

The Experiences of Parents with an Eating Disorder

by

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Declaration

I, Natalie Stitt, certify that:

1. Except where due acknowledgement has been made, the work is that of mine alone;
2. The work has not been previously submitted for a degree in any University, College of Advanced Education, or other educational institution, and to the best of my knowledge does not contain any material previously published or written by another author except where due reference is made in the text;
3. The content of this thesis is the result of work that has been carried out since enrolment into the course;
4. Ethical principles and procedures specified in the Monash University Human Research Ethics Committee (MUHREC) document have been adhered to in the preparation of this thesis {5 March 2012}: CF11/3529-2011001872.

Natalie Stitt

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Abstract

There is a lack of research on the experiences of parents who have an eating disorder and their perception regarding how their eating disorder impacts on parenting and children. Using a qualitative approach and semi-structured telephone interviews, the current study identified themes raised by nine parents with an eating disorder. According to participants, their eating disorder had an adverse impact on their children, including social isolation, emotional absence and the parentification of their children. Participants worried about what kind of role model they were, expressed guilt about prioritizing their eating disorder before their children and described how they kept the eating disorder a secret from their children. Furthermore, few parents reported being able to access adequate treatment as a parent with an eating disorder. The paper concludes with practice implications and suggestions for future research.

The Experiences of Parents with an Eating Disorder

The mental health of parents may deleteriously affect their child-rearing practices and may constitute a risk-factor for the development of behavioural and emotional difficulties within their children (Hosman, van Doesum, & van Santvoort, 2009; Leschied, Chiodo, Whitehead, & Hurley, 2005). There are numerous studies identifying the experiences of parents with mental health issues such as depression, schizophrenia and various affective disorders, though these typically do not differentiate between disorders (Ackerson, 2003; Bassett, Lampe, & Lloyd, 1999; Diaz-Caneja, & Johnson, 2004; Dipple, Smith, Andrews, & Evans, 2002; Nicholson, Sweeney, & Geller, 1998; Ritscher, Coursey, & Farrell, 1997; Sands, 1995; Treasure et al., 2001; White, Nicholson, Fisher, & Geller, 1995; Woodside & Shekter-Wolfson, 1990). What is missing is research on the experiences of parents with eating disorders (ED). This is important information that can be used to inform service delivery and interventions.

Both women and men with ED struggle to adjust to parenthood and model aberrant eating behaviours (Blissett & Haycraft, 2011; Koubaa, Hallstrom, & Hirschberg, 2008). Marked by symptoms from one of three eating disorders, anorexia nervosa (AN), bulimia nervosa (BN) and ED not otherwise specified (EDNOS), an individual with an ED experiences severely disturbed eating behaviour with significant physical, emotional and lifestyle effects including but not limited to episodic binge eating, abstinence from food, purging after eating or a general preoccupation with weight, shape and dieting (American Psychiatric Association, 2000). Associated with high levels of psychological distress, parents with diagnosed ED report impairments in social and emotional functioning, low life satisfaction, little self-esteem and a general lack of

enjoyment of parenthood (Klump, Bulik, Kaye, Treasure, & Tyson, 2009; Koubaa et al., 2008). Additionally, ED are often comorbidly linked with psychological conditions such as depression and anxiety, which carry significant consequences not only to the individual, but also to their family (Mond & Hay, 2007).

Since a preoccupation with dieting and weight often begins in adolescence, emphasis to date has been placed on the treatment of young children and teenagers (Ghaderi & Scott, 2001). There is a paucity of data concerning ED in adult males and females generally, and even less on those who are also parents.

Currently ED inflicts approximately 6% of Australian women, a statistic on the rise (Hay, Mond, Buttner, & Darby, 2008). Epidemiology studies have been carried out in both clinical and community populations and estimate that ED affect approximately 4% of the population (Garfinkel et al., 1995; Striegel-Moore, Garvin, Dohm, & Rosenheck, 1999). Whilst the precise aetiology of ED remains unknown (Schmidt, 2002), ED are common in people of reproductive age and are more prevalent in females than males (Hoek, 2006).

Motherhood is often considered a normalizing life experience and an opportunity to develop competencies and provide meaning to adulthood (Nicholson et al., 1998). Sands (1995) found that mothers with a mental illness relied on 'motherhood' to provide a sense of normalcy to their lives. Despite the emotional benefits of parenting outweighing the stresses, mothers with a mental illness report numerous difficulties that need to be overcome (Ackerson, 2003).

