B.</td>
<td>Explanatory Statement</td>
<td>58</td>
</tr>
<tr>
<td>Appendix C.</td>
<td>Consent Form (Adult Child)</td>
<td>60</td>
</tr>
<tr>
<td>Appendix D.</td>
<td>Ethics Approval from MUHREC</td>
<td>62</td>
</tr>
<tr>
<td>Appendix E.</td>
<td>Permission Letter from Professor Don Jeffery</td>
<td>63</td>
</tr>
<tr>
<td>Appendix F.</td>
<td>Advertisements Provided Online and to Peer Support Groups</td>
<td>64</td>
</tr>
<tr>
<td>Appendix G.</td>
<td>Newspaper Advertisement in the Leader Community</td>
<td>65</td>
</tr>
</tbody>
</table>
Declaration of Originality

This project contains no material that has been submitted by the candidate for examination in any other course, or accepted for the award of any degree or diploma in any University. To the best of the candidate's knowledge it contains no material previously published or written by any other person, except where due reference is made in the text.

The work undertaken for this project was duly authorised by the Monash University Human Research Ethics Committee (MUHREC) on {5 March 2012}: CF11/3529 – 2011001872.

Name of Candidate:

Amy Louise Ross

Signature:
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Abstract

Australian literature has indicated that 21-23% of children have at least one parent diagnosed with a mental illness, with varying levels of risk. However, there is limited research on the experiences of those who have grown up with a parent with Obsessive-compulsive Disorder (OCD). Accordingly, the present research aimed to provide an in-depth understanding of the subjective and retrospective experiences of adults whose parents have OCD. Within a qualitative approach called Interpretative Phenomenological Analysis (IPA), semi-structured telephone or face-to-face interviews were employed. Four inter related themes were identified by eight adults between the ages of 19 and 46 years, with a parent who has OCD. According to participants, having a parent with OCD meant a highly controlled home environment characterised by frequent arguments, social isolation, a negative impact on schooling, assuming aspects of the parenting role and participating in their parent’s rituals. Participants emphasised the need to distance themselves and establish boundaries in the relationship with their parent. Furthermore, some participants expressed concern about the secrecy around OCD in their family. Participants indicated that they were not able to access adequate treatment services during their childhood and adolescent years. The paper concludes with implications for clinical practice and suggestions for future research.
Walking on Eggshells: Having a Parent Who Has Obsessive Compulsive Disorder

Mental illness can be defined as a wide range of psychiatric symptoms that persist over time and result in significant impairments of an individual’s cognitive, affective or relational abilities (Australian Health Ministers, 1998). The National Survey of Mental Health and Wellbeing (ABS, 2007) found that one in five (20%) Australian adults experience mental illness in any given year and many of these individuals are parents (Maybery, Reupert, Patrick, Goodyear, & Crase, 2009). Difficulties such as social isolation, marital discord and financial hardship are not uncommon experiences for families where a parent has a mental illness (Beardslee, Versage, & Gladstone, 1998; Hosman, van Doesum, & van Santvoort, 2009; Nicholson, Biebel, Kinden, Henry, & Stier, 2001). Commonly, mental health professionals often perceive the individual with the illness as the only member of the family who requires support and assistance, and are often not aware that their clients are parents (Aldridge & Becker, 2003; Blanch, Nicholson, & Purcel, 1994; Fudge & Mason, 2004; Murdoch & Hall, 2002). As a result, the needs of the clients’ families, particularly the children are often overlooked (Devlin & O’Brien, 1999; Kroll & Taylor, 2000). However, compared to other children, those who have a parent with a mental illness are at a greater risk of developing a mental illness themselves, (Clarke et al., 2001; Lieb, Isensee, Hofler, Pfister, & Wittchen, 2002; Orel, Groves, & Shannon, 2003; Rasic, Hajek, Alda, & Uher, 2013; Weissman et al., 2006) functional impairment, and of experiencing suicidal ideation and suicidal attempts (Hosman et al., 2009). This paper examines a subset of these young people – those whose parents have Obsessive-compulsive Disorder (OCD).

Prevalence and Negative Impact of Parental Mental Illness
Australian epidemiological data indicates that 21-23% of children have at least one parent who has been diagnosed with a mental illness (Maybery et al., 2009), with varying levels of risk, depending on genetic, child, parent, family and environmental factors (Hay, 2004; Hosman et al., 2009).

Past research has indicated that a common issue for children living with a mentally ill parent (predominantly in sole parenting families), is their tendency to undertake additional age-inappropriate emotional and domestic responsibilities (Aldridge, 2006; Aldridge & Becker, 2003; Dearden & Becker, 1998; Fudge & Mason, 2004; Hayman, 2009; Nicholson, Sweeney, & Geller, 1998; Polkki, Ervast, & Huppoonen, 2004). These children are often required to fulfill multiple roles, such as supporting their mentally ill parent and assuming a number of adult responsibilities (e.g. looking after younger siblings, housekeeping duties and acting as a family representative; Cowling, 2004). This is often referred to as parentification of children as such acts of caregiving responsibilities may result in forced maturity at a younger age (Hayman, 2009). Parentification has been associated with the restriction of children’s recreation, social, educational performance and personal development (Atkin, 1992; Dearden & Becker, 2000; Frank, Tatum, & Tucker, 1999). Furthermore, parentification has been found to negatively impact on children’s future relationships, with research highlighting an association between parentification during childhood and insecure attachment to partners in adulthood (Bourassa & Allen, 2010).

Family dynamics can be adversely affected by parental mental illness. For example, through interviews and participant observations Mordoch and Hall (2008) investigated the impact of parental mental illness including, depression, bipolar disorder and schizophrenia on 22 children (6-16 years). The authors found that for children, maintaining distance and clear boundaries between themselves and their
parent was important. Further consequences of parental mental illness for children include, problems in social relationships (e.g. hesitant to invite friends over) (Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004), restricted leisure time (Cooklin, 2006), disrupted schooling (Becker, Aldridge, & Dearden, 1998), and interruptions to family life (Mordoch & Hall, 2008).

A related body of research has investigated the experiences of adult children, asking them to reflect back on their younger years of growing up in a family where a parent experienced a mental illness. For example, Foster (2010) explored the experiences of 10 adult-children (aged 25-57 years) who had parents with a range of mental illness including, schizophrenia, severe depression, bipolar disorder, substance abuse, alcohol abuse and schizoaffective disorder. Similar to other research (Knutsson-Medin, Edlund, & Ramklint, 2007), Foster found that adult children recalled having high levels of caregiving responsibilities. Additionally, participants noted the potential strain that parental mental illness has on the child-parent relationship and described experiencing a range of uncertainties during childhood and adulthood, such as not knowing what to expect on a daily basis.

In a somewhat dated paper, Dunn (1993) explored adult children’s experience of parental psychosis and found that most participants described negative experiences with health professionals and a lack of information regarding their parents’ mental illness. Additional findings of an often-chaotic family life, frequented by neglect and abuse were also noted (Dunn, 1993). Regardless of these challenges, participants emphasised the guilt and loyalty they felt towards their parent.

A lack of communication may exist in families with a parent experiencing a mental illness. Many parents do not want to place a burden on their children (Montgomery, Tompkins, Forchuk, & French, 2006; Stallard et al., 2004) or consider
their children too young to understand or be aware of their illness (Stitt & Reupert, 2013). Interestingly, several studies have demonstrated children’s desire for more information, as ascertained from both children and adult children retrospectively (Cogan, Riddell, & Mayes, 2005; Falkov, 1998; Hinshaw, 2004; Polkki et al., 2004; Stallard et al., 2004). Similarly, Knutsson-Medin et al. (2007) explored the experiences of 36 adult children of former psychiatric inpatients who described a lack of information and support from health professionals and a desire for further explanation and additional support for themselves.

Most of the research in this area has focused on parental diagnoses such as attention-deficit hyperactivity disorder, depression, bipolar disorder, eating disorders, and schizophrenia (Biederman et al., 2001; Biederman, Faraone, & Montiiteaux, 2002; Del Bello & Geller, 2001; Fellowes-Smith, 2001; Goodman et al., 2011; Leverton, 2003; Montgomery et al., 2006; Reupert, Maybery, & Kowalenko, 2012). Overall, studies tend to group diagnoses together, without distinguishing between diagnostic categories and the potential differences that might arise for families across diagnoses. Minimal research has specifically explored the experiences of adult children of a parent experiencing OCD and the impact it may have on family life. This information is useful as it can be used to inform intervention supports and resources.

**Nature and Prevalence of OCD**

OCD is a common, serious mental illness that affects approximately 2-3% of the population (Heyman, Mataix-Cols, & Fineberg, 2006; Kessler, Berglund, Demler, Jin, & Walters, 2005). The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V; American Psychiatric Association, 2013) defines OCD as recurrent obsessions or compulsions that are time consuming and cause marked distress or interfere with one’s life. Obsessions are unwanted ideas, impulses or images that
repeatedly enter an individual’s mind (Greist & Jefferson, 2007). Common obsessions include: unrealistic and distressing worries about contamination, fear of making a mistake, and fear of harm coming to oneself or others (e.g. the fear that their children might be abducted) (Greist & Jefferson, 2007). In response to obsessions, individuals usually attempt to ignore, suppress or neutralise the unwanted thoughts with an alternative thought or action, which is referred to as a compulsion (Greist & Jefferson, 2007). Compulsions are repetitive, stereotyped behaviours or mental acts that individuals feel compelled to do in response to an obsession, often intended to neutralise the high degree of anxiety triggered by obsessions or in accordance to rigid rules (Abramowitz, Taylor, & McKay, 2009). Such rituals are typically not enjoyable for the individual; instead individuals feel uncertain about whether they have done enough to prevent potential harm, risk, or danger (Greist & Jefferson, 2007). Given the nature of the disorder, OCD has an impact not only on the life of the person with the diagnosis but also on family members.

**Stigmatisation**

The stigma associated with mental illness across disorders has been well established (Angermeyer, Schulze, & Dietrich, 2003; Koschade & Lynd-Stevenson, 2011; Östman & Kjellin, 2002; Stengler-Wenzke, Trosbach, Dietrich, & Angermeyer, 2004). Stigma not only impacts on the individual experiencing the mental illness, but also their families including children (Koschade & Lynd-Stevenson, 2011; Östman & Kjellin, 2002). This notion is referred to as associative stigma (Angermeyer et al., 2003; Chang & Horrocks, 2006; Veltman, Cameron, & Stewart, 2002), which describes the stigma experienced by others who are associated with the ‘marked’ individual (Corrigan, Watson, & Miller, 2006).

Stengler-Wenzke et al. (2004) employed semi-structured interviews with nine
spouses, 10 parents and three children of clients experiencing OCD and specifically examined how relatives of people with OCD experience stigma and discrimination in their lives. The authors found that that the disorder was perceived as stigma provoking and embarrassing; due to the fear of rejection, family members often concealed the illness from others. Consequently, research has found that not only do children have to cope with the difficulty of having a parent who has a mental illness (Angermeyer & Matschinger, 2005), but they may also need to manage the associated stigma from the community (Koschade & Lynd-Stevenson, 2011).

**Family Accommodation**

Families of individuals diagnosed with OCD often attempt to stop the rituals and/or participate in rituals to decrease their relative’s distress (Amir, Freshman, & Foa, 2000; Bloch, Lebowitz, Panza, & Su, 2012; Stewart et al., 2008; Storch et al., 2007). This notion is referred to as ‘family accommodation’ and approximately 70-88% of family members report engaging in this behaviour (Stewart et al., 2008; Storch et al., 2007). However, such accommodation inadvertently reinforces the individual’s fears that underlie rituals and maintains the OCD symptomology (Ferrao et al., 2006; Storch et al., 2007) and increases symptom severity (Merlo, Lehmkuhl, Geffken, & Storch, 2009).

Family members may involve themselves in the individual’s symptomology in a variety of different ways. Albert et al. (2010) interviewed 141 family members of clients with OCD, including 80 parents, 48 spouses, five adult children (18 years+) and eight siblings, to ascertain the manner in which family members accommodated their relative’s OCD over the previous month. Themes generated from interviews found that family members directly participated in the rituals, assisted the individual to complete their rituals, and/or changed their personal routine (e.g. leisure activities,
work agenda) to work around the individual’s symptoms (e.g. not inviting people to the family home). Similarly, Van Noppen and Steketee (2009) investigated family accommodation with adult clients who had a diagnosis of OCD and their adult relatives, including 20 partners and 14 parents. Interview results identified family accommodation as the largest contributor to predicting OCD symptom severity, with families marked by high levels of dysfunction, high levels of burden and rejecting attitudes towards the OCD sufferer.

**Research Focusing on The Experiences of Children Living with a Parent with OCD**

Parental mental illness is a well-established risk factor for children (Hay, 2004; Stallard et al., 2004), and there are certain quantitative studies that have explored the impact of parental OCD on this cohort. One factor known to adversely impact on children involves parenting interactions (Di Bartolo & Helt, 2007). Challacombe and Salkovskis (2009) investigated interaction styles between mother-child dyads. Questionnaires were administered to mothers experiencing OCD and panic disorder, and who had at least one child between 7 and 14 years of age and were compared to mothers not experiencing a mental illness. In observed interactions between mother-child dyads, mothers experiencing OCD and panic disorder were found to be less promoting of psychological autonomy and exhibited less warmth towards their children, than healthy/unaffected parents without OCD. Another similar study found that OCD-affected families scored significantly poorer on communication and general functioning factors, than families without an OCD parent (Black, Gaffney, Schlosser, & Gabel, 1998). At follow up periods, these children were more likely to suffer from a range of internalising disorders, including, depression, anxiety
disorders, experience social problems and broadly defined OCD symptoms, than children from other unaffected families (Black, Gaffney, Schlosser, & Gabel, 2003).

Only two studies have been located that present the lived experiences of children with a parent with OCD (Belman, 1999; Griffiths, Norris, Stallard, & Matthews, 2012). In a case study approach conducted in the UK, Belman (1999) interviewed five children aged between 15 and 25 years from one family, of which their mother had OCD. Griffiths et al. (2012) employed semi-structured interviews with 10 children between 13 to 19 years of age whose parent had OCD, also in the UK. Participants across both studies described the practical and emotional support they provided to their parents. They also described accommodating for their parents in a number of ways, such as providing reassurance and avoiding situations that were likely to trigger symptoms, (Belman, 1999; Griffiths et al., 2012). Additionally, participants described their methods of help as, comforting their distressed parent and avoiding certain behaviours or actions that might make their parent upset (Griffiths et al., 2012).

In regards to mother-child interactions, Belman (1999) found that the mother often used acts of manipulation, guilt, overprotection and restriction to avoid feared settings. As a result, children experienced high levels of frustration and anxiety. Griffiths et al. (2012) added to this when authors found that parental OCD provided various challenges for children, including issues with parental control and negotiating boundaries between themselves and their parent. Participants described that both their space and possessions were intruded upon by the parent, along with their freedom to make choices.

Lastly, participants in both of these interview-based studies expressed concerns about stigma and their own mental health. They were more open to discussion about
OCD when their parents were in control of their symptoms, and described feelings of frustration toward the lack of recognition regarding the difficulties they face (Belman, 1999; Griffiths et al., 2012). Many viewed OCD as a sensitive and embarrassing topic to address with others. As a result, participants reported that they kept the knowledge of their parents’ OCD a secret, and were very selective about whom they told (Griffiths et al., 2012). Participants felt that although they had accepted their parent’s illness, they recognised their own need for more support and felt additional information and support would be helpful. A common theme across several studies is participants’ concerns about their own mental health and more specifically that they might develop OCD themselves (Black et al., 2003, Griffiths et al., 2012; Stengler-Wenzke et al., 2004).

The previously mentioned research suggests that parental OCD can potentially lead to adverse consequences for children in social relationships, school, leisure, family life and relationships (Belman, 1999; Black et al., 1998; Black et al., 2003; Griffiths et al., 2012). Two studies (Black et al., 1998; Black et al., 2003) employed a mixed method approach, including participant self-reports and brief narratives rather than in depth interviews to capture the voices of these children. Further, both studies were designed to identify pre-morbid signs of OCD as a guide for treating clinicians. Only two studies in the aforementioned literature (e.g. Belman, 1999; Griffiths et al., 2012) have explored the child’s individual, subjective experiences of having a parent who has OCD. However, both studies were conducted in the UK and participants were recruited from a clinical setting via their parents, who were provided with mental health services. How other young people whose parents are not currently in treatment manage their parents OCD has not been ascertained. Identifying participants drawn from the community rather than via parents attending treatment centres might
assist in understanding how parental OCD may impact on children in different ways. For example, parents who are receiving treatment for their OCD might manage family life differently than those who are not receiving treatment, and their children might also experience these differences.

Thus, given the limited research in this area, this research will examine the experiences of those who grew up with a parent experiencing OCD, but this time drawn from the community rather than via parents attending treatment centres. This allows for claims to be made about the validity of the two previous qualitative studies, which might then be applicable in more than one context, especially outside of treatment settings. Moreover, adult children have the language development and opportunity for reflection (given their maturity), to provide an in-depth retrospective view of what it is like to live in these families, that young people who are presently immersed in these families, may not. The information collected from these adult children may provide valuable insight to inform service delivery and policy, and will assist in providing appropriate support to children and families with parents who have OCD.

**Research Aim**

The current study aimed to use a qualitative methodology to explore the subjective experience of being an adult child of a parent with OCD, by obtaining retrospective accounts of their experiences during childhood/adolescence, whilst living in these families. An exploratory approach was adopted in which themes were identified, sought from participants rather than predetermined hypotheses (Reupert & Maybery, 2009).

**Method**

An interpretive approach to data collection was employed in order to explore
and understand the lived experiences of adult children with a parent who has OCD, through their individual perceptions and experiences as interpreted by the researcher. Reflecting this explorative approach, in-depth, one-to-one, semi-structured interviews with young adults were employed as the method of data collection. A qualitative, interview framework is appropriate given participants’ potential vulnerability and the need to discuss their experiences in a reflective manner.

**Participants**

Eight adults were recruited from social media and a community based agency to participate in the present study. It is important to note that differently to other studies, participants recruited from the agency were clients of the service and not recruited via their parents, who were receiving mental health services by the agency. All participants were between the ages of 19-46 years and had a parent who had been diagnosed with or demonstrated OCD symptoms. Of the eight adults, the mean age was 29 years ($SD = 8.64$). Six adults had a parent diagnosis of OCD, and two participants had a parent presenting with OCD symptoms, but had not received a formal diagnosis. Four of the eight parents were also diagnosed with a secondary mental illness. All participants but one lived in Australia, with one participant residing in the United States of America. Two of the eight adults were currently residing with their parent. See Table 1 for participant demographics. Two of the eight participants were siblings.
Table 1

*Participant Demographics*

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Number of Participants</th>
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<tbody>
<tr>
<td>Age range</td>
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<tr>
<td>18-23</td>
<td>2</td>
</tr>
<tr>
<td>24-29</td>
<td>4</td>
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<tr>
<td>30-35</td>
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</tr>
<tr>
<td>36-41</td>
<td>1</td>
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<td>42-47</td>
<td>1</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
</tr>
<tr>
<td>Gender of Parent with OCD</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
</tr>
<tr>
<td>Parents’ Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Obsessive Compulsive Disorder (diagnosed)</td>
<td>6</td>
</tr>
<tr>
<td>Obsessive Compulsive Disorder (undiagnosed)</td>
<td>2</td>
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<tr>
<td>Parents’ Secondary Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
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</tr>
<tr>
<td>Trichotillomania</td>
<td>1</td>
</tr>
<tr>
<td>Depression/Anxiety</td>
<td>1</td>
</tr>
<tr>
<td>Generalised Anxiety Disorder/Agoraphobia</td>
<td>1</td>
</tr>
<tr>
<td>Participants’ Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
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<tr>
<td>Co-morbid Generalised Anxiety Disorder/Depression</td>
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</tr>
<tr>
<td>Depression (previous not current diagnosis)</td>
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<td>Co-morbid Obsessive Compulsive Disorder/Depression/Anxiety</td>
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<tr>
<td>Parents’ Currently Engaged with Treatment Services</td>
<td></td>
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<tr>
<td>Psychiatrist</td>
<td>1</td>
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<td>Psychologist/Psychiatrist</td>
<td>1</td>
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</tbody>
</table>
Recruitment Procedure

Once ethics approval was granted from Monash University Human Research Ethics Committee (MUHREC) (see Appendix D), prospective participants were invited to participate in the study. Participants were recruited through:

1) social networking sites such as Facebook and online advertisements. Websites included the National Children of Parents with a Mental Illness Initiative (COPMI), Anxiety Disorders Association of Victoria (ADAVIC) and the Anxiety Recovery Centre Victoria (ARCVIC) (see Appendix F).

2) advertisements were provided to peer support programs offered across Victoria for individuals whose parent have OCD, via the peer support group facilitator at ARCVIC (see Appendix F).

3) a seven-day newspaper advertisement was placed in the Leader Community newspaper (see Appendix G).

4) advertisements seeking individuals whose parent have OCD were provided to the Melbourne Clinic in Richmond, with the permission of Professor Don Jefferys, a Clinical and Counselling Psychologist (see Appendix E).

Criteria for inclusion included males or females who were over 12 years of age, and had a parent who had been diagnosed with or demonstrated symptoms of OCD. It needs to be noted that while recruitment targeted children over 12 years of age, those who elected to participate were all over 18 years of age. Parental consent was required for those under 18 years. The criteria were purposefully broad given the exploratory nature of the study. All potential participants were invited to contact the researcher for more information regarding the study (see Appendix B and C). Prior to
ADULT CHILDREN WHO HAVE A PARENT WITH OCD

interviews, all participants received an explanatory statement (see Appendix B) and were required to sign a consent form prior to participation (see Appendix C). As all of the participants were over the age of 18 years, parental consent was not required.

**Interview Procedure**

Semi-structured interviews were conducted either face-to-face or via telephone by the researcher, at a pre-arranged negotiated time (see Appendix A). The interview schedule was guided by the literature review and the research intentions of the project but was flexible to explore the subjective experiences of participants. The schedule included a series of questions relating to family circumstances, including the participants’ relationship with their parent, how they coped (or did not cope) living with parental mental illness and sources of support they drew on or wanted to draw on, as a young person. Such as, “How was school life for you?” and “How did you first learn about your parent’s mental illness?” Interviews ranged from 30-60 minutes in duration and with participant consent were all digitally voice recorded, to allow the researcher to have accurate recordings of the interview data in a usable format. The researcher sent the participant the transcript and they were given the opportunity to modify or add to any responses, in a process referred to as ‘respondent validation’ (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008). Analysis commenced once participant feedback had been incorporated.

**Data Analysis**

Data analysis drew on 78 pages of interview data. Analysis was framed using Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2004). IPA is a qualitative approach that aims to identify themes within the participant’s subjective experience and was completed in two parts; (1) intra-interview analysis and (2) across-interview analysis. Firstly, individual interviews were analysed using a process
described by Burnard and colleagues (2008), in which key themes were identified, then organised and refined in each individual transcript. Analysis was then conducted across transcripts, and common and/or pertinent themes were identified. Next, the researcher reviewed the notes and broader patterns in the data, and identified categories, which overlapped or were very similar. This shorter list formed the final category system that was used to present the findings from the interviews Burnard, Gill, Stewart, Treasure, & Chadwick, 2008). Another researcher reviewed all of the data independently, and any discrepancies were discussed and resolved (Barbour, 2001).

**Results**

Overall, participants were responsive to the topic and open and willing to share their experiences of having a parent with OCD. While they each had their own unique story to tell, some common experiences were identified, as summarised in Table 2 and further elaborated below. Participant quotes are distinguished by gender (M= male, F= female) and number (Participant 1 = 1).
Table 2

Identified Themes and Sub Themes

<table>
<thead>
<tr>
<th>Main Themes/Sub Themes</th>
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<tr>
<td><strong>Impact on Children</strong></td>
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<tr>
<td>• Highly controlled home environment- ‘a lot of arguments’</td>
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<tr>
<td>• Effect on schooling</td>
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<tr>
<td>• Social isolation</td>
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<tr>
<td>• Parentification of children</td>
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<td>• ‘Followed all of the rules’</td>
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<td>• Positive impact- ‘it makes you more open-minded’</td>
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**Participants’ Perceptions of Parental Rearing**

• ‘It would override what she wanted to do’
• Relationship with their parent- ‘it’s really difficult’
• Empathy for their parent- ‘it’s not your parent’s fault’
• Distancing oneself and negotiating boundaries

**Secrecy**

**Treatment Services**

**Impact on Children**

According to M1, F1, F2, F3, F5, F6 and F7, their parent’s OCD impacted on them in several, and usually adverse ways, as outlined below. In sum, these included a highly controlled home environment characterised by frequent arguments, social isolation, a negative impact on schooling, having to assume aspects of the parenting role and participating in their parent’s rituals to decrease parental distress. It is also important to note that one participant (F4) described her parents’ OCD to have little if any impact on her and her family life, given that his obsessions were related to his working environment. She commented, “...it’s [OCD] got to do with his work and that he needs everything to be done perfectly, that’s about it really.”.

**Highly controlled home environment- ‘a lot of arguments’**.

M1, F1, F2, F3 and F7 described a controlled home environment fuelled by
ADULT CHILDREN WHO HAVE A PARENT WITH OCD

the parent’s need to complete their OCD rituals, resulting in tension and family arguments. F1, F2 and F7 described the specific rules they were required to follow to accommodate for their parent’s OCD. F1 said, “...whenever we came inside from outside we had to go into the shower straight away before touching anything”. Similarly, F7 reported, “...she [mother] tapes notes that say, ‘do not use the kitchen’, ‘do not use the bathroom’...we don’t watch our T.V, we are not allowed to use the computer”.

This controlling environment lead to family arguments. F3 indicated, “...[there was] constant screaming in the house all of the time”. The controlling nature of home life was the source of these arguments, as the same participant (F3) described “...her [mother’s] obsessions took over to the point where I couldn’t have any freedom of self-expression”. M1 said his mother “...would use her authority ...like a teacher and a bad student, like do this or else”. Similarly, F7 reported, “...[the parent is] a very, very mean person when it comes to things not being absolutely perfect and very unforgiving and very judgemental”.

Arguments also occurred between other family members, as F2 described, “...my mum and dad can argue a lot because my mum seems to expect a lot from my dad. She expects him to know the way that she wants things done”.

Effect on schooling.

F1, F2, F3, F5 and F7 reported that their parent’s mental illness impacted on their schooling, with F5 describing her high school experience as, “...completely disorganised, forgetting things, forgetting homework, almost failing subjects”. F1, F2 and F3 noted that their parents’ OCD had an adverse impact being able to complete homework; “...It just pushed me to the edge, homework was too hard and I didn’t pass year 11” (F1), “…the house was too hectic with her [mother]” (F3) and
“...homework was dirty and it was something we were bringing into the house...if I heard her coming, I would throw the bed sheets over my homework. It’s like I was doing something wrong” (F2).

F1, F5 and F7 described erratic school attendance, for example,

...if I said to her in the morning that I was scared about something at school that day or whatever, then she would say, oh you can just stay home... It’s because she thought that was great for me not to go out of the house, [and] then have to clean everything and do the whole OCD thing (F1).

F5 said that she couldn’t rely on her mother for transportation to school stating,

“...home life was very unpredictable...was she going to take me to the station or not? Every morning it was like the lotto”.

Social isolation.

F1, F2, F5 and F7 reported that their parent’s illness limited their ability to have friends visit the house and if they did have friends over, it was a highly anxious environment for them. For example, one participant (F5) said:

...when I was a teenager and having friends stay over night, I would know they would be in the bathroom and would know that they might put their make up on down on the sink without putting the towel underneath it... she would walk past and give the look and it was my responsibility to let them know.

Similarly, F1, F2, F5 and F7 described not being able to bring peers home, for example, “...I couldn’t have anyone over, so I couldn’t have the same relationships that other kids had” (F2). Three participants highlighted having to make excuses to their friends as to why they could not go to their house.

...I would be 7 or 8 having to say, ‘oh no we can’t go to my house because ah, nah, can’t we just stay here and play something different?’ It was me having to deal with her anxiety (F5).

F2 further explained how not being able to bring peers home had a negative impact on her peer relationships, “...they took that and used it against me...”.
described feeling worried about the reaction of her friends to her parent’s behaviour, and referred to this as “walking on eggshells” as further elaborated here:

...on the very few occasions I was allowed to bring a friend over, my mum didn’t put on that outside happy face and I was mortified of some of the things that she would say in front of my friends. I would pretty much be walking on eggshells.

F5 described being isolated from other children at a younger age, stating, “...I had never been to a playground, never gone down a slide, never climbed anything, never hung out with other children...I got to school it was just absolutely daunting”.

**Parentification of children.**

F5, F6 and F7 described assuming extra responsibilities at a young age, often undertaking household chores and/or looking after themselves and their siblings; “...at some stages she was relatively unable to parent. She was a person who just used to lie in bed all day... so a lot of the household chores fell to her children” (F6).

Similarly, F7 reported, “[I] would cook from about 8-9 years old...I guess I just took on the role by myself because I was the oldest”.

F5 described having to make independent decisions from a young age and not being able to rely on her parent; “…I was left a lot to my own devices” and “…there was never any, have you got any homework? When’s it due?”

‘Followed all of the rules’.

MI, F1, F2, F3, F5 and F7 described engaging in their parent’s OCD rituals in order to decrease their parent’s distress. F2 commented, “…most of my life I spent living as an OCD patient...we have been doing the rituals as well and is definitely still present, otherwise she would get too anxious...”. Similarly, F6 reported:

...it was just something that was happening and we had to get things done. I remember mum used to complain that we left dirty dishes in the sink and that we didn’t wash them as soon as we used them. She would say that it was so unhealthy, that it was making everyone in the family sick.
F7 indicated that she didn’t have any choice but participate in her parent’s rituals:

...it made us afraid of [parent’s reaction] everything that was out of place. We were all so [anxious] all of the time to make sure that everything was perfect, all of the time, we never let our guard down or relaxed. I was the inside person, so laundry, dusting, vacuuming, toilets that kind of thing.

F3 highlighted a different form of accommodation, which involved not being given any responsibilities as a child. She stated, “...my mum did everything for me, she didn’t make me make my own bed or wash the dishes or anything, because I never had the chance”.

Positive impact- ‘it makes you more open-minded’.

M1, F1, F2, F5, F6 and F7 described a number of positive characteristics associated with having a parent with OCD, including resilience, empathy and independence. For example, “...the best thing that it did for me was teach me to have empathy for others” (F7) and “...it has made me resilient and independent” (F5). F6 described having “...more sympathy for others who have mental illness, because my mother and myself do [OCD and Depression]” and also stated, “you are more alert to the complexities of human experience”.

F1, F2, F4 and F7 also reported currently studying/working in psychology, social work and youth welfare fields.

Participants’ Perceptions of Parental Rearing

F1, F2, F3, F5, F6 and F7 described the parenting style they had been exposed to as children, in terms of the difficulty their parents’ often had managing their OCD. Other related themes were the impact of the parent’s OCD on the parent-child relationship and the need for negotiating boundaries with their parent.

‘It would override what she wanted to do’.
F1, F2, F3, F5, F6 and F7 recognised a tension between their parents’ ability to care and how their parents managed their OCD symptoms. F7 commented, “…[the parent] was verbally abusive because of her OCD... and there was never any nurturing that I recall”. F1 noted: “…she would want to act a certain way and obviously she would want us to do well at school, whereas she couldn’t help but not be comfortable enough to let us do homework in the house”.

F5 described the uncertainty she felt as she often could not rely on her mother, describing her as, “…often at times absolutely paralysed by anxiety” and her mother’s behaviour as “… Extremes. In the chaos times, she can’t do anything”.

**Relationship with their parent- ‘it’s really difficult’**.

Past and current relationships with the OCD-affected parent were another repeated theme. F1, F2, F3 and F7 described finding it difficult to have a good relationship with their parent during their adolescence years. F1 stated, “… I was completely against everything that she did, so I would rebel against all of the stuff, just to make her kind of take the opposite approach to what my dad had been doing, letting her do everything”.

F1, F2, F5 and F7 acknowledged that their relationship with their parent was more difficult whilst they were living with their parent and found their relationships improved, once residing elsewhere. For example, “…I couldn’t deal with it anymore and I got sick of her. So, I finished high school and then moved out and it [the relationship] was a little bit better” (F2) and “…I don’t live there anymore, so it’s more of a secondary thing now, that I can completely shut off from” (F5). F1 reported, “…things are much more calmer and the relationship is much more better when you’re living way from them”.
F3, F5, F6 and F7 indicated that their parents’ OCD still adversely impacted the relationship with their parent. F3 stated, “...I don’t have that much contact with her that I would like to have, if she had some of these things addressed I would love to spend more time with her” and F7 said “...it has affected my health and the health of my kids...I have realised how venomous and toxic she can be”. However, the same participant hoped that this relationship would change, at least from her perspective, “...and I’m hoping that I will come back to a place of compassion”.

M1, F1, F2, F4 and F5 stated that they now have a close relationship with their parent, “...I have a good relationship with her now” (F2), yet one participant (F5) highlighted the complexity around these relationships describing it as, “...bordering on dependency”.

Empathy for their parent- ‘it’s not your parent’s fault’. F1, F3, F6 and F7 stressed that their parents were not responsible for their behaviour, given they had a mental illness. Comments included, “...it’s not your parent’s fault as well, they are sick” (F6), “...it’s not in my opinion the intent of a parent to cause damage to their child... there is a lot of pain from both sides” (F7), and “...she is a good person, there is genuine love but she can’t express it properly” (F3). These statements appear to demonstrate that they have an understanding of the impact of the illness on their parent.

Distancing oneself and negotiating boundaries.

The need to establish clear boundaries between themselves and their parent was noted by F3, F5 and F6. For example, “I have to actively disengage as I find her worries are worrying for me” (F6) and “...as an adult, [you] don’t let it consume your own life... [instead] work out where the boundaries are” (F5).
F3, F5, F6 and F7 used the word “distancing” when describing these boundaries. For example, “I have to distance myself, if not, it really affects my mental health in a negative way” (F3), “...distance yourself...you can get too enmeshed in it all by yourself” (F6) and “...distancing myself and getting the boundaries sorted and identifying what is normal behaviour and what isn’t.... when you are bought up in a house where everything is over the top, it is hard to pull it back” (F5).

At the same time, F5 and F7 described the guilt that they felt when disengaging from their parent, with F7 stating, “I loved my mum and couldn’t stand to be around her, and so I knew that I had that, so I had a lot of guilt”.

Secrecy

F5 and F7 conveyed that whilst growing up they were not allowed to discuss their experiences with others outside of the family home:

...my friends wouldn’t have even known what was going on for me, because that was something that was so instilled in me that we just don’t talk about it (F5).

F7 summarised this element of secrecy, by observing her mother’s behaviour inside and outside of the family home:

...I can remember particularly when she would be taking to neighbours and wanting to hug my mum and go up to her because she was talking so nice, I would kind of get shooed away and told later that I interrupted, but it was like her whole energy changed when she was outside versus when she was inside.

In comparison, F1 and F2 reported that their family openly spoke about their parent’s OCD, with the parent (with OCD) initiating the conversation. F1 commented: “...I never learnt that it’s something to be quiet about and hide. I think it’s a good way, that it doesn’t create fear around the subject of talking about it”. Yet, F2 reported that although it was generally openly spoken about amongst her family, there were occasions when her parent would ask her to conceal some of her behaviours from other family members. For example:
... [Her father’s] friend rubbed my head in an affectionate way, like a pat, and I went inside and my mum wiped my head down with [a] Pine O Cleen wipe kind of thing and would say, ‘don’t tell your father, don’t tell your father’.

F4 was 19 years of age when she talked to her father for the first time about his OCD. He subsequently acknowledged that he had a diagnosis of OCD and was open to discussion about it. Prior to this she was uncertain about whether he was a perfectionist or did have the illness. She initiated this conversation, after being educated about OCD whilst studying a Psychology degree at university.

Two participants indicated that their parents had not addressed their OCD symptomology, did not engage in family conversations about their symptoms nor had they sought professional help. M1 stated that his mother had just been diagnosed within the last six months, and noticed she had difficulty engaging in conversations about the illness, stating, ‘...she did tell me but [she] did not really want to talk about it, which is really weird for my mum because she is really open about everything’.

Treatment Services

F1 and F2 described accessing treatment services during adolescence; F2 saw a psychologist for additional support in year 12 and F1 saw a psychiatrist for depression. Looking back, they felt the services were inadequate to address their needs as a child/adolescent living with parental mental illness. They described therapy sessions as, ‘...never really getting to my actual emotions’ (F1) and ‘...it was talking about her [parent] more and wasn’t really getting to more things that I need to talk about’ (F2). F1 also stated that, ‘...that sort of tainted my view of seeking that sort of support’.

F1, F2 and F7 indicated the need for peer group support as a child/adolescent, with one comment being, ‘...having people who have been through it and taking the shame away from it and normalising it a bit more would be really good’ (F7). Many
suggested that targeted intervention would have been useful, with F3 commenting, “...if I started psychological counselling a lot earlier I don’t think I would have ended up with this anxiety disorder and depression to this extent”. F1 and F2 reported that while the school knew about their family circumstances, it would have been useful if staff had referred and encouraged them (as a child) to see the school counselling service. F1 reported: “...I was never really encouraged to build a relationship with the support workers” and “...you’re experiencing it every day, it never seems like there is one day in particular that you need to go and speak to someone”.

F6 highlighted that whilst residing with her parent, she was unaware of the availability of welfare and financial assistance.

...They’re available, and that might not be common knowledge, they can be scary and difficult to access and make use of it as you’re in an emotionally vulnerable state, and earlier intervention it seems to me would save money in the longer term, for the community at large.

F3, F6 and, F7 reported being currently engaged with treatment services for their own mental health issues.

**Discussion**

Parental OCD presented challenges for the participants, as can be demonstrated from the interviews. Some of the themes identified here overlap with other literature on children living with a parent with a mental illness (across diagnostic groups) and some of the findings are consistent with specific research on parental OCD. Findings which augmented with research across diagnostic groups included, parentification of children (Foster, 2010), the need for more support and information during their childhood and adolescent years (Cogan et al., 2005; Falkov, 1998; Polkki et al., 2004; Stallard et al., 2004), and the secrecy surrounding their parent’s OCD (Griffiths et al., 2012; Kroll, 2004; Montgomery et al., 2006; Stallard et al., 2004; Stitt & Reupert, 2013). Some themes however, appear to be specific to
ADULT CHILDREN WHO HAVE A PARENT WITH OCD

parental OCD, especially around the need to support parents in rituals, a finding that mirrors OCD specific research (Albert et al., 2010; Van Noppen & Steketee, 2009).

In terms of the participant’s own mental health, six out of eight participants had been diagnosed with at least one disorder themselves. This is consistent with numerous studies, suggesting that individuals who have a parent with a mental illness (diagnosis not specified) are at a higher risk of developing a disorder themselves (Clarke et al., 2001; Lieb et al., 2002; Orel et al., 2003; Weissman et al., 2006). Therefore, there appears to be an inter-generational impact of mental illness in families, highlighting the need for service providers to identify the parenting status of clients and acknowledge the impact mental illness has on families, particularly the children.

A significant theme found in this study was the parentification of children who have a parent with OCD, which aligned to research for children across parental diagnostic groups (Aldridge, 2006; Aldridge & Becker, 2003; Foster, 2010; Fudge & Mason, 2004; Hayman, 2009) as well as other OCD specific research (Belman, 1999; Griffiths et al., 2012). Given that the parentification of children has the potential to adversely affect a young person’s wellbeing and future relationships (Atkin, 1992; Bourassa & Allen, 2010), it is important for treatment strategies to address this potentially common theme among all children who have a parent with a range of mental illness.

The impact that parental OCD had on a young person’s education during their adolescence was raised by several participants in this study. Participants suggested that parental OCD affected their school attendance, similar to Dearden and Becker’s (1998) study of 2,303 young carers of parents living with mental illness or disability. A specific issue around homework was highlighted in this study, with two
participants’ parents identifying homework as, ‘dirty’ and would not allow it into the house, an issue that appears to be particularly pertinent to their parents’ OCD.

Another important finding was the relationship between parental OCD and participants’ social relationships, with participants reporting restricted opportunities for social networking and for developing peer relationships. In particular, many participants were not allowed to have friends visit the family home and constantly had to make excuses to their friends as to why they could not visit. If they did have friends over, participants were often worried that their parents’ obsessions or rituals would make their friends feel uncomfortable, an experience one participant described as “walking on eggshells”. This restriction on social interactions is similar to research conducted by Stallard et al. (2004) on 26 children who have a parent with a range of mental illness, which found that parents expressed concerns about stigma regarding their own mental health issues, which impacted on children’s ability to have friends over.

Moreover, an interview-based study conducted by Griffiths et al. (2012) with children whose parent had OCD, reported children feeling restricted by their parents illness, and often not allowed to have friends visit because they would make the house ‘dirty’. Findings suggest that parental OCD may result in a similar tension on social relationships for children with parental mental illness. Here, parents did not want visitors in the house due to the obsessive nature of the disorder, with rigid rules, and subsequently restricted their child’s social life. Peers can be a particularly important form of social and emotional support, and can help to enhance one another’s self-esteem, and contribute to an individual’s developing sense of identity (Berndt & Hestenes, 1996). Accordingly, treatment approaches and services may need to encourage peer relationships for all children who have a parent with a mental illness,
across diagnostic groups. Peer support programs might provide this form of peer interaction (see for example, CHAMPS; Goodyear, Cuff, Maybery, & Reupert, 2009; PATS; Hargreaves, Bond, O'Brien, Forer, & Davies, 2008; SMILES; Pitman & Matthey, 2004).

Participants emphasised that they often directly participated in their parent’s OCD rituals, and/or in other ways appeased or managed their parent’s symptoms in order to decrease their parent’s distress. Additionally, one participant expressed anxiety and fear around how their parent would react if they did not comply and complete their rituals. This finding is consistent with previous research, which found that family members accommodated their relative’s OCD, by participating in their relative’s rituals, providing reassurance, and adjusting their routine (Albert et al., 2010; Calvocoressi et al., 1995; Van Noppen & Steketee, 2009). Thus, it is essential that clinicians include parenting protocols in the treatment regime for such individuals and also work with all family members, including children when treating a client with OCD.

Participants particularly emphasised the impact that parental OCD can have on the child-parent relationship. Many participants suggested that their parents had difficulty managing their OCD, which often compromised what they wanted to do for their children. Interestingly, this seemed to coincide with participants’ display of genuine empathy for their parents’ situation and illness as adults. Yet this empathic understanding was more difficult to attain during childhood/adolescence and while residing with their parent. Similarly, participants suggested that whilst growing up they often had trouble understanding their parents’ difficulties and so were often angry and anxious. Given the impact parental OCD has on interfamilial relationships, there is a need for service providers to not only intervene with the affected parent but
also their families, particularly their children and consider their family in their treatment plan.

This study provides insight into the child-parent relationship when parental OCD is present, with participants reporting the importance of maintaining boundaries with their parent. This research aligned to previous research on parental mental illness, across diagnostics groups (Mordoch & Hall, 2008) and research specific to OCD (Griffiths et al., 2012), which found that children reported issues with parental control and needed to maintain distance and define boundaries with their parent. This suggests that this issue may not be specific to parental OCD but may occur in families where a parent has various mental illnesses. Here, adult children also stressed the importance of not taking responsibility for their parent’s behavior and the need for boundaries. It appears that establishing boundaries in dysfunctional families, including families with parental mental illness, is an essential self-care behavior for these young people.

Some (but not all) described the secrecy about the parents’ OCD in families, as maintained by the parent. This was consistent with other research across parental diagnoses (Kroll, 2004; Montgomery et al., 2006; Stallard et al., 2004; Stitt & Reupert, 2013) as well as for relatives and children of individuals with OCD (Griffiths et al., 2012; Stengler-Wenzke et al., 2004). Conversely, participants from families who were open to discussion about parental OCD reported being able to disclose their situation with selected close friends and seeking psychological support. The importance of open communication is further underscored by these participants, with one suggesting that these discussions did not “... create fear around the subject”. This suggests that treatment services should encourage and educate parents about how to engage in open communication about their mental illness with their children, at an
While participants were able to access appropriate supports as adults, the same was not found when they were younger and living at home. Here, two of the eight participants’ parents had not been diagnosed with OCD and an additional two of the eight had not been diagnosed until adulthood, so as children participants had not been identifiable by health or other welfare services. Treatment issues as young people were around access and a lack of recognition of family difficulties, which is consistent with research on parental mental illness across diagnostic groups (see for example, Cogan et al., 2005; Falkov, 1998; Knutsson-Medin et al., 2007; Polkki et al., 2004; Stallard et al., 2004). Moreover, similar to previous research (Blanch et al., 1994; Fudge & Mason, 2004) participants indicated that mental health professionals working with their parent did not offer them acknowledge their needs as children.

Additionally, as well as being unaware of the services available, children may have also questioned whether others would understand their circumstances. For example, two participants described having unhelpful experiences with professionals during adolescence, which negatively impacted on their view of treatment services. As a result, participants described family members, including siblings and their ‘well’ parent, along with peers with whom they had strong relationships with, as their main source of support whilst growing up. Participants further highlighted the importance of this informal support with one stating, “I held my friends very, very close, because I kind of needed that support, that time away from home life”. These findings accentuate the significance of both formal support from treatment services and informal support from family members, peers and school staff being provided to children living with parental mental illness.

Although parental OCD has a potentially profound negative impact on
children (Black et al., 1988, Black et al., 2003; Challacombe & Salkovskis, 2009), some participants highlighted the potential positive facets of having a parent with this illness. Here, participants expressed the desire to maintain a good relationship with the parent despite its challenges, which was augmented by past research also investigating parental OCD, which found 13-19 year olds also had a desire to maintain a good relationship with their parent (Griffiths et al., 2012). Participants also acknowledged some personal positive qualities that have come from having a parent with OCD such as, being more open-minded, independent and empathic of others. Here participants displayed genuine empathy for their parent’s situation and illness as adults yet this mindset/viewpoint was more difficult to attain during childhood/adolescence whilst residing with their parent.

**Limitations of the Present Study**

A number of factors limit the interpretations that can be drawn from this research. In particular, there are characteristics of the sample that may limit the generalisability of findings, including a small sample size, two parents did not have an official diagnosis of OCD and the majority of parents had secondary diagnosis of various mood disorders. However, it needs to be noted the qualitative research does not claim to be generalisable (Polit & Beck, 2010). Notwithstanding the potential problems related to the reliability of memory and self-report, the retrospective design of the project, which relied on participants’ memories of events and treatment, was able to provide rich, retrospective accounts of growing up in these families, that young people who are presently immersed in these families may not have been able to articulate. Subsequent research needs to look at a broader number of adult and younger offspring, with parents who have a formal diagnosis of OCD.

**Future Research Directions, Implications and Conclusions**
The role of school staff is underscored in this study, and in particular the need for staff to be proactive by identifying these young people, providing them with information about mental health and appropriate support, including appropriate referrals as required. Additionally, education about mental health and available support should be included in the curriculum and through the education system, this will be of particular help for those young people who are assuming a demanding caregiving role (Fudge & Mason, 2004).

This study also highlighted the value of peer support for those growing up in families where a parent has OCD. There are some peer support programs available (CHAMPS; Goodyear et al., 2009; PATS; Hargreaves et al., 2008; SMILES; Pitman & Matthey, 2004) and these need to be promoted and made readily available to young people whose parents have a mental illness, across diagnostic groups. These groups aim to educate participants about mental illness, enhance peer relationships, and promote the adaptive coping skills of these young people (e.g. negotiating boundaries with parent). Importantly, the programs aim to normalise their experiences of parental mental illness, by being with others experiencing similar issues.

As mentioned above, there appears to be an inter-generational impact of mental illness in families. Therefore service providers should first identify their clients who are parents and then consider addressing the issue of parental OCD with the whole family not only their client, as children may benefit from being integrated in the treatment plan. Treatment may involve family as well as individual counselling and appropriate referrals for more specific concerns (Foster, O’Brien, & Korhonen, 2012). Family therapy might provide parents with an opportunity to consider how their illness impacts on their children and allow for any tensions or misunderstandings to be addressed whilst young people are residing with their parents. Furthermore
treatment services should encourage and educate parents about how to engage in open communication about their mental illness with their children and ensure that children be provided with age appropriate psycho-education in regards to their parents’ mental illness and mental illness in general.

In summary, the present study highlighted that having a parent with OCD can result in numerous challenges for children, as ascertained from adult accounts of their childhoods. The study aimed to explore and understand the present lived experiences of adults with a parent who has OCD. Using retrospective accounts of adults, several concerns regarding the impact of parental OCD on children were highlighted, such as a highly controlled environment, participating in family accommodation, difficulties in the relationship with the parent with OCD such as secrecy around their parent’s diagnosis and minimal access to treatment services during adolescence.
References


with schizophrenia: Trend analysis based on data from two population surveys in Germany. *British Journal of Psychiatry, 186*, 331-334. doi: 10.1192/bjp.186.4.331


NJ: Lawrence Erlbaum.


Bourassa, K., & Allen, J. (2010). *Compulsive caregiving: Emotional parentification*


Foster, K. (2010). ‘You’d think this roller coaster was never going to stop’: Experiences of adult children of parents with serious mental illness. *Journal of Clinical Nursing, 19*(21-22), 3143-3151. doi:10.1111/j.1365-2702.2010.03293.x


ADULT CHILDREN WHO HAVE A PARENT WITH OCD


Appendix A: Schedule for the Adult Semi-structured Interviews

Thank you for agreeing to participate in this interview.

The aim of this interview is to gain a better understanding of the experiences of having a parent with a mental illness and how it impacts your life and your family life. This information will help develop programs for people living in families such as yours and will help researchers gain a greater understanding of what it is like for people who have a parent with a mental illness.

I just need to check that you have received and read the information statement that I sent you?

I also need to let you know that your participation in this research is entirely your choice and even though you are participating you can withdraw from the project at any time without giving a reason, and it’s also entirely up to you whether you want to answer all of my questions. So if there’s a question that you’d rather not answer, you can just let me know and we’ll move straight on to the next question.

Finally, all the data that I collect from you will be treated in a confidential manner, so I’ll be removing all information that identifies you from the transcript, and you can check that yourself because you’ll be receiving a copy of the transcript before I do any analysis on it. So you can make any changes to it.

Any questions so far?

Even though I understand that you have provided consent to having this interview being taped, I would like to ask you again, whether you are okay with having the interview recorded?  (If yes, switch on tape recorder)

Before we begin I’ll just have to collect some demographic information from you.

1. How old are you?
2. What is your parent’s mental illness?
3. Have you been diagnosed with any disorders yourself?
4. Tell me about your family?
5. Tell me about your father/mother?
6. What do you know of your father/mother’s mental illness? (Take note of how the young adult labels the mental illness).
7. What are your thoughts about your father/mother’s mental illness? Does it affect you in any way? If so, how? (Tell me more. Can you give an example?)
8. Do you think your father/mother’s mental illness affects her? Do you think it affects him/her parenting in any way? If so, then can you give me some examples?
9. How does it affect the relationship you have with him/her? Or the relationship she has with your mother/father or other siblings?

10. How was school life for you? Did your father/mother’s mental illness affect you in any way with your schooling? Or with your current schooling?

11. Do your friends know about your mother’s mental illness? If so, all your friends or only some? How did they find out? What do they think of this? And how does this affect your relationship with them, if at all?

12. How did you learn about your parent’s mental illness? How old were you? Did someone tell you? If so, who? If they did, how did they talk to you about this? If no one, talked to you about this, how did you find out? How old were you? How would you want to find out about this? Do you want to know more about your father/mother’s mental illness? What additional information would you like to know?

13. What help or support do you get, if any? From whom? And how? And how do you find this? Is it helpful? Have you ever been offered help that you thought wasn’t helpful?

14. What other supports might you need? Could you access them? What might stop you from getting these sorts of supports?

15. How did you find a way to manage all of these situations so well? Do you talk to anyone? Who? What about?

16. As you’re an adult now, you may have developed some useful strategies or some perspectives or opinions on how to cope and manage with having a parent who has a mental illness. Are there any strategies or perspectives that have helped you cope?

17. What support do you think your parent needs, if any?

18. What support do you think your siblings need if any?

19. What would you tell others who are in a similar situation as you, who also have a parent with a mental illness?

20. What have you found to be helpful?

21. Is there anything else that you could think of that would help you most right now?

22. What supports or assistance does your family get or use in relation to your parent’s illness?

23. Is there anything that worries you about the future?
24. What are some good things about having a father/mother with a mental illness, if any?

25. Is there anything else you think is important for me to know about?
Appendix B: Explanatory Statement

The experience of parents and children where a parent has a mental illness.

EXPLANATORY LETTER:
FOR ADULTS WHOSE PARENT HAS OBSESSIVE COMPULSIVE DISORDER

This sheet is for you to keep.

Our names are Krystel Goodman and Amy Ross and we are doing a project with Dr Andrea Reupert from Monash University.

We are seeking your permission to take part in this research, which is exploring the experiences of people who have a parent with Obsessive Compulsive Disorder.

We are trying to find out your experiences of having a parent with a mental illness and how it impacts your life and your family life. This information will help develop programs for people living in families such as yours and will help researchers gain a greater understanding of what it is like for people who have a parent with a mental illness.

If you decide to take part, you will be required to participate in either a face-to-face or telephone interview including questions about mental illness and your family life. The interview will last approximately 30-60 minutes and will be audiotaped unless you prefer that it wasn’t, you can let the research team know.

You do not have to take part in this research; it is entirely up to you. Even if you participate at the start you can change your mind and choose to withdraw later on. All you need to do is tell the interviewer and the interview will stop. You can also decide not to answer any questions if you are not comfortable or do not wish to do so.

The interview will be typed out and you will see a copy of this. You can decide to take information out if you want or add something. However, you will only have about two weeks to do this.

All interviews will only be read and listened to by members of the research team. Also, the information that you disclose will be used in reports and papers however, your first name, family name and any other personal information that could infer your identity will not be revealed. All information will be recorded on password-protected computers.

You might find it upsetting to talk about your family and your experiences. If this is the case the interviewer might arrange for you to talk to a counsellor. You might also want to contact a counsellor yourself. Here is a list of agencies that might help you:

Lifeline 13 11 14
If you would like to know more about what we found at the end of the project please contact Andrea at andrea.reupert@monash.edu.au

<table>
<thead>
<tr>
<th>If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:</th>
<th>If you have a complaint concerning the manner in which this research is being conducted, please contact:</th>
</tr>
</thead>
</table>
| Dr Andrea Reupert  
Email: andrea.reupert@monash.edu | Executive Officer  
Monash University Human Research Ethics Committee (MUHREC)  
Building 3e Room 111  
Research Office  
Monash University VIC 3800  
Tel: +61 3 9905 2052  
Fax: +61 3 9905 3831  
Email: muhrec@monash.edu |

If you want to take part:

- You have to fill out Adult Involvement (aged 18 and over) Consent Form
- Email or send it back to us in the envelope provided

If you have any questions or worries please contact Andrea or one of the researchers listed below.

Thanks for taking the time to read this.

Kind regards,

Andrea Reupert  
Krystel Goodman  
Amy Ross
Appendix C: Consent Form (Adult Child)

The experience of parents and children where a parent has a mental illness

NOTE: This consent form will remain with the Monash University researcher for their records

I agree to take part in this project. I have had the project explained to me, and I have read the Explanatory Statement, which I keep for my records. I understand that agreeing to take part means that:

I will be interviewed over the telephone or face to face at a pre-arranged time. This interview will be about my experience of living with a parent who has a mental illness. The interview will last for approximately 30-60 minutes.

I agree to be interviewed by the researcher
☐ Yes ☐ No

I agree to allow the interview to be audio-taped
☐ Yes ☐ No

I understand that I don’t have to do this research unless I want to.

I can stop being a part of this research up to the point of viewing the typed notes of my interview.

I understand that the information that researchers get from the interview will not contain my name or my family name or any other information that is identifying.

I understand the information from the interview will be kept on pass word protected computers and destroyed after five years.

Participant’s name: ______________________________

Signature: ______________________________
Preferred contact details (phone and/or email):

___________________________________________________________________

___________________________________________________________________

Date: ________________________________
Appendix D: Ethics Approval from MUHREC

PLEASE NOTE: To ensure speedy turnaround time, this correspondence is being sent by email only. MUHREC will endeavour to copy all investigators on correspondence relating to this project, but it is the responsibility of the first-named investigator to ensure that their co-investigators are aware of the content of the correspondence.

Dear Researchers

Thank you for submitting a Request for Amendment to the above named project. This is to advise that the following amendments have been approved and the project can proceed according to your approval given on 5 March 2012:

Changes to Procedures
   · Changes to the proposed interview schedule

Changes to Recruitment
   · Inclusion criteria now includes adult children over the age of 18
   · Professor Don Jefferys will contact eligible participants to see if they are interested in the study – if they are adult children of parents with a mental illness, he will directly approach them without approaching the parent. For children under the age of 18, he will alert their parents to the study, for their own involvement as well as for the involvement of their children - please note that parents can be involved without their children being involved. If participants show interest in the study and/or want more information, he or she will be invited to contact the chief investigator via email or post.

Explanatory letters and consent forms (along with a stamped envelope) will be provided to eligible participants by Professor Don Jefferys.

Thank you for keeping the Committee informed.

Professor Ben Canny Chair,

MUHREC
Human Ethics Monash Research Office
Appendix E: Permission Letter from Professor Don Jeffery

Monash University
Building 3E, Room 111
Clayton Campus
CLAYTON VIC 3168

Dear Sir/Madam,

Re: Project Number: CF 11/3529-2011001872
Title of Project: "The experience of parents and children where a parent has a mental illness".
Chief Investigator: Andrea Reupert, Faculty of Education

I give permission for Krystel Goodman and Amy Ross to recruit children (12-18 years; with the permission of their parents), as well as adult-children (18+ years) whose parents have Obsessive Compulsive Disorder for this study. The children (12-18 years) and his or her parent will be approached via myself the clinician. Adult children (aged over 18) will be approached by myself as well, not necessarily with their parent’s knowledge.

The participants which Krystel and Amy will have access to and are known to me, will be ones of a level of wellness that will enable consent to participate. At no time will coercion be used, in fact, most of the participants are most willing to participate in advancing the understanding of the disability arising from Obsessive Compulsive Disorder (OCD). They will be provided with information to contact the appropriate person if they wish to participate in the study. I will not require any information about whether they are or are not in the study and their involvement or non-involvement will not impact on the services provided by myself.

Yours faithfully,

[Signature]

Professor Don Jeffery
Are you a person whose parent has Obsessive Compulsive Disorder?

Monash University is currently investigating the impact of parental Obsessive Compulsive Disorder (OCD) on children. We are trying to find out more about the experiences of having a parent with a mental illness and how it might impact on children's life and family life.

This is an important study because this information can be used to inform service providers to better support children and parents where a parent has a mental illness. This information will also be extremely useful to help develop programs for people living in families with parental OCD.

We are looking for participants (aged 12 years to adult), who have a parent with OCD.

**What does it involve?**
You will be required to participate in a one off interview either a face-to-face or telephone interview, asking questions about mental illness and your family. The interview will last approximately 30-60 minutes.

**How to get involved?**
If this study relates to you and you are interested or would like more information, please e-mail: monashresearchers@gmail.com

Participants will be rewarded with a $20 iTunes voucher OR $20 K-mart voucher.
Appendix G: Newspaper Advertisement in the Leader Community Newspaper

Are you a person whose parent has Obsessive Compulsive Disorder?

Monash University is currently recruiting participants (aged 12 years to adult) to understand the impacts of mental illness specifically Obsessive Compulsive Disorder. You would be involved in a 30-60 minute one-off interview which can be done face to face or via telephone. If you are interested or would like more information, please e-mail monashresearchers@gmail.com

Participants will be rewarded with either a $20 iTunes voucher, $20 K-mart voucher or $20 Village Cinemas voucher