Parents as partners in the treatment of adolescent Anorexia Nervosa: Experiences and insights for practitioners

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A thesis submitted for the degree of
Doctor of Philosophy (Social Work)
The University of Newcastle

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June 2014
Declaration

This thesis contains no material which has been accepted for the award of any other
degree or diploma in any university or other tertiary institution and, to the best of my
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Signed………………………………………………………………………………

Dated………………………………………………………………………………
Acknowledgements

It is unwise to be too sure of one's own wisdom. It is healthy to be reminded that the strongest might weaken and the wisest might err.

Mahatma Gandhi

The way we learn about ideas is only limited by the way we choose to think. The learnings involved in this PhD were inspired by a view that what we think we know is challenged by the complexity of life. I would like to thank the following people for supporting my doctoral journey.

To my doctorial supervisors: Associate Professor Debbie Plath and Professor Lauren Williams. I simply cannot thank you enough for your time, encouragement and astuteness over the years. You both provided specific and grounding mentoring that helped me to continually place one step in front of the other. I would also like to thank Dr Jill Gibbons who commenced this journey with me, and for her inspiring mind and belief in me.

To my wonderfully supportive partner Deaynne who has been patient, supportive and understanding and my daughter Eva who has just entered our lives, thank you both for being such a joy in my life, I love you dearly.

To my mother Violet, aged 91, who has waited with great anticipation for this to be completed: mum it’s done! To Sharyn Bourke, thank you, for your generosity in transcribing the interviews; you saved me hours.

Finally to all of the participants in this study, thankyou for allowing me into your worlds and trusting that I reflect your views to others.
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Abstract

Anorexia nervosa (AN) is a life threatening mental illness that is “too cunning a problem for any one-size-fits-all approach” to treatment (Maisel, Epston & Borden, 2004, p.2). Applying a critical perspective to treatment experiences and practices is important in adolescent AN because it helps practitioners reflect upon how best to assist families manage the complexities of the illness. A systematic review of the literature revealed that while there is growing evidence for existing types of family-based interventions, such as manualised Maudsley family therapy (Maudsley), (Lock, Le Grange, Agras & Dare, 2001), the evidence for other types of family-based interventions is scarce. Furthermore, qualitative research on the experience of parents or caregivers caring for someone with AN shows high levels of burden and fatigue, difficulties accessing treatment and a sense of alienation from treating teams. The interplay of such findings suggest the need for a fresh approach to thinking and behaving in treating adolescents with AN to assist parents help their child recover from one of the most perplexing and complex disorders with the highest rate of mortality of all of the psychiatric illnesses.

This exploratory study of parents’ experiences of treatment for adolescent AN commenced in 2007, with the intent of recognising the experiences from parents and clinicians perspectives. It sought to understand how parents and clinicians made sense of their experiences of either receiving or providing treatment for adolescents with AN. The study aimed to identify the means by which treatment processes for adolescent AN can be optimised and thus enhance the recovery process. A mixed methodological approach was undertaken in two inter-connected studies: one with parents and one with clinicians. Interpretivist and positivist paradigms were fused to provide a flexible approach to the research design and enrich the findings of the small number of participants who took part in this study. The study was carried out in Newcastle, Australia, in Child and Adolescent Mental Health Services (CAMHS). Data was collected from 15 parents, who had received family-based treatment for their adolescent with AN and from 20
clinicians experienced in providing this treatment. Parents and clinicians were invited to participate in a survey questionnaire, that yielded quantitative and qualitative data, and/or to participate in a semi-structured interview. Thirteen parents participated in the survey questionnaire and of those, seven participated in a semi-structured interview. Two parents participated in the semi-structured interviews only. All 20 CAMHS’s clinicians participated in both the survey questionnaire and semi-structured interview.

Data were analysed using Interpretative Phenomenological Analysis (IPA) (Smith, 1996). IPA was chosen as a method of analysis for its focus on understanding the core nature of how people make sense of significant life experiences, while also recognising the dynamic process involving the ‘interpretative’ activity of the researcher (Smith, Jarman, & Osborn, 1999). Qualitative data analysis yielded core themes structured around the following three broad domains: parenting an adolescent with AN; experiences of treatment in CAMHS; and helpful and effective treatment. The themes revealed that treatment for adolescent AN is enhanced when knowledge for practice is obtained through synthesising and critically evaluating scientific knowledge with an understanding of individual and cultural experiences of families.
Chapter 1. Introduction

1.1. Researcher’s perspective

I am writing the introduction in the first person in order to provide some background on what brought me professionally to undertake this research. I am a social worker who has worked at one of the study sites for about 15 years. In the last nine years I have additionally held the role of Head of Discipline for Social Work in mental health for the health district, and am therefore in a professional leadership role for the social workers who are represented amongst the clinicians involved in this study. When I commenced practising in adolescent mental health, the service was known as the Adolescent Psychiatry Team. There were only two social workers who worked in child or adolescent mental health, myself in adolescent psychiatry and one other, located in what was then known as the Child Psychiatry Team. Both teams were multidisciplinary in nature but psychology was the dominant profession in each team. During this time I worked with adolescents who had a diagnosable mental health disorder and developed a particular interest in work with people who had eating disorders and the social factors that shaped acceptable, accessible and socially inclusive service provision.

In 2006, an intensive manualised outpatient treatment for adolescents with anorexia nervosa (AN) known as Maudsley therapy (Lock et al., 2001), was promoted within the service as the ‘best practice’ treatment for adolescents with AN. Some clinicians were trained as Maudsley therapists and others were not. Those that were not trained in Maudsley therapy undertook co-therapy and supervision with trained family therapists in CAMHS to acquire skills in this area and/or utilised generic training and skills in working therapeutically with families gained through their professional qualifying degrees and subsequent professional practice experience. As one of the clinicians in the service, I was trained during this period to provide Maudsley therapy. All of the clinicians involved in providing family based treatment for adolescent AN
undertook supervision with Maudsley trained clinicians. In this way all clinicians had some exposure to the principles and procedures of Maudsley. Maudsley was viewed as having an evidence base for practice unlike any other approach which team members were using and, as such, it was considered superior. As a clinician working in this area, I experienced the emergence of a specific model for treating adolescent AN as exciting. It raised concerns for me from a social work perspective. These concerns related to a sense that no one model of treatment could possibly apply to all families who present for help. A one-size-fits-all approach to treating adolescent AN left no room for practising in either complementary or alternate ways with families, particularly when some existing methods had been successful with families in the past.

Given what I understood to be a huge commitment required of families to undertake Maudsley based treatment, I questioned whether a manualised approach to Maudsley (Lock et al., 2001) treatment should be the only treatment on offer for every family who attended a generalist adolescent mental health service. From my experience, I anticipated that many families would not meet the rigors of manualised treatment and consequently may be excluded from receiving any service. As a generalist service provider, I felt there was an obligation to offer a service to families that was inclusive of different methods and approaches that could engage all families in treatment, not just those who could undertake Maudsley. Furthermore, as a social worker, I felt treatment needed to be contextually driven. I concluded that the most useful way of understanding how to help families receive appropriate services was in fact to ask them what treatment they had found helpful and effective.

I enrolled in my PhD and began reflecting upon my views with my academic supervisors about the most appropriate methodology to enquire about parents’ views. My supervisors helped me realise that the best way to create new knowledge in this area was to build upon existing methods used by Maudsley researchers. I located a satisfaction survey used by Maudsley researchers Krautter and Lock (2004), sought and gained permission for its use in this study and
presented the idea to my colleagues. They were also curious about what parents said of their experiences of all treatment provided for adolescent AN. I then felt it was important to ask clinicians about their views on treatment experiences of parents, so any dissonance in findings between parents and clinicians could inform new knowledge to enhance service delivery.

Maudsley and non-Maudsley clinicians were aware that I was approaching this through the lens of a social worker who was interested in critical postmodernism and a pragmatic approach to evidence-based practice. As a generalist adolescent service provider I felt an ethical obligation to create new knowledge and alternative ways of thinking that complement and expand upon existing treatment modalities rather than diminish or disrespect any views. I wanted a methodology that appreciated the views and findings of experimental designs whilst incorporating knowledge from other sources, such as qualitative research. A mixed-methods research design provided the most respectful way forward in asking parents about processes and practices they found helpful and effective in treating adolescent AN in Child and Adolescent Mental Health Services (CAMHS).

1.2. Social work practice context in mental health

Social workers have been working across a range of clinical areas in mental health for many years. Social work initiatives that promote the wellbeing of consumers and family members have been influential in the development of mental health practice and policy in Australia (Bland, Renouf, & Tullgren, 2009). The actions of social work in mental health have been important in shaping service delivery and developing new treatments for complex presentations. Social work research has an important role to play in creating new understandings about treatment and adding knowledge to an existing scientific base.

While scientifically driven evidence-based practice in mental health seeks to improve practice, strict adherence to this paradigm can reduce the social worker’s capacity to be flexible and responsive to complex needs. Social workers in mental health identify and act upon complex
needs associated with the social consequences of mental illness (Australian Association of Social Workers, 2008). Social work interventions to address the social consequences of mental illness can include:

1. Work with families and carers to reduce a burden of care that may be associated with supporting a loved one with a mental illness.
2. Facilitate improved relationships between service providers and consumers to reduce effects of stigma and blame.
3. Shape service delivery to best respond to complex needs not otherwise accounted for in clinical trials.

Social consequences of mental illness are the domain of social work practice. They are multifactorial and dependent on the social, economic, geographical and political context in which they are experienced. While recognised as influencing treatment, these social factors pose a challenge for clinical trials as they are generally difficult to define and control. It is therefore important for social work research to explore the social dimension of mental illness, to complement existing scientific knowledge, to guide social work practice, and to augment current mental health practices across a range of professions.

Current research practices are subject to the processes of globalisation that promote economic determinants of wellbeing. Under a globalised economy, governments buy goods from providers who can demonstrate a contractual worth, a value for money to the purchaser (government). For example, effective clinical interventions in working with people are often determined through clinical trials that measure and analyse the economic cost associated with various interventions, against outcomes produced. If the health and economic analysis of a particular treatment or program suggests one is more cost-effective than another, even if the outcome is the same, the cost-effective intervention is more likely to be deemed the treatment of
choice and therefore purchased. This has had a significant impact upon the way professional skills and knowledge are constructed, where skills aligned to processes that measure or quantify actions are valued above those of negotiating and reflecting, and knowledge gleaned from positivistic research is privileged over applied qualitative-interpretivist approaches to knowledge attainment. This has resulted in a devaluation of service delivery and practice outside economic paradigms (Fook, 2012). Notions of efficacy in research are valued above professional processes, because they pay tribute to market forces that support competitiveness for service delivery, particularly in the area of publicly funded human service delivery, the purchaser-provider split (Fook, 2012). Fook (2012, p.23) suggests notions of “excellence, efficiency and effectiveness” are promoted in an economic rationalist paradigm alongside a devaluation of the inherent worth of professional skills because they are more readily costed and measured in terms of objected outcomes. However, Fook (2012) suggests, this promotes professional programme based practices because skills and practices are technocratised for ease of measure and marketability.

Critical approaches to knowledge attainment suggest that the organisation of society is embedded in layers of “culturally, historically and socially produced ‘truths’ that become ‘normal’ given their dominance at a particular time” (Macfarlane 2009, p.202). Macfarlane (2009) suggests mental health researchers have privileged some truths over others by subjugating processes that promote the experiences of consumers in favour of the objective distance associated with ‘patrolling the boundaries’ of reason and unreason through research designs that support grand narratives associated with the Diagnostic and Statistical Manual (DSM). Whilst ever experimental designs define how treatment is delivered, processes related to clinical judgement that are informed by consumer experiences and shape service delivery, are underexplored. Omitting these less tangible processes from research designs creates potential for multifaceted layers of disadvantage and oppression in service delivery. This is of concern to social workers where issues of access and equity in service delivery are paramount.
This research focuses on one area of mental health practice: adolescent AN. The research brings the lived experience of treatment for adolescent AN to a table that usually seats randomised controlled trials. Maudsley family therapy, that has since come to be known as the ‘Maudsley model’, is a prominent family therapy treatment program for adolescent AN that is detailed in the manual by Lock and Le Grange (2001, 2013). Maudsley family therapy is an outpatient treatment that involves the family working together over approximately one year to defeat AN. It is characterised by three phases of treatment. In Phase 1, parents are responsible for refeeding their child and regulating their child’s unhealthy behaviours. During Phase 2 of treatment, parents negotiate new patterns of relating to their child, where decision making about food and activities are handed back to their child once they are physical healthy. In Phase 3 of treatment, the focus is on the adolescent returning to developmentally appropriate tasks or resolving any family issues that were placed to one side in earlier phases of therapy, before proceeding to terminate treatment.

Evidence sourced from randomised controlled trials (RCTs) continues to support Maudsley to guide practice in adolescent AN. Despite this, it is this researcher’s intention to demonstrate that findings from experimental designs do not fully reflect the reality of service provision. It is hoped that the results of this research will present a workable paradigm for practice in the treatment of adolescent AN incorporating knowledge sourced from experimental and qualitative designs, to enhance meaningful interventions with parents of adolescents presenting for treatment.

Parents play important roles in family-based treatment for adolescent AN sufferers (Lock et al., 2001; Lock & Le Grange, 2013). They are responsible for: bringing their child to treatment; re-nourishing their child; halting unhealthy behaviours such as purging or obsessive exercise; re-establishing eating patterns; and navigating a path to recovery by slowly handing decisions about eating and activities back to their child. The current research seeks to make a significant contribution to practice knowledge for mental health practitioners working in this area by
focusing on actions and behaviours that optimise parents’ experiences of treatment for adolescent AN.

1.3. **What is AN?**

AN arises most commonly in adolescence. The highest risk group is the 15-22 years age bracket (Eisler, Simic, Russell, & Dare, 2007). It is characterised by high levels of psychiatric co-morbidity such as depression and anxiety including obsessive-compulsive disorder (Halvorsen, Andersen, & Heyerdahl, 2004; Hay et al., 2003; Treasure, 2008; Hatch, et al., 2010). AN has lifetime mortality rates estimated at up to 15% (Krautter & Lock, 2004) with half the deaths resulting from suicide (Herzog et al., 2000). Of significant concern is that AN has the highest mortality rates of any psychiatric illness (Harris & Barraclough, 1997; Birmingham, Su, Hlynsky, Goldner, & Gao, 2005; Morris & Twaddle 2007; Berkman, Lohr, & Bulik, 2007; Arcelus, Mitchell, Wales, & Nielsen, S, 2011).

There are two kinds of AN. There is the restricting subtype, where the person has not regularly engaged in binge eating or purging behaviour, and the binge eating/purging type, in which the person has regularly engaged in these behaviours.

The Diagnostic and Statistical Manual DSM-5 states there are three essential features of AN as follows:

1. “Restriction of energy intake relative to requirements” to maintain body weight for age, sex and height
2. “Intense fear of gaining weight or becoming fat or persistent behaviour that interferes with weight gain”, even though underweight
3. “Disturbance in the way one’s body weight, or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight”

(American Psychiatric Association 2013, p.338)

Broadly speaking, behaviours and beliefs that sustain AN are: restriction; fear; overvaluation; and disbelief. AN is a virulent disorder that demands the adolescent assume it as their prime identity and has them deny a problem exists (Pereira, Lock, & Oggins, 2006). These psychological complications are associated with impaired cognitive functioning as a result of malnutrition (Pereira et al., 2006). Cognitive deficits associated with AN are characterised by rigidity in thinking, which challenge the individual to move from one set of circumstances to the next (Cooke-Darzans, Doyen, & Mouren, 2008). Small sequential steps to recovery are blocked by rigidity of thought, making it difficult for the person to understand why treatment needs to occur in a particular sequence.

Decision-making capacity is also compromised by the effects of AN (Russell, Schmidt, Doherty, Young, & Tchanturia 2009; Cooke-Darzans et al. 2008). Impaired decision making distorts a person’s judgement regarding interpersonal relationships, making engagement and joint work to change, difficult (Diamanti, et al., 2008; Hatch et al., 2010). Generally, the primary psychological feature of AN is the “extreme overvaluation of shape and weight” (Morris & Twaddle, 2007, p.894). This, combined with cognitive distortions, provides a perfect breeding ground for fear and denial that obstruct pathways to recovery.

1.4. Prevalence

To date, population-based studies estimate the prevalence of AN to be about 0.9% in young Western women (Hoek & van Hoeken, 2003). Overseas prevalence rates are often applied in Australia, “due to insufficient Australian data” (Deloitte Access Economics, 2012, p. 20). Few
studies report incidence rates for males (Muise, Stein, & Arbess, 2003); however, Rosen (2003) however estimates that adolescent males account for approximately 5-10% of those diagnosed with AN, while for the general population Hoek (2006, p.391) suggests incidence amongst males “is below 1.0 per 100,000 persons per year”.

While AN in children born in New Zealand and Australia crosses a diversity of cultural groups, little information has been gathered regarding our Aboriginal population (Royal Australian and New Zealand College of Psychiatrists, 2004). Additionally, Hoek (2006) reflects on population-based studies “hardly any epidemiological studies of AN were conducted outside Western countries” (Hoek, 2006, p.392). Generally, research in the area of AN reveals inconsistent findings and gaps in knowledge related to prevalence amongst gender and cultural groups (Eating Disorders Association Incorporated Queensland, 2008). Hay, Buttner, & Darby (2008) study of prevalence in the Australian context, suggest that data may be more a reflection of over-representations in data samples than actuality.

1.5. Parental involvement in care and treatment

Several small Australian qualitative studies of parental perceptions of caring for a child or adult with AN all reveal high levels of distress in accessing treatment services, in not having parental competencies recognised, and being excluded from or not listened to in treatment (Honey, Boughtwood, Clarke, Halse, Kohn, & Madden, 2008; McMaster, Beale, Hillege, & Nagy, 2004; Tierney 2005; High, Thompson & King, 2005; Hillege, Beale & McMaster, 2006).

Understanding the lived experience of a parent who is caring for someone with an eating disorder is important due to their own high levels of psychological distress and burden (Zabala, MacDonald, & Treasure, 2009; Ma, 2011) that may serve to maintain the symptoms (Treasure et al., 2007) and reduce the family’s ability to use adaptive mechanisms to help in treatment (Eisler, 2005).
The parent perspectives of an adolescent with AN in relation to the acceptability, effectiveness and usefulness of treatment has been given little attention in Western literature, with the exception of studies that are specific to manualised family-based treatments for AN (Krautter & Lock, 2004; Rhodes, Brown, Baillee, & Madden, 2005; Rhodes, Baillie, Brown, & Madden, 2008). The dominant manualised treatment for adolescent AN is the Maudsley approach to family therapy and to date it has the strongest evidence base for treatment of AN in adolescence (Keel & Haedt, 2008). This approach provides a sequential description of the application of family therapy to stages of recovery from adolescent AN. Conjoint family work is an integral component of Maudsley because family members, who reside in the home of a young person, are considered as resources in treatment. For example, interventions in Maudsley such as the family meal, where parents are instructed to bring a meal into treatment, and, encouraged to feed their starving child one more mouth full than their child is prepared to do, includes all household members. Each family member has a role to play in this session; a parent encourages their child to eat, and siblings, provide uncritical support and empathy. Maudsley will be detailed further in Chapter 2.

Other research in family-based treatment states; however, family work is not recommended in families with high expressed emotion and/or parental criticism (Eisler et al. 2007). Other treatment approaches include: multiple family therapy approaches (Eisler, 2005) and non-manualised, strength-oriented family therapy where parents are involved in helping their child overcome AN (Ma & Lai, 2009).

1.6. Recovery

There is no consistent definition of recovery for AN in the literature (Couturier & Lock, 2006; Bulik, Berkman, Brownley, Sedway, & Lohr, 2007; Bardone-Cone, Sturm, Lawson, Robinson, & Smith, 2010). Although restoration to healthy weight in the early stages of treatment is considered a significant and crucial step (National Institute for Clinical Excellence, 2004; Lock,
Couturier, Bryson, & Agras, 2006; Treasure, 2008; Diamanti et al., 2008; Hatch et al., 2010), complications associated with treating co-morbidities, eating pathology and achieving the developmental tasks of adolescence, prove a challenge to defining recovery in a meaningful way (Gowers et al., 2007; Bardone-Cone et al., 2010). Some studies indicate that median time recovery in adolescent-onset AN is approximately 4-7 years (Halvorsen et al., 2004; Morris & Twaddle, 2007).

The notion of full recovery proves elusive for many clinicians, families and individuals. While in most cases an adolescent will gradually recover, “anorexia nervosa is also known for its severe complications, with chronicity and death being the two most feared consequences” (Wentz, Gillberg, Anckarsäter, Gillberg, & Råstam, 2009, p.168). Determining processes in treatment that assist in full recovery is therefore crucial. While there is some empirical evidence that supports recovery through family based treatments in adolescent AN (Russell, Szmukler, Dare, & Eisler, 1987; Le Grange, Eisler, Dare, & Russell, 1992; Robin, Siegel, Koepke, Moye, & Tice, 1994; Robin, Siegel, & Moye, 1995; Eisler et al., 2000 et al.; Eisler et al., 2007; Le Grange & Lock 2005; Lock et al., 2001; Lock, Agras, Bryson, & Kraemer, 2005; Lock et al., 2006; Lock, Le Grange, Agras, Moye, Bryson, & Boool, 2010; Krautter & Lock 2004; Wallis, Rhodes, Kohm, & Madden, 2007) the manner in which change moves towards recovery is still “largely speculative” (Le Grange & Eisler, 2009, p.169).

### 1.7. Significance of the current research

This research investigates treatment for AN in one clinical service within a public health service in regional NSW. The delivery of treatment for AN within the study site, Hunter New England Child and Adolescent Mental Health Service (HNE CAMHS), is strongly influenced by the manualised Maudsley treatment model (Lock et al., 2001). However, clinical practice is not exclusively manualised, as some families are assessed as not being in a position to commit to
the rigours of this form of treatment or it is contraindicated for other clinical reasons, such as high levels of criticism in the family.

This research is the first Australian study to take account of a) therapists’ and parents’ views of treatment in a child and adolescent community-based mental health team and b) treatment experiences beyond manualised treatment modalities. Options for treating an adolescent with AN need to be flexible to respond to familial capacity in managing this serious mental illness. Descriptions of what is deemed useful and effective by both parent and clinicians will help to promote interventions across family-based treatment modalities. A limitation of the study is that the adolescents with AN were not included as participants and therefore the experiences and perspectives of those undergoing treatment are not directly examined. The scope of the research has been limited to exploring processes that help parents remain engaged in treatment despite their child’s probable apprehension to attend. This focus was chosen as it is a critical aspect of adolescent engagement in treatment. Whilst supporting Ma’s (2011) claim that the voices of adolescents are as important as parents’ perspectives on family treatment for adolescent AN, the focus this research is to examine ways to enhance collaboration with parents in treatment. A potential pitfall, had both parents and adolescents been included in the research, is that parents may have elected not to participate if their child had been informed about the research through receiving an invitation to participate themselves. Given the relatively population from which the sample group was drawn, a well-defined and focused study in which participation could be maximised was a priority.

By adding the dimension of parents, who may have participated in different types of treatment with different clinicians, this research aims to add to the evidence base on family interventions in this field. In particular, it accounts for aspects of care that may be facilitated through the therapeutic alliance. Little is written about organic applications of the therapeutic alliance in practice, yet clinicians generally believe it to be important in facilitating recovery from AN (Pereira et al., 2006).
1.8. Research question and aims

This research generates findings in answer to the research question: What processes optimise parents’ experiences of treatment for adolescent AN in an adolescent community mental health setting?

The aims of the research were to identify:

1. The key features of treatment that enhance recovery in family based community treatments from the perspectives of adults in parental roles.
2. The key features of treatment that enhance recovery in family-based community treatments from the perspectives of clinicians.
3. The processes that engage parents in treatment.
5. Implications for enhanced practice with AN in adolescent mental health treatment services, and the role for social work within this practice.

In relation to the first aim, key features of treatment are examined and interpreted through an exploration of parents’ experiences of treatment and how parents make sense of parenting a child with AN. Conclusions drawn from the interpretation of parents’ experiences are addressed in Chapters 6 and 7. The second aim is explored and interpreted through clinicians’ descriptions of service provision, including their views on practices that optimise treatment for parents and the sense clinicians make of parenting a child with AN. Inferences from clinicians’ conceptualisations are addressed in Chapters 6 and 8. The third and fourth aims are addressed in the synthesis of all findings which are discussed in Chapter 9. In relation to the final aim, an interpretation of the implications for practice is made through drawing together and interpreting
findings from all data. This interpretation is offered in the conclusions and recommendations presented in Chapter 10.

1.9. Introduction to methodology

This study is exploratory in nature (Alston & Bowles, 2003) given that little is known about the specific aspects of family-based treatments found to be effective and helpful in treating adolescent AN in child and adolescent community mental health settings.

The study employed a mixed-methodological research design (Tashakkori & Creswell, 2007) incorporating the use of a self-report survey (generating qualitative and quantitative data) and in-depth semi-structured interviews (producing qualitative data). A mixed-methods approach was adopted because no one method addresses both the complexities of effectiveness across treatment modalities and the voice of parental experiences. A mixed-methods research design can integrate specific information on the attitudes of the two participant groups regarding effectiveness with detail regarding the experience of parenting a child in treatment and meanings behind these experiences.

A survey questionnaire was used to measure parents’ and clinicians’ views on the effectiveness and helpfulness of components of treatment. The survey was an adaptation of the Outcome Effectiveness Scale (OES) used in a Stanford University study that measured parent and child satisfaction with manualised treatment for AN (Krautter & Lock, 2004). The original OES has been modified for this research with permission from the researcher who developed it, Dr James Lock. The scale measures perceived effectiveness of family-based treatment either received by parents’ or provided by clinicians’.

Alongside the survey questionnaire, qualitative data was gathered through semi-structured interviews which explored the experience (phenomenology) of parenting an adolescent in
treatment for AN and how the parent and clinician made sense of it (interpretation). Thematic interpretation, using Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009) was used to provide a descriptive balance of experience with insightful interpretation. An idiographic and meaning-making focus was maintained, rather than creating broad generalisations.

The participants were:

a) Parents and their partners who have an adolescent:

- aged between 12-18yrs
- diagnosed with AN within the last 3 years (from 2009)
- now within the healthy weight range, and
- either currently receiving treatment from CAMHS or recently discharged

b) Clinicians employed in Hunter New England Health District CAMHS who provide family-based treatments to adolescents with AN. Professions included: psychiatry; social work, psychology; dietetics and nutrition; nursing; Aboriginal counselling and occupational therapy.

It is important to note that this study was designed around parents and clinicians’ experiences of treatment for adolescent AN influenced by Lock and his colleagues’ (2001) edition of the Treatment Manual for Anorexia Nervosa. While this manual was updated by Lock and Le Grange in 2013, the changes are small and the tenets of Maudsley remain the same.

1.10. Overview of the thesis

This chapter has provided the study’s context including: definition of AN; its prevalence; a synopsis of parents’ involvement in treatment; notions of recovery; the study’s significance; the research question; the study’s aims; an introduction to methodology and an overview of the thesis. A literature review is presented in Chapter 2. Chapter 3 develops the understanding of
how knowledge is constructed to support prevailing views of treatment and deconstructed to support alternate paradigms in working with families. The theoretical framework for research methodology is presented in Chapter 4. Within the context of this framework, Chapter 5 describes the research methods used in the parents’ and clinicians’ studies. Chapter 6 presents the findings from surveys of parents and clinicians. Chapters 7 and 8 describe the phenomenological findings from the qualitative data gathered from the parents and clinicians. All findings are discussed in Chapter 9 and related back to issues identified from the literature. Conclusions from the research, recommendations for further research and the implications for social work practice are presented in Chapter 10.
Chapter 2. Literature Review

This chapter reviews the literature related to community-based treatments of adolescent AN, including research and literature informed by positivist and interpretive research paradigms. It begins with a brief reflection on a history of AN followed by a review of literature informed by Western and non-Western thinking in relation to adolescent AN and families in treatment.

This chapter provides: a) an examination of evidence for practice in treating adolescents with AN and how that is applied in community contexts; b) a critique of the limits of evidence from experimental studies in informing practice in this area; and c) comment on the interplay of differing paradigms evident in the literature and how these can impact on work with adolescents with AN.

2.1. Historical perspective on AN

Morbid self-starvation was recognised by the medical establishment as a separate clinical entity, AN, around the time an English physician named Sir William Withey Gull addressed the annual meeting of the British Medical Association in London in 1868 (Vadereycken & Van Deth 1989). In an invited lecture to his peers, Sir William Gull described the underlying pathology of two young women presenting to him with unexplained weight loss as “hysteric aepsia” (Gull 1868). In the absence of a biological cause for the emaciated presentation of these two women, Sir William Gull inferred the cause to be a hysterical response that involved the failure of the digestive functions (apepsia). In 1874 William Gull published his 1868 address but abandoned his old term ‘apepsia hysterica’ and substituted two Latin words to describe a loss of appetite due to a nervous state, ‘Anorexia Nervosa’ (Vadereycken & Van Deth 1989). The description of the condition, anorexia nervosa, outlined in William Gull’s (1874) publication of ‘Anorexia Nervosa’ “still forms the basis of modern day definitions of anorexia” (Madden, 2004, p.149).
2.2. Literature on treatment for adolescent AN

2.2.1. Inclusion and exclusion criteria

The literature on treatment for adolescent AN reviewed for this chapter includes research studies using experimental designs, qualitative research studies and research-based practice guidelines. The search for research on efficacy of treatment for adolescent AN has been limited to randomised controlled trials and systematic reviews from 1987 to 2011. Research on experience and meanings associated with treatment for parents was sourced from qualitative studies from 1995 to 2011. Different time periods were selected due to the increase in research related to efficacy of family therapy in treating eating disorders over the last 25 years (Downs & Blow, 2013), commencing with the first RCT that focused exclusively on adolescents with AN in 1987 (Lock, 2011) and the limited attention to treatment experiences of parents prior to 1995.

2.2.2. Literature search

**Databases and search terms.** For this review, 12 databases were searched. The initial search commenced with The Cochrane Collaboration libraries. Other databases searched were: CINAHL, Blackwell Synergy, Wiley Interscience, Informaworld, SpringerLink, Social Work abstracts, PubMed, Ovid, Medline, Proquest 5000 and PsycINFO. Subject headings used in this search included: eating disorder*, family therapy*, adolescent*, anorexia*, anorexia nervosa*, adolescent anorexia nervosa*, treatment outcome*, outcomes*, male*, male anorexia nervosa*, Aboriginal anorexia nervosa*, family*, family treatment*, family functioning* for the period 1987-2011. An electronic search was made of the: International Journal of Eating Disorders; Eating Disorders: The Journal of Treatment and Prevention; Eating Disorders Review; European Eating Disorders Review; Research on Social Work Practice; and Social Work in Mental Health conducted for the period 1995-2011.
The search yielded: 14 articles reporting findings from randomized controlled trials of community-based treatment for adolescent AN; five systematic reviews of randomised controlled trials of community based treatment for adolescent AN; two sets of treatment guidelines for adolescent AN; 28 qualitative studies outlining either parents’ or clinicians’ experiences of treatment; ten articles related to overall management of adolescent AN based on randomised control studies; and 15 articles related to a historical perspective of family therapy in the treatment of adolescent AN. No article was retrieved for Aboriginal AN; however, one treatment guideline referred to AN in the Australian Aboriginal population.

2.2.3. Research on treatment efficacy

Establishing effective treatment options is paramount in light of United States (US) data that indicates AN is equal in cost or more expensive to treat than schizophrenia (Lock, 2003). Treatment is complex and difficult to manage as the illness has substantial medical as well as psychiatric components (Bulik et al., 2007; Gowers et al., 2007; Keel & Haedt, 2008). However, there is considerable agreement about the value of family interventions in the treatment of adolescent AN (Le Grange et al., 1992; Robin et al., 1994; Robin et al., 1995; Robin et al., 1999; Geist, Heinmaa, Stephens, Davis, & Katzman, 2000; Lock et al., 2001; Lock et al., 2010; Eisler et al., 2007; NICE, 2004; RANZCP., 2004; Fisher, Rushford, & Hetrick, 2004; Le Grange & Lock, 2005; Bulik et al. 2007; Cook-Darzens et al. 2008; Ma & Lai, 2006; Ma, 2008; Barton & Nicholls, 2008; Lock & Fitzpatrick, 2009; Attia, 2010; Herpertz-Dahlmann & Salbach-Andrae, 2008; Keel & Haedt, 2008). Systematic reviews of RCTs of treatments for adolescent AN in community settings (Bulik et al., 2007; Gowers et al., 2007; Cook-Darzens et al., 2008; Keel & Haedt, 2008 & Fisher, Hetrick, & Rushford, 2010) show that family based therapy is the most often tested. While these reviews cite methodological limitations and potential bias in each of the RCTs conducted, each review concludes that family therapy appears to be effective in the treatment of adolescent AN.
At the time of this review, the most recently published systematic review of family therapy for AN across all age groups Fisher et al. (2010), evaluated the relative efficacy of different forms of family therapy, as described in clinical trials, compared to any other intervention. The authors concluded that children and adolescents treated with behaviour-based family therapy demonstrated greater improvements in measures of weight gain and cognitive distortions at the end of treatment compared to other forms of treatment in the short term (< 12 months). However, family therapy was of little advantage over other forms of psychological treatment in terms of rates of remission. At five years of follow-up there was no great difference in outcomes between other psychological treatments and family therapy. They also noted the following: a) the lack of males included in clinical trials suggests results of RCTs may not be generalisable to males with AN; b) there were few trials conducted overall; and c) each trial had small numbers of participants. Fisher and colleagues’ conclusions suggest the scientific community may benefit from a large, well-conducted clinical trial.

2.2.4. Family therapy in treating adolescent AN

Traditional models of family therapy view the patient’s problem developing in response to external factors such as familial, socio-cultural or genetic backgrounds and models of family therapy conceptualise the problem or symptom as “belonging to the entire family” (Lock & Le Grange, 2013, p.14). Significant shifts in approaches to family interventions for the treatment of adolescent AN have occurred over the past 40 years (Cook-Darzens et al., 2008). Foundational publications within family therapy movements indicate family therapy was first viewed as an effective way to treat adolescent AN in the 1970 Minuchin, Rosman, & Baker, 1978; Selvini Palazzoli, 1974).

According to Lieberman and colleagues (1983), Minuchin’s and Selvini Palazzoli’s ideas shaped the structural school of family therapy and provided a basis for research in treatment for adolescent AN. This approach emphasised the notion of family dysfunction in the development of the disorder and therefore a need in treatment for restructuring family relationships.
Structural family therapy represented a psychosomatic approach to treatment and suggested the main contributor to AN in childhood was family pathology. A psychosomatic family model was developed to assist in the resolution of family dysfunction where interventions in therapy were designed to challenge the structure and organisation of the family system that disrupted parental efficacy. Minuchin added a therapeutic family meal to interventions in working with children with AN, where parents were encouraged to take charge of the meal.

Another approach to family therapy in treating children with AN, derived from structural family therapy, is systemic family therapy, developed by the Milan group (Selvini Palazzoli 1974; Selvini-Palazzoli, Boscolo, Cecchin, & Prata, 1980). Systemic family therapists believed that AN evolved as an active participant in patterns of relating in the family. These patterns of relating were referred to as ‘family games’. Families were viewed as rigidly organised units that were resistant to change, a view developed by Selvini Palazzoli in 1974. Rather than providing direct advice to families, systemic family therapists questioned processes within the family and encouraged members to be observers and challenge their own processes. A neutral stance was adopted by the therapist to avoid homeostatic resistance to change from the outside.

At around the same time as the Milan group were working with AN, other family therapy approaches such as strategic family therapy pioneered by Haly (1973) and Madanes (1981) also observed specific characteristics of families with AN. Strategic family therapists viewed AN as a problem that occurred because the family was viewed as inflexible, not pathological. In this model, strategic therapists believed that change and recovery occurred in families by adopting an agnostic view of AN. These therapists concluded that change occurs by the therapist acting in a neutral way to unpack vicious cycles of relating through paradoxical interventions aimed at limiting the impact of the illness on the family.

By the mid 1980s, shifts occurred within the family therapy movement when researchers questioned the view that families were responsible as the cause of AN (Dare, 1985). Family
causation models became less relevant and proved to be less useful in guiding treatment than those that concentrated on factors that maintained AN in the family (Eisler, 2005). The most recent model of family therapy, the Maudsley model, emphasises behavioural recovery by “empowering family members to support the recovery of their child in the home setting” (Fisher et al., 2010, p.3).

2.2.5. Maudsley family therapy

In 1985, Dare and colleagues, based at the Maudsley Hospital in London, promoted a model for treatment for adolescent AN referred to as Maudsley family therapy (Dare, 1985). In this model of family therapy, the family is seen as integral to the healing process (Dare & Eisler, 1997). Treatments aligned with this theoretical stance place the AN problem outside of family dysfunction. Maudsley family therapy has influenced the development of family-based treatments that regard causation of adolescent AN as being of little relevance (Lock et al., 2001; Rhodes, 2003).

Maudsley family therapy is a model that integrates theory from several family therapy approaches. It has been strongly influenced by Selvini Palazzoli (1974) and Minuchin’s (1978) structural family therapy where the aim of family therapy is to re-align the hierarchy of the family. From this perspective parents are ‘placed in charge’ and the symptom (AN) is no longer required. Maudsley therapy also uses techniques such as family meals, borrowed from Minuchin structural family therapy and specific techniques for family empowerment based in the non-authoritarian stance of strategic family systems therapy (Lock et al., 2001). It has also been influenced by strategic family therapy, where the notion that the family dynamic is a direct causative agent in the development of AN, is disregarded. Michael White’s (1987) work in externalization of the problem is also influential in Maudsley treatment. White (1987) externalizes the problem of ‘anorexia’ as the ‘nazification’ of everyday life, as a torturer and tyrant that gradually assumes full control. The process of externalizing the problem from the family allows ‘the anorexia’ to be personified as the oppressor, rather than family members, and
its impact on the family can therefore be traced back to the identified oppressor, AN (Rhodes, 2003).

In 2001, family-based treatment, also known as ‘Maudsley family therapy’, was systematically detailed and published in manual format in the US (Lock et al., 2001). The intent of a manualised approach was to provide a systematic description of the three phases of family therapy (Dare, Eisler, Russell, & Szmukler, 1990) used at the Maudsley hospital in its treatment studies for adolescent AN, that could be standardized, replicated and researched across sites (Lock & Le Grange, 2001). In manualised format, it also allowed for a consistent approach that was less dependent on the influence of individual characteristics of therapists and provided a clear path for treatment (Lock & Le Grange, 2001).

The stated aim of the manualised format of Maudsley family therapy is restoration of health to the adolescent with AN (Le Grange, 1999) over a period of 6-12 months in an outpatient setting (Lock et al. 2001). Manualised therapy proceeds over three distinct phases described by Dare, Eisler, Russell, and Szmukler (1990) as follows:

Phase 1 – Refeeding the Client

In the first phase of treatment, intervention is characterised by intensive refeeding. This initial phase of treatment is solely focused on restoring nutrition to the malnourished young person. Parental action is directed to “the best way to refeed their anorexic child”, according to commonsense parameters, and restoring their child’s weight as the primary concern of treatment (Lock et al., 2001, p.2). Siblings are enlisted to help their sister or brother in a supportive role. Psychological interventions are not explored in this phase (Lock et al., 2001). Parents are absolved of any responsibility for the creation of the problem within the family and attention is drawn to positive aspects of parenting that may be used to assist with problem solving. The therapist is active in reinforcing a strong parental alliance in their efforts to refeed their child,
whilst aligning the sibling relations as potential emotional support (Le Grange, 1999). AN is externalized in order to manage guilt and expressed emotion, both viewed as ‘the tricks’ that AN uses to maintain itself (White, 1987). In this first phase, parents refeed their adolescent and manage anorexic behaviours until 90-95% of ideal body weight (IBW) is attained (Lock et al. 2001).

Phase 2 – Negotiations for a New Pattern of Relationships

The second stage of treatment moves the family into a negotiation of relationships by gradually handing control for eating over to the adolescent. It is a phase that facilitates the transition between refeeding and parental control to an enquiry about more general adolescent issues. While parents are encouraged to refeed their child, the therapist negotiates between parent and adolescent to assist with decreasing parental control and sibling support whilst enabling the adolescent to assume more responsibility for their own behaviour at meal time (Lock et al., 2001; Rhodes, 2003). This phase is completed at the return of menses or 100% ideal body weight (IBW) and the adolescent has control over his or her own food intake. Should a relapse occur, where parents do not feel confident that they can deal with food related areas and the adolescent has lost weight below around 90% of IBW, the family returns to Phase 1 of treatment.

Phase 3 – Termination

The final phase of treatment focuses on general adolescent issues and termination of treatment (Lock et al., 2001). This stage is deemed necessary as AN has robbed the adolescent of his or her transition through their developmental trajectory. In termination stage, families are supported to return to their ‘normal’ family life cycle. Parents are encouraged to forsake attitudes and skills that were deemed necessary in the earlier stages of treatment. Family therapy
is not re-initiated if marital or partnership issues persist beyond the treatment of AN. In such instances, parents are referred for relationship counselling (Lock & Le Grange, 2001).

The second 2013 edition of the Treatment Manual for Anorexia Nervosa by Lock and Le Grange was published. It follows the same rationale and sequential structure for treatment as the 2001 edition, where all components of family based treatment deemed necessary for recovery, are embraced in manualised format to keep the clinician and family on track. The essential differences in the editions are related to the authors’ analysis and integration of further research in Maudsley over the last 10 years. This is reflected in the manual’s specific intent to move away from a mechanistic approach to treatment and the inclusion of greater flexibility, including “the judgment of individual clinicians” in recognition of the fact “no treatment works for every patient or family under all conditions” (Lock & Le Grange, 2013, p.30). Such flexibility may see the clinician including other developmentally appropriate approaches to treatment in the form of guidance to parents to help their child meet developmental mental tasks, or provide greater support for single parents and longer periods of treatment. However, the authors remain emphatic that key principles related to Maudsley should be upheld in all instances. These key principles include: an agnostic view of causation; empowering parents to be active in recovery; the whole family (living in the family home) is an important resource in recovery; and adolescent needs for autonomy and control are respected (apart from those associated with weight). The essential differences between the first and second edition will be discussed, in relation to the findings of this study, in Chapter 9.

An evaluation of a body of evidence suggests Maudsley family therapy has been one of the most researched models for adolescent AN (Cook-Darzens et al., 2008). Within the English language literature, RCTs supporting Maudsley family therapy have provided some evidence of effectiveness in treatment (Le Grange et al., 1992; Lock et al. 2001, Lock et al., 2005; Lock et al. 2006, Lock et al., 2010; Krautter & Lock, 2004; Wallis et al., 2007) and to date, has the strongest evidence base for treatment of adolescent AN (Rhodes, 2003; Bulik et al., 2007; Le
The Maudsley model posits families as active and resourceful in recovery (Lock & Le Grange, 2005a) where therapeutic alliance with both parents and adolescents contributes positively to treatment retention and outcome (Pereira et al., 2006).

Changes over the years in clinical approaches to treating adolescent AN include a greater emphasis on inclusivity and empowerment. Studies exploring family experience of manualised family therapy suggest that patients and parents view manualised family therapy as effective and acceptable in treating adolescent AN (Krautter & Lock, 2004; Rhodes et al., 2008). Rather than feelings of blame, treatment can result in ‘experiences of gain’. In the clinical management of AN; however, “the field moves only slowly” (Palmer, 2006, p.5).

2.2.6. Research comparing the effectiveness of different types of treatment

Within a scientific or positivist framework, RCTs have come to be accepted as the gold standard of evidence to guide practice (Gray, Plath, & Webb, 2009). However, it is important to note that there are few randomised controlled studies in the community context that investigate psychotherapeutic interventions for adolescents with AN (Russell et al., 1987; Le Grange et al., 1992; Eisler et al., 1997; Eisler et al., 2000; Geist et al., 2000; Lock et al., 2005; Lock et al., 2006 & Lock et al., 2010; Robin et al., 1994; Robin et al., 1995 & Robin et al., 1999; Eisler et al., 2007; Gowers et al., 2007; Gowers et al., 2010) and that many of the trials involve the same authors examining a limited number of treatments. Most of the research has examined the effectiveness of Maudsley treatment rather than comparing different approaches (Gowers et al., 2007; Keel & Haedt, 2008; Fisher et al., 2010). Although much of the research has been undertaken by the disciplines of psychology or psychiatry, social workers were enlisted as therapists in two of the RCTs cited (Lock et al., 2005; Geist et al., 2000). No RCT has been conducted by the profession of social work.
The current empirical evidence sourced from RCTs, examining the effectiveness of family therapy in the treatment of adolescent AN, can be summarized in six key areas relevant to practice:

1. *Family Therapy vs Individual Therapy*: In determining whether family therapy or individual therapy was more effective in the treatment of adolescent AN, Robin et al. (1994) compared behavioural family systems therapy (BFST) with ego-orientated individual therapy (EOIT). In BFST, parents were initially encouraged to assume control of re-nutrition of their adolescent. The family was seen and treated as a unit. In EOIT, the goal was enhancement of adolescent self-esteem and assertiveness. Although EOIT had a component of family treatment, it primarily involved supporting the autonomy of the adolescent. Robin et al. (1994) concluded that behavioural family systems therapy was superior to individual therapy in increasing Body Mass Index and restoring menstruation. However, neither therapy improved outcomes associated with mood (Robin et al., 1994; Robin et al., 1995; Robin et al., 1999). These findings were replicated in a similar, more recent, study that compared manualised Maudsley with adolescent focused individual treatment Lock et al. (2010).

2. *Conjoint vs Separated Family Therapy*: Following on the work of Robin et al. (1994) on effectiveness of family therapy, Eisler, Dare, Hodes, Russell, Dodge and Le Grange (2000) from the Maudsley hospital, proceeded to determine whether treating the family as a whole was the necessary ingredient for effectiveness, or whether the same results could be reproduced by counseling parents and child separately. Eisler and colleagues (2000) compared the efficacy of two forms of family therapy, specifically the efficacy of conjoint (family seen and treated as a unit) with separated (adolescent and family seen separately with some time aside for family unit) family therapy. Both forms involved initial parental focus on re-nutrition of the adolescent. Eisler and colleagues (2000) concluded that conjoint family therapy has significantly better outcomes over separated family therapy in
terms of mood and eating, but not for weight. The importance of early treatment (less than 12 months from onset of illness) was a mediator of success in this study. However, by the five year follow-up, the effects of separated family therapy were superior to conjoint family therapy, where adolescents experienced high levels of parental criticism (Eisler et al., 2007). This study affirmed that those adolescents who experienced high levels of expressed hostility or criticism within the family fared less well in conjoint family therapy than separated family therapy.

3. **Long-term vs short-term therapy.** Lock and colleagues (2005) compared efficacy of short and long term family therapy, randomising 86 adolescents with AN into either short term family therapy (10 sessions over 6 months) or long term (20 sessions over 12 months). The interventions adopted a manualised based approach (Maudsley) to treatment. This research found no difference in treatment outcomes for either group, suggesting term does not impact on outcome for this intervention. Longer term family therapy was suggested for adolescents with severe eating-related obsessive thinking, or where families are non-intact (Lock et al., 2005).

4. **Timing of treatment.** Russell and colleagues (1987) found in a study comparing individual and family treatment for adults and adolescents that family therapy was more effective in younger adolescents if treated early. This study indicates that family therapy is more effective with adolescents who have had AN for less than 3 years than it is for older adolescents with an illness deemed chronic (>3yrs). These findings were supported in a 5 year follow-up study conducted by Eisler and colleagues (1997).

5. **Family Therapy vs Groupwork:** Innovative approaches to treatment for AN are yet to be subjected to the methodological rigors required for ‘gold standard’ evidence. Worthy of note is a Canadian trial conducted by Geist and colleagues (2000). This study compared individual family therapy with family group psycho-education as a treatment option in
working with adolescents with AN. They compared family therapy and family group psycho-education over a four month period by randomising 25 female adolescents who required hospitalisation with newly diagnosed AN to either family therapy or family group psychotherapy. Although no significant psychosocial outcome was reported for either group, weight restoration was achieved in both groups. They concluded that family group psycho-education is equally as effective as family therapy for treatment with newly diagnosed and medically compromised adolescents with restrictive eating disorders, and their families.

6. **Treatment Setting**: For those adolescents with AN who are not severely ill, debates about where to offer treatment to them and their families (specialist, generalist, community or inpatient settings) relate to clinical judgment, models of service and available resources. Gowers and colleagues (2007) undertook a large multi-centre trial involving 167 young people with AN in the United Kingdom (UK), to evaluate the effectiveness of three National Health Service treatment sites for adolescents (aged 12-18) with AN. The treatment sites were: in-patient psychiatric treatment; specialised out-patient program and community Child and Adolescent Mental Health Teams. The main findings were that there were no advantages related to any treatment setting over the others. From an economic perspective, it is less expensive to treat adolescent AN in a community setting and, on the basis of these findings, just as effective. Specialist eating disorders community treatment settings were found to be more cost effective than general mental health community settings and received higher rates of treatment satisfaction from parents (Gowers et al., 2010).

The evidence from RCTs suggests that family interventions in treating adolescent AN have promising outcomes (Russell et al., 1987; Le Grange et al., 1992; Eisler et al., 1997; Eisler et al., 2000; Lock et al., 2005; Lock et al., 2006; Robin et al., 1999; Eisler et al., 2007; Fisher et al., 2010). Most of the family-based treatment research subscribes to the Maudsley model of
family therapy (Le Grange et al., 1992; Eisler et al., 2007; Lock et al., 2005; Lock et al., 2006; Lock et al., 2010; Lock, 2011) and although the findings from this research suggests manualised based family therapy may have some benefit in treating adolescent AN, Gower and colleagues (2007) suggest that it does little to address core eating pathology and weight concerns for the adolescent. Furthermore, Gower and colleagues (2007, p.433) claim that differences in the research design of these trials “makes for uncertainties in interpretation, primarily as this treatment has not been fully tested against other approaches”.

2.3. Lived experiences of parents

a) Caring for a child with AN

The burden of care is greater for parents and relatives of children with psychiatric problems, and their subsequent quality of life poorer, in comparison to the general population (Guethmundsson & Tomasson, 2002; Fleischmann & Klupp, 2004). The few studies that have investigated the experience of caring for someone with AN have suggested it is comparable to caring for someone with schizophrenia (Treasure, Murphy, Szmukler, Todd, & Joyce, 2001; Santonastaso, Saccon, & Favaro, 1997). This information serves to conceptually link clinicians, and families themselves, to an experience of caring for someone with a severe mental illness. Recent studies regarding the experience of living with someone with AN suggests that AN adversely impacts upon the quality of life of all family members in terms of burden, depression, distress and anxiety (Haigh & Treasure, 2003; Zabala et al., 2009; Ma 2010). Other qualitative studies that consider the impact of AN on family functioning suggest parents: experience social, occupational and economic strain (Hilleg et al, 2006); deal with difficult behaviours and cope with feelings of loss and guilt (Treasure et al., 2001); experience difficulties in trying to understand the illness (Ross &Handy, 1997); adjust their interactions with their child (Hoskins & Lam, 2001); and re-organise daily activities to care (Gilbert, Shaw, & Notar, 2000).
Ma’s (2010) investigation into the impact of an adolescent’s eating disorder on Chinese families revealed parents’ well-being and family functioning are adversely affected by the experience of caring for a child with an eating disorder. Further, Ma (2010) found that mothers self-reported higher levels of depression and anxiety than did fathers. Cultural differences influencing an interpretation of, and reaction to, AN has been of interest to qualitative researchers. Emanuelli et al. (2003) compared British and Italian mothers’ perception of family functioning, to examine whether cultural differences influenced the actions taken by parents towards their child with AN. Italian mothers were found to have more difficulties in establishing rules for behaviour, because rules within the family in Italian culture are not overt, but are agreed upon by family members. The strength within Italian family functioning was in communication. In contrast, British mothers reported less healthy patterns of communication and role definition, but greater clarity in the establishment of rules. The findings of this study revealed culturally divergent views of family life may have different influences on parental actions in adolescent AN, and could have an impact on how treatment is received. The results are of importance in the field given that other qualitative research has concluded that parents who firmly take charge of their child’s eating, is highly significant in predicting weight maintenance after discharge from hospital (Wood, Flower, & Black, 1998). Understanding cultural factors that may influence parental interactions with their adolescent around re-nourishing or managing unhealthy behaviours cannot be understood through clinical trials alone, yet they may be crucial to our understanding of processes that may support the recovery process.

AN thus poses significant disruption to family functioning and organisation. Although there are only a few studies that explore the experience of caring for a person with AN they all show that patterns of communication within families are substantially undermined by a focus on managing and coping rather than on progressing family ideals and/ or goals. Using a critical social work perspective and phenomenological approach to enquiry, this thesis aims to understand how multi-dimensional phenomena within families can be understood and embraced so that novel ways to involve parents in treating AN can be considered.
b) Parents experiences of treatment

Qualitative studies within Australia that examine parental experiences of seeking treatment for their child’s AN reveal this to be a frustrating venture. While parents are actively involved in activities such as seeking, negotiating and evaluating treatments (McMaster et al., 2004), several studies indicate high levels of distress in accessing services, not having parental competencies recognised, and being excluded from or not listened to in treatment (Honey et al., 2008; McMaster et al., 2004; Endacott et al., 2006; Tierney, 2005; Highet et al., 2005 & Hillege et al., 2006). Difficulties in accessing services are of concern, given the need to activate parental assistance with refeeding in the early stages of adolescent AN treatment to address complications related to malnutrition (Hatch et al., 2010).

While obtaining help through health services causes parents significant stress (Kyriacou, Treasure, & Schmidt, 2007), deciding on the best place to treat adolescent AN has been a problem for researchers. In the absence of any significant outcome associated with the optimal treatment setting for adolescent AN, beyond specialist outpatient as the most cost-effective (Gowers et al. 2010), understanding what constitutes quality treatment is of importance. In determining quality, the voices of service users are paramount. To explore the notion of a quality service, Roots, Rowlands, & Gowers, (2009) undertook a mixed-methods analytic approach to data taken from an RCT ([the TOuCAN trial] Gower et al., [2007]), comparing user satisfaction of generalist and specialist CAMHS for eating disorders, to determine quality in service delivery. By analysing the TOuCAN trial survey data of 215 participants and their parents and conducting focus groups with study participants, the researchers found parents had higher levels of satisfaction with specialist community-based services than general CAMHS. Parents valued expertise offered in specialist clinical settings by clinicians trained in more specialised individual and family therapeutic interventions. Although parents in this study also indicated they were satisfied with generic psychotherapeutic skills provided through generalist
CAMHS, the generalists were perceived by parents as lacking expertise in eating disorders. It may be that the absence of a specialist treatment setting for adolescent AN may see parents fail to commit to interventions provided by generalist CAMHS, due to a perceived lack of confidence in clinical judgement or ability. Roots and colleagues’ research provides a good example of qualitative findings enhancing our understanding of RCTs’ findings.

Other qualitative findings suggest cultural factors may impact upon help-seeking behaviours in adolescent AN. Patel, Phillips & Pratt (1998) suggest that in non-Western cultures, health care is directed at curing and preventing disease. In such cultures, AN need not be viewed as a critical illness in need of medical treatment. From such a perspective it is likely to be deemed a family problem and subsequently not something to be addressed by mental or medical health professionals. This is of particular interest in light of recent qualitative research into Asian-American adolescents and their non-Asian peers in the United States, suggesting acculturated Asian girls demonstrate unhealthier attitudes and psychopathology towards eating than their Anglo-Saxon peers (Lee & Lock, 2007). Qualitative findings such as these shed some light on the low participation rates in clinical trials, and the over-representation of white Anglo-Saxon young females in treatment.

2.4. Critique of the dominance of manualised treatments and RCT-reliant evidence in treating AN

The review of literature incorporated material that offered a critical appraisal of the impact of RCTs and treatments which are standardised in family and social work practice in mental health. Ten books, published from 1970 to 2010, providing an analysis of these practices were reviewed. Given that this critique is not the thesis’s central focus, only books regarded as seminal in the field of family therapy and or social work were included. The following critique draws on those works.
Fook’s assertion paves a path towards a critique of current RCT research:

*It is one thing to provide clear data or ‘evidence’ in situations that are known and testable. It is far more complex a task to ensure standards and improvement in situations which are new and relatively unresearched or ‘unresearchable’.*

(Fook, 2004, p.39)

### 2.4.1. Measures used in RCTs

Scientific measures used within clinical trials for adolescent AN are more expert driven and deductive, differing from inductive measures that are shaped by client and contextual perspectives. Measures used in clinical trials focus on clinical changes in weight or mood, are measured by standardized scales. While scientific instruments such as The Anorexia Nervosa Stages of Change Questionnaire (ANSOCQ) (Rieger, Touyz, & Beaumont, 2002) or The Eating Disorder Inventory developed by Garner, Marion, Olmstead and Polivy in 1983 (Dare et al., 2000) focus solely on the adolescent, a fundamental gap exists in accounting for the impact of family and context on outcomes, despite the influence in recovery of the family acknowledged by authors, and in clinical guidelines (NICE, 2004; RANZCP, 2004; Eisler, 2005; Bulik et al., 2007; Cook-Darzens et al., 2008; Ma, 2008; Barton & Nicholls, 2008; Rhodes et al., 2008; Lock & Fitzpatrick, 2009; Attia, 2010; Herpertz-Dahlmann & Salbach-Andrae, 2008; Keel & Haedt, 2008).

One scale used to measure outcomes in terms of family context is Haigh’s and Treasure’s (2003) Carers’ Needs Assessment Measure (CaNAM). The CaNAM was developed in the United Kingdom following a series of focus groups with carers of people with eating disorders. The intent of this measure is to identify and address unmet needs of carers. Haigh and Treasure (2003) suggest that if unmet needs of carers are addressed, then they will be more effective in their ability to care for their loved one with an eating disorder. With the family playing a
significant role in the recovery process of adolescent AN, measuring, addressing and reporting on the contextual needs of the family would take us a step forward in addressing the gap in the existing literature.

2.4.2. Participation and success rates in RCTs

Given the influence of RCTs in shaping service delivery to young people with AN, it is essential to understand characteristics of participation rates to assess the validity of claims of outcomes associated with clinical trials. Drop out is common in the treatment of AN (Rienecke Hoste, Zaitsoff, Hewell, & Le Grange, 2007; Gowers et al., 2010). While a recent review of dropout rates in community clinical studies for adult eating disorders (Fassino, Piero, Tomba, & Abbate-Daga, 2009) reveal poor treatment compliance within RCTs (29% and 73%), rates for adolescent RCTs on treatments for AN are much lower (10% and 20%) (Szmukler, Eisler, Russell, & Dare, 1985; Lock et al., 2005; Lock et al., 2006; Eisler et al., 2000). Participation of adolescents in clinical trials may differ from adult participants due to parental involvement in treatment that increases adolescents’ compliance and attendance (Hoste, Zaitsoff, Hewell, & Le Grange, 2007; Halmi, 2008). Parents may also influence participation rates by providing consent for participation that may result in a sense of commitment to the process.

It is interesting that five years following the publication of manualised family therapy for adolescent AN (Lock et al., 2001), some of the manual’s authors note:

... drop out is a considerable problem for feasibility of a clinical trial, since assessment of outcome depends on maintenance of sufficient participants in random conditions for meaningful data analysis (Lock et al., 2006 pp. 639-640).

Empirical support for manualised Maudsley family therapy has to date failed to account for the third of those who enter clinical treatment trials and simply do not recover (Le Grange & Lock, 2005). This is apart from the 10% - 20% who drop out of clinical trials. Maudsley family
therapy has been heralded as the most promising clinical intervention for adolescent AN (Loeb et al., 2007). Yet with a 67% recovery rate measured in terms of weight gain in clinical trials (Le Grange & Lock, 2005), questions remain about how to engage and treat the proportion who do not start treatment, drop out of treatment or fail to attain remission in terms of weight and eating-related psychopathology. Perhaps the promise of Maudsley needs to be treated with greater caution, given the lack of attention to those who withdrew from treatment in RCTs and the failure of clinical trials to account for 33% of study participants not recovering. Meaningful data analysis from Maudsley RCTs needs to be viewed with prudence given the 43% – 53% of adolescents enlisted in Maudsley clinical trials who remain unwell.

2.4.3. Socio-cultural factors impacting on participation and success rates for Maudsley

To appreciate the success of Maudsley we need to understand the variables associated with a failure to recover under Maudsley. For example, are there principles underlying the Maudsley approach that are inappropriate or unable to be applied in particular religious; cultural; gender or socio-economic contexts? Maudsley family therapy was developed in London (Dare, 1985) and later manualised in the United States (Lock et al., 2001). As such, its origins are in Western cultural values. The Maudsley model pays no attention to the potential impact of non-Western culture, which would be of particular relevance in Phase 1 of treatment (refeeding). An example of the influence of culture on refeeding is the pattern of behaviour during the time of Ramadan for Muslim families. During Ramadan no food is consumed from sunrise to sunset for an entire month as a sign of spiritual and religious respect. Graham, Bradshaw, & Trew, (2009) suggest Muslim parents struggling to refeed their adolescent with AN face a complex interplay of culture and illness during this time. This may be perceived as resistant to treatment requirements of Phase 1 in the Maudsley model.

Furthermore, conventional methods of refeeding adolescents, proposed by Maudsley, may pose a challenge for some cultural groups, which may not allow them to participate in Western
clinical trials or interventions. In thinking about Muslim families, attending clinical trials or treatment poses a direct contradiction to “informal ‘policies’ that promote resolving issues within the family” (Graham et al., 2009, p.550). In Chinese families “due to the diversity of Chinese families” participation in manualised approaches to treatment may result in “unmet needs”, such as recognition of family poverty or marital conflict that impact upon recovery (Ma & Lai, 2006, p.62). Although Lock and Le Grange (2013) note clinical trials using the Maudsley model have been conducted in non-Western countries, where adolescents and their families were willing to undertake this approach, there is an absence of accounting for the multiple discourses of cultural context that may impact on weight restoration within Western trials. The challenge for social workers is to be aware of becoming “dangerously positivistic and scientific” at the expense of exploration of knowledge and skills within a context (Fook, 2002, p. 10).

Given the limitations of scientific research, we cannot make definitive choices about the most effective family therapy treatment for mood improvement and weight gain for adolescents with AN for all presenting clients. We only know that Maudsley works for approximately two thirds of adolescents with AN who remain for the duration of clinical trials (Le Grange & Lock, 2005).

**2.4.4. A critique of positivism in research**

Researchers have examined components of family therapy to test which components produce the most effective outcome in treating eating disorders generally, and for AN specifically. In determining manualised, empirically supported treatments for eating disorders, researchers then examine fidelity to manualised treatments (Simmons, Milnes, & Anderson, 2008). Yet this positivist approach has resulted in gaps in knowledge in relation to: those with severe psychiatric disorders whose parents may seek assistance beyond standardised treatments evaluated in randomised controlled trials (Lock et al., 2006); males, who are under-represented in randomised control trials (Bulik et al., 2007; Rosen, 2003); and cultural or ethnic groups that are not reported (Bulik et al., 2007; RANZCP, 2004).
Researchers undertaking clinical trials control variables such as socio-cultural contexts that may impact upon an intervention, so the “experiment is able to identify whether there is a causal link between the intervention and the outcome” (Gray et al., 2009, p.32). However, Gray and colleagues (2009, p.32) point out that these controlled conditions oversimplify