One such difficulty for mothers with a mental illness is the fear of custody loss. Sands (1995) found mothers would minimize their illness and were reluctant to ask for help in case this led to their children being taken away from

them. Similarly, Nicholson et al. (1998) suggest that the worry of custody loss contributes to a mother's decompensation and according to Ackerson (2003) accumulates at times of psychiatric crisis. Another study found that 68% of mothers with a mental illness were permanently separated from at least one child before the age of 18 (Dipple et al., 2002). The implications of this threat are that mothers do not talk about their parenting responsibilities when they present for treatment, therefore the children miss out on additional supports that might be required.

Another theme commonly identified across the literature is dealing with the 'stigma' of mental illness and the shadow that such stigma casts over a woman's ability to be a competent mother (Ackerson, 2003; Diaz-Caneja & Johnson, 2004; Nicholson et al., 1998). Diaz-Caneja and Johnson (2004) employed semi-structured interviews with 22 women with schizophrenia, bipolar affective disorder and severe depression with psychotic symptoms. They found that the stigma of having a mental illness, whilst being a mother, hindered women's ability to ask for help or discuss any difficulties they may be having. Furthermore, the children of mentally ill mothers also suffered consequences from the stigma of mental illness and were at risk of being rejected by their peers because their mother was mentally ill (Diaz-Caneja & Johnson, 2004). Similarly, Nicholson et al. (1998) suggest that it is not just societal attitudes that give credence to the belief that mentally ill mothers are incompetent, but mothers' beliefs themselves. Nicholson et al. (1998) explain that women come to perceive themselves to be inadequate mothers because societal assumptions convince them that any problem the child has is due to their mental illness. Therefore, even normal developmental difficulties faced by the child are

construed as faults of the mother.

Another repercussion from the social stigma of mental illness is that of social isolation (Ackerson, 2003). Ackerson (2003) purports, the harassment and abuse that can result from the stigma of mental illness can encourage social withdrawal and reclusiveness. Research shows that a social network can be both a buffer against stress and a source of competence (Bassett et al., 1999; Ritscher et al., 1997). As hospitalization can be a frequent occurrence when living with a mental illness, women rely on their social supports to help in looking after their children (Ackerson, 2003; Bassett et al., 1999; Ritscher et al., 1997).

In addition, managing a mental illness may place a mother in conflict with the needs of her children. Exploring the significance of children for mothers with a mental illness, Mowbray, Oysermon and Ross (1995) discovered that a mother would prioritize her children's needs over her own mental self-care. In comparison, Nicholson et al. (1998) found that some women use their children's needs to motivate themselves into recovery.

As well, mothers' competence can sometimes be compromised by mental illness (Ackerson, 2003; Bassett et al., 1999). Interviewing 13 mothers with either a severe psychotic disorder or a severe mood disorder, Ackerson (2003) discovered that mothers were more often lax in their disciplining and boundary setting of their children because they felt sorry for their children having to "put up" with their mental illness.

To date, most research has investigated the experience of parenting by mentally ill mothers with the diagnosis of schizophrenia, depression or bipolar. Much of the research has grouped these disorders together without considering the differential impact of various disorders on children and/or parenting

behaviour. Uncertainty remains as to whether a mother with abnormal eating habits experiences the same issues in parenting as other mentally ill mothers. Accordingly, further exploration is needed to ascertain the individual impact that ED can have on a mother, and parenting behaviour and attitude.

Past research on parenting with ED has primarily focused on the logistics of parenting such as feeding time regimes, birth weight, and/or on how the development of the child is effected by a parent's ED. Stein, Woolley, Cooper and Fairburn (1994) compared two groups of primiparous mothers and their infants. One group had ED during the postnatal year whilst the other group was free of any psychopathology. The mothers with ED were found to be more intrusive with their babies during mealtimes (Stein et al., 1994). Similarly, another study found mothers with AN deliberately underfed their children, hindering their growth (Russell, Treasure, & Eisler, 1998). Extending these studies, Stein et al. (2006) compared the eating habits of children whose mothers had ED to those whose mothers did not and found that children of mothers with ED adopted disturbed eating habits and attitudes and were at risk of developing an ED psychopathology themselves.

Other research has examined early maternal adjustment in an attempt to document the struggle of motherhood for women with past or present ED. Koubaa et al. (2008) compared 44 nulliparous women before pregnancy with 67 control women. Using self-report questionnaires, Koubaa et al. (2008) found that adjustment to motherhood was clearly impaired in women with past or present ED and up to 92% of women with ED reported clinically significant maternal adjustment problems at the same time.

Some studies have investigated attachment styles in relation to pregnancy

and ED (Pui-yee Lai, So-kum Tang, & Kwok-lai Tse, 2006; Rocco et al., 2005). Pui-yee Lai et al. (2006) used self-report questionnaires on 131 Chinese pregnant women with a history of BN and found that a weak maternal-fetal attachment during pregnancy resulted in exacerbating ED symptoms.

Only one study has been located that describes the experiences of parents with ED. This qualitative, interview based study interviewed seven mothers with ED, with children under five, to gauge their experience of parenting within the context of a support program (Bryant-Waugh, Turner, East, & Gamble, 2007). Specific concerns for participants included fear of passing on problematic eating patterns and behaviour to their children, difficulties in preparing food, and a lack of knowledge in how to regulate nutritional intake during pregnancy. At the same time, mothers highlighted a concern around fulfilling societal expectations of motherhood and queried their ability to cope with the demands of parenting. How other mothers, not in a specifically designed support program and with children older than five, manage their ED and the role of parenting has to date not been explored. It is also important for research to be conducted in other contexts to gain a sense of what issues and needs might be generalizable. Identifying the experiences and needs of parents with ED assists in understanding how having an ED might impact on children, other family members, and the parent. Such findings might be useful in developing appropriate rehabilitation and support programs for parents with ED.

Accordingly, the current study aimed to use a qualitative methodology to identify the themes and issues that parents (mothers and fathers) with ED consider to be pertinent, and their required supports. How a parent's ED impacts on the parenting role and his or her children, and also how having children might

impact on having an ED was also explored.

Method

Research Design

An interpretive approach to data collection was employed here, in order to present lived experiences and meanings of parents with ED, as interpreted by the researcher. Reflecting this interpretivist framework, in-depth, one-to-one, semi-structured interviews with parents were employed as the method of data collection, followed by member checks (Burnard, Gill, Stewart, Treasure & Chadwick, 2008), to allow for the negotiation of meaning between each parent and the researcher. Moreover, interviews are considered a sensitive and representative way of ascertaining the experiences of mental health consumers (Ponterotto, 2005).

Participants

Interviews were conducted with nine mothers. Nine is considered a sufficient number to identify valid themes in under researched areas (Strauss & Corbin, 1990). Participant demographics are outlined in Table 1 (page 14). No fathers were recruited. Of the nine mothers, the mean age was 36.1 years of age. The age of the children ranged from five months old to 27 years of age. All but four of the eldest children lived with their mothers. All women had or previously had a diagnosis of either AN, BN or EDNOS and all were diagnosed with a secondary mental illness. Demographic information relating to relationship status and specific ED diagnosis was collected to gauge a broader view of the family and those issues that might impact on the parent's perceptions of their children and parenting.

Table 1.

Participant Demographics

Demographics	Number of Participants
Age Range	
20-29 years	2
30-39 years	4
40-49 years	3
Child Age Range	
0-9 years	8
10-19 years	8
20-29 years	3
Mother to Child Ratio	
1 child	3
2 children	4
4 children	2
Gender of Children	
Female	8
Male	11
Diagnosis	
Bulimia	4
Anorexia	4
EDNOS	1
Secondary Diagnosis	
Depression	2
Anxiety	3
Depression/PTSD	1
Anxiety/Depression	1
Anxiety/PTSD	1
OCD	1
Marital Status	
Single	4
Partnership	5

Procedure

Following ethical approval from the Monash University Human Research Ethics Committee (MUHREC) (see Appendix A), participants were sourced through advertisements posted online (see Appendix B). The websites included Eating Disorders Victoria (EDV), Children of Parents with a Mental Illness (COPMI), Centre of Excellence in Eating Disorders (CEED), Butterfly

Foundation for Eating Disorders and National Eating Disorders Collaboration (NEDC). A three day newspaper advertisement was also placed in the Herald Sun. Criteria for inclusion included women or men who have, or had a diagnosed ED and who have, or had dependent as well as adult children. The participants may or may not have had custody of their children. The criteria were broad because of the exploratory nature of the study. Prior to interviews all participants received an exploratory statement (see Appendix C) and were invited to sign a consent form (see Appendix D).

Semi-structured phone interviews were conducted, guided by the literature review and research aims, but were flexible to allow for the participants to discuss issues they considered to be most important in relation to parenting with an ED. The interviews ranged from between 30-60 minutes. Open ended questions related to participant's relationship with their children, how they managed their ED and parenthood, sources of support, their needs as a parent and what effect they think their mental health has on their children (see Appendix E). All interviews were digitally voice recorded (with consent).

Research Analysis

Data analysis drew on 133 pages of interview data. Analysis was undertaken using interpretative phenomenological analysis (IPA) (Smith & Osborn, 2004). IPA is a qualitative approach that aims to identify themes within the participant's subjective experience. The analysis was conducted in two parts; intrainterview analysis and then across-interview analysis (Smith, 1996). Firstly, intrainterview analysis started with the voice recordings of the interviews transcribed verbatim. After carefully reading each transcript thoroughly, items from each interview were coded in order to identify key themes based on the

underlying meaning of the theme, and not just the frequency (see Appendix F for an example of an analyzed transcript). Key themes were then sorted and refined, some themes were broken down whilst others were merged with other themes. At this point, member checks were employed. After participants' feedback was incorporated, analysis was then conducted across-interviews and common themes were identified. To assess the validity of the analysis process and the emerging themes, an additional researcher (supervisor) also identified themes from some of the transcripts and comparisons were made (Barbour, 2001). A consensus about the themes was made through discussion.

Results

Analysis of the transcripts identified three broad themes, with ten sub themes as outlined in Table 2 and further detailed below.

Table 2.

Identified Themes

Main Themes/ Sub Themes

Impact on Children

- Social Isolation
- 'Full Head' – Emotional Absence
- 'Easier To Say Yes' – Lack Of Discipline
- The Parentification Of Children

Parenting with an ED

- Modeling ED Behaviour
- ED Comes First
- 'There Would Be No World Without Them' - Children Motivate Recovery
- 'They Keep Me Normal'
- Older Children Vs Younger Children
- Secrecy

Treatment Services

Impact On Children

According to participants, their ED had an often adverse impact on their children including social isolation, emotional absence, a lack of parental

supervision and their children assuming aspects of the parenting role.

Social isolation.

Many participants suggested that they isolated themselves and their children, due to their fear of eating in public, for example, “I would avoid things where there was food”. They acknowledged how this impacted on their children. In the words of one participant “I just can’t be in that situation....so I deny my kids going there”, and another “I can always find an excuse why we can’t go somewhere”. To compensate for this, a participant reported:

I ended up putting my daughter in day care for the simple reason that she needed socialization just one day a week because I wasn’t able to take her to playgroup and those sorts of activities.

Even when children were older and did not rely on their mothers for transportation, one participant nonetheless still identified how her children were socially isolated because “....my illness has had a massive financial blow to our family and that’s affected what they can do socially.”

‘Full head’- emotional absence.

As well as being socially isolated, many of the participants reported little emotional energy left for their children “....because my head’s too full.... from [what] I’ve had to eat and my head’s too full with all the negative aspects of that....” One participant reflected that “.... it would be nice to be able to be just 100% into enjoying my children...[instead of] all I’m ever thinking about is, ‘Oh my God, oh my God. What have I eaten? When am I going to eat next? What am I going to do?’ – always thinking about that”. Another summarized these sentiments when she reported:

....how much time you spend in your head obsessing about your weight or how you look, or whether you've eaten, or what you've eaten, if you look back you probably lost time that you could of just spent doing things with the kids....I sort of wonder, how much times did I lose, or, how many times did I snap at them, how many times was I unfair.

Easier to say yes - lack of discipline.

Some participants indicated that disciplining their children was compromised because of their ED, in terms of letting the children get away with whatever it was they wanted. One participant said:

....I was so caught up in my ED that I just let him get away with stuff and just not really do anything....I was more interested in keeping him quiet, so I could go and exercise....burn calories.

Another participant reported feelings of guilt because of her ED, which made her "softer on them [kids]". Similarly, the same participant admits that when she says yes to her children's requests to stay at their friends houses, she is really thinking "Great – I don't have to eat tonight....there is no obligation [to eat]."

For many, another reason for a lack of discipline was a confusion about what was 'normal' discipline: "....I don't know what's the best thing for me to say because I don't know if it's coming from my ED voice or if it's actually coming from a normal mum."

The parentification of children.

Two participants expressed concern about their children having to look after them, with one describing the impact of her ED on her children was "....not so much my parenting but them parenting me and worrying about me." Another participant described the guilt she felt every time her 13 year old daughter had to

get her out of bed and say “...C’mon, up you get, lets go and have a shower...”
or “...C’mon mum you have to get up to get the boys ready...”

Parenting with an ED

Participants recognized a discrepancy between managing their ED and their parenting, with concerns raised about being an inappropriate role model and prioritizing their ED before the needs of their children. At the same time, they described relying on their children to motivate themselves into recovery.

Modeling ED behaviour.

All of the participants expressed concern about being an inadequate role model to their children, for example, “...one of my worst nightmares is if my kids developed an eating disorder.” This fear encompassed their children copying their attitude towards food, coping behaviours and developing an ED. As reported by one mother “Probably the biggest thing is that what if they copy....it’s my coping thing and I’m scared that they might see....okay, well Mum does this to cope so we will too”. Similarly, others described a continuous awareness around “...not wanting any of my bad behaviour to rub off on her [child] and influence her in any way whatsoever”. One participant explained that wanting to be a good role model underlined her denial of having an ED, “...in denial about my own condition...enough awareness there that I wanted to be very careful not to, I guess, pass my demons on.”

ED comes first.

Commonly reported amongst most participants was prioritizing the needs of the ED before the needs of their children. In the words of one participant “...I don’t want my children to worry but the disorder overrides all of that.” Similarly, another participant reflected, “...because in my ED mind, the food

comes before anything – the love of the kids, anything. It’s all about the food and losing weight”.

Having children was seen by some as an interruption to important food related rituals, in particular purging, “...like I have my routine that yeah, and I get angry [when her children interrupt her]...when it’s time to purge and it’s like what am I going to do now? Yeah I get really frustrated and try and get them out as soon as I can.”

One participant reported that whilst she was not prepared to prioritize her children before her ED she felt she was able to reduce the negative impact her behaviour had on her children by shifting from binge eating to restrictive eating.

....it [binging and purging] was getting quite regular and they were aware of it and I wasn’t comfortable with them knowing mummy’s always sicky sick....I had to change it and in my weird twisted mind, the way I changed it was by stopping eating, which is not so much of an issue in terms of family life....

‘There would be no world without them’ – children motivate recovery.

All of the women interviewed reported that having children motivated them to do something about their ED.

Even now if I didn’t have them I really don’t think I would be motivated to do anything about it [ED].

I don’t want my kids growing up with a mother who’s dysfunctional in any way....I’m dealing with it for their sake....the inspiration and drive for me to fix myself is so that they can grow up in a healthy environment.

If it hadn’t been for him, I would probably be, either dead or still well and truly in relapse, to be honest.

Conversely, when children left home the reason for recovery was no longer there, with one participant describing a relapse because "...around them [children] leaving home and not having the focus on you know, going to work, coming home, cooking dinner..."

'They keep me normal'.

The majority of participants talked about their desire to be 'normal', with a few disclosing that the only way they can feel 'normal' is by having their children with them, "They really keep me normal...." and "...when I've got my girls around me, I'm that perfect normal mum...."

One participant indicated that even with her children around, her desire for normalcy was not achieved because her "...illness just wouldn't allow that."

Older children Vs younger children.

Some participants reported that their ED did not impact substantially on their children because they were too young. One participant stated "...I'm lucky that they are young, because it doesn't impact them quite so much." Further comments included "...when they're little it's a lot easier to get away with it...." and "...it's impacted my children in their sort of later adolescence and early adulthood more than it probably did through their developing years."

Secrecy.

Eight of the participants admitted to hiding their ED from their children. Whilst they were aware that the children observed ED behaviours, the participants felt the children did not associate the behaviour with an ED. "I would do it [purge] even if they could hear me....obviously at age four and five they don't understand what I am doing....". Some believed that if their children were not asking questions they were not aware of the ED. "I don't think they

know....they haven't mentioned anything" and "...I haven't seen any signs that he knows....".

One participant reported attributing her weight loss to a physical illness rather than a mental one as she felt her children would better understand this.

I'm also diabetic so anytime things might come up to do with the medical side of things, they think it's because of Mum's diabetes....it's like this massive lie I live....I do it ultimately to protect my kids, they couldn't handle knowing....

Similarly, another participant explained her lack of disclosure was about protecting her children from worry.

[after visiting participant in hospital]...he became quite concerned about my eating, and [husband] and I had a talk about that [ED] and about making that something that's not discussed in front of the kids....He [son] was really stressed about it and that's not okay for a 10 year old to have that sort of burden.

In contrast, one participant reported talking to her child about her ED.

...when she got old enough [five years of age] to realise what was going on and why I was the way I was we [participant and husband] talked to her and explained everything so she had a good understanding of things.

This one participant discussed her ED with her daughter because she "[did] not want any of my bad behaviour to rub off on her and influence her..."

Treatment Services

While all sought treatment for their ED when becoming a mother, few found these services to be adequate to address their needs as mothers.

Participants reported that services were geared towards younger people with an ED, and were not suited to older women with children, with one representative

comment being that services were “....directed at younger people and not older people and so there- yeah there isn’t [aren’t] methods that include family life”.

An issue for many was the service requirement for mothers to set ‘meal plans, (structured eating over the day, involving what is eaten and when) within the context of family life’.

I can’t set my meal plans....when you’ve got kids your life isn’t your own to manage as you would like....

It’s not appropriate for me as an adult to have my mother come and take control of my food, and while my husband, I guess, was willing and able to do that, that’s sort of not really an appropriate balance in the relationship either.

Another limitation of services was the expectation that mothers have babysitters.

....therapists don’t quite get that everybody doesn’t have babysitters they can ring up at short notice....I actually had one woman whobasically said “If you can’t commit to come every single week then I can’t treat you” and I said “Look, I’m trying but my kids sick, what do I do....

Discussion

Mothers with ED, who have children of varied ages, have lives that are multifaceted, and unique to each family and individual. Whilst open to fathers, it is important to note that no fathers were recruited to this study. The lack of fathers willing to participate in this study is unsurprising given that ED are more prevalent in females than males (Hoek, 2006). It also needs to be acknowledged that research with these populations requires a great deal of time and effort for relatively small sample sizes. At the same time, the information presented here

provides a window into the needs and experiences of an often neglected group of women and their perceptions of parenting with ED.

Overall, whilst many participants acknowledged the impact of their ED, in terms of social isolation and being distracted by their ED, some indicated that the impact was minimal with younger children. For many, the resonating narrative is juggling the demands of being a “good” parent, and providing an appropriate role model, while at the same time dealing with the competing demands of the ED, which for some (but not all) was prioritized over children’s needs. Together these themes provide a foundation upon which to build tailored treatment strategies for mothers and their families.

Some of the themes identified here overlap with other literature on mothers with a mental illness generally. For example, in this study, many mothers described being lax in their discipline, similar to Ackerson’s (2003) study on mothers with a psychotic or mood disorder. Here, mothers with ED described allowing their children to do or have whatever they wanted, because they either felt sorry for them (having a parent with an ED), or because they wanted to focus on the thoughts and rules surrounding their ED. Being socially isolated also resonates with Ackerson’s study. Such findings suggest that there are some common issues for parents and children, across diagnostic categories. However, specific to ED, mothers in this study report being limited in their social interaction because of their fear of being around food, not because, as Ackerson (2003) reports, of the stigma of having a mental illness, perhaps because it is easier to hide an ED than other mental health disorders.

Another theme that augments previous research is the parentification of children whose parents have a mental illness. Others have also described this in

terms of “role reversal” or “caring” (Aldridge, 2006). Here, mothers describe their children cueing them to perform basic self-care or reminding them to look after the younger children. In considering that parentification of children has the potential to adversely affect the child’s relationship patterns and levels of intimacy in adulthood (Earley & Cushway, 2002), it would be prudent for future treatment strategies to address this common theme, for all children whose parents have a mental illness.

A significant theme was the emotional absence of mother for child and the inability of some to prioritize the child’s needs over their own. The mothers in this study had a strong awareness that they could not be present for their children due to their thoughts being consumed by rules around what they have and have not eaten. In the words of one participant, her ED was a “selfish” condition, which will always come first. This finding is different from some research, which postulates mothers, despite mental illness will put their children first. For example, Nicholson et al. (1998) found that mothers with affective disorders prioritized their children’s needs even to the detriment of their own long-term recovery. It is possible the current study’s findings are specific to mothers with ED due to the controlling nature of the disorder, which renders a sufferer preoccupied and rigid with rules (around eating/not eating) and subsequently might draw parental attention away from the child.

Nonetheless, many mothers reported relying on their children to feel “normal” and were motivated to deal with or otherwise manage their ED because of their children. This is similar to other research, which found that the parental role provides a sense of purpose (Nicholson et al., 1998; Sands, 1995). Such a result emphasizes the importance of acknowledging a client’s parenting role

when being treated for his or her mental illness and highlights the importance for clinicians in assessing the parenting status of their clients.

At the same time, however, it has been argued that an external motivation (such as the children were for the mothers in this study) for accessing treatment is not necessarily conducive for long-term recovery (Federici & Kaplan, 2008; Vansteenkiste, Soenens, & Vandereycken, 2005). This is evident when one mother reported relapsing after her children left home and losing motivation to address or manage her ED. This mother claims that once she no longer had to look after her children, she no longer felt the need to stay in recovery. Accordingly, clinicians need to be mindful of relapse issues and promote intrinsic motivation for long-term recovery.

There are many seemingly contradictory results in this study. Whilst many mothers acknowledged the adverse impact of their ED on their children, some minimized the impact this had on younger children. Interestingly, one mother hinted that this minimization was part of her denial about having an ED. The secret shame associated with ED and the subsequent hiding of their ED from their family is perhaps associated with this perception. Some mothers report prioritizing their ED over the needs of their children's needs and yet, at the same time, report being motivated to enter treatment and recover for their children. This would indicate that mothers are juggling with competing demands of both the ED and their children, and being pulled from one to the other, in a way that they are unable to resolve for themselves. As such, this presents an ideal opportunity to support mothers with ED, if clinicians acknowledge and support their client's parenting role.

The concern about role modeling maladaptive behaviour is a broader aspect of parental expectations and not unique to mothers with ED (Diaz-Caneja & Johnson, 2004). Specific to the women in this study however was the belief that their mental health did not affect their children until they were adolescents. The finding suggests that despite young children being more highly dependent on their mothers, it is not until the children become more independent that conflicts arise and mothers feel more challenged. This study adds to Bryant-Waugh's et al. (2007) research on mothers with ED parenting children under the age of five, by looking at mothers with older children. Also, in highlighting mothers' perceptions that their ED doesn't have an impact until children are older, clinicians can be sensitive to the fact that mothers with ED may not be receptive to treatment whilst their children are young.

Finally, the women in this study reported the need for parent specific intervention programs. They expressed concern that current treatment groups solely catered for adolescents and that professionals did not acknowledge or incorporate their parenting role and responsibilities in treatment.

A limitation of this study was the small sample size. Subsequent research needs to look at a broader number of parents, with greater specificity of the ED diagnosis (for example, gauging whether there are differences between different types of ED). Further, as all women in this study had secondary diagnosis of various mood disorders, current mood states may have led the reporting of events in a mood-congruent way. A further limitation is a reliance on participant self-reports. At the same time however, the inclusion of subjective self-report data is a representation of the perceptions and unique experiences of mothers with ED. It has been found that the perspective of children differs from their parent(s)

(Maybery, Ling, Szakacs, & Reupert, 2005), so the perspectives of others—children, spouses, and former spouses—is also needed regarding the impact of a mothers' ED on the family unit. Fathers with ED is also another avenue for future research.

The current findings highlight important treatment implications for mothers with ED. First, treatment needs to be mindful of the parenting status of clients and their childcare arrangements. It would be prudent for clinicians to tailor treatment with a women's role as a caregiver in mind and focus on both general parenting skills (concerns about adequate role modeling) as well as those specific to mothers with ED (placing the rules and regulations of the ED before the needs of the children). Support programs would benefit from having flexible contact hours that could accommodate the inconsistencies of child rearing such as when a child falls ill, and the programs may also address the juggle between the competing demands of a child's needs and those of the ED. Also, in order to minimize relapse, treatment programs need to educate on and help prepare clients for life after children.

In summary, the current study provides foundations upon which to shape support programs and treatment strategies for mothers with ED. The study aimed to explore the unique experience of parents with ED and identified several concerns regarding the impact their ED has on their children; ambiguities between expectations of motherhood and those of managing their ED; and difficulties accessing flexible treatment that encourages and supports the role of motherhood. Further research is needed to corroborate these findings.

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Appendix A



Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

Date: 5 March 2012

Project Number: CF11/3529 - 2011001872

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

Chief Investigator: Dr Andrea Reupert

Approved: From: 5 March 2012 to 5 March 2017

Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. **Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

Professor Ben Canny
Chair, MUHREC

cc: Ms Wendy Brewster; Ms Natalie Stitt; Ms Titania Henderson

Appendix B

DO YOU WORK WITH OR ARE YOU A PARENT WHO HAS AN EATING DISORDER?

A team of researchers from Monash University are conducting a study on the experiences of families where a parent has an eating disorder.

We are keen to interview parents with an eating disorder.

Your children can be any age, including adult children. Your children can be living with you or elsewhere.

The interview will take about 60 minutes and with consent, will be audiotaped. The interviews will be conducted over the phone or face to face. All the information collected will be de-identified and no names or identifying information will be used.

If you are interested or want more information please contact:

Natalie Stitt: nsti2@student.monash.edu

Dr Andrea Reupert: andrea.reupert@monash.edu

Thanks

Appendix C

MONASH University



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

EXPLANATORY LETTER:
FOR PARENTS INVOLVEMENT

This information sheet is for you to keep.

Our names are Titania Henderson, Wendy Brewster and Natalie Stitt and we are conducting a research project with Dr Andrea Reupert a senior lecturer in the Faculty of Education towards a Master of Psychology (Counselling or Education and Development) at Monash University. This means that each of us will be writing a thesis which is the equivalent of a short article.

We are interested in learning about the experiences of parents who have either depression or anxiety or an eating disorder (or a combination of these diagnoses). Such information can be used to inform service providers to better support children and parents where a parent has a mental illness.

To be eligible you:

- Must have depression or anxiety or an eating disorder (or a combination of these)
- Be a parent (you can have young children or adult children; you can have your children living with you or not with you – as long as you are a parent).
-

The study involves one audio-recorded interview lasting approximately between 30 and 60 minutes between the researcher at Monash University and yourself. This will be conducted over the telephone or face to face, depending on what suits you and the researcher. With your permission the interview will be audiotaped. Sample questions include:

- How does your mental illness impact on parenting, if at all?
- How does having children impact on your mental illness, if at all?
-

The transcripts of those interviews will be sent or emailed back to you for your approval. At this point you will be invited to add or change any part of this.

You can withdraw from the study at any point up to when your transcript is approved.

It can be potentially become uncomfortable discussing family experiences. In this case, the interview will stop. The interviewer will talk to you about accessing some support services. As well, if you find that you are distressed after the interview you might like to contact any of the following organisations:

Relationships Australia	1300 364 277	http://www.relationships.org.au/
Lifeline	13 11 14	
Beyond Blue Info line	1300 22 4636	
KidsHelpline	1800551800	or http://www.kidshelp.com.au/

Your involvement in this study is voluntary and you are under no obligation to participate. Your involvement or non-involvement will not impact on any clinical services you or your children receive.

You will not be identified in the report. As well, audio recordings of interviews will be stored securely and in a password protected computer.

A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Information collected from a range of parents might be used for journal articles, book publication or conferences.

If you would like to be informed of the aggregate research finding, please contact Dr Andrea Reupert at andrea.reupert@monash.edu. The findings are accessible until the end of December 2012.

If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:	If you have a complaint concerning the manner in which this research is being conducted, please contact:
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:

- Fill out the parent consent form.
- Email or send back to us in the envelope provided

If you have any queries or concerns please do not hesitate to contact me.

I appreciate your time in reading this letter. With your support, we can ensure that service providers are better informed to support families such as your own.

Signatures

Andrea Reupert
Titania Henderson
Wendy Brewster
Natalie Stitt

Appendix D

MONASH University



CONSENT FORM: PARENT INVOLVEMENT

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 being a parent with 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 my participation is voluntary, and that I can withdraw at any point up to approving my interview transcript.

I understand that the information I provide will be used in reports or published findings and will not, under any circumstances, contain names or identifying characteristics.

I understand that the information I provide is confidential.

I understand that data from my interview will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a 5 year period.

Participant's name:

Signature

Preferred contact details (phone and/or email):

Date

Appendix E

Demographic information collected:

- Age
- Gender
- Mental illness diagnosis
- Number and age of children
- Married/single/ de facto/other

How long have you been diagnosed with your current mental illness?

Is there a secondary diagnosis?

How do you think your eating disorder impacts on you?

How much is 'secondary diagnosis' related to your eating disorder?

If a secondary diagnosis – is that the main reason things are limited (ie: do you not go out in public because of anxiety or fear of eating in front of people).

How do you think your eating disorder impacts on you parenting skills?

Do you think your eating disorder plays a role in how you discipline your child/children?

What role does your eating disorder play in feeding your children?

Do you worry about your children's eating behaviour/weight?

How do you think your eating disorder impacts your children and or spousal relationship?

What sort of difficulties do you face as a parent with an eating disorder?

What sorts of things have helped you deal with these difficulties?

How do you manage your mental health?

Do you think parenting with an eating disorder poses barriers in raising children?

Do your children hear/see things? Do they understand what they are hearing/seeing?

What has been your experience of dealing with mental health services?

Do you feel that mental health services understand your concerns as a parent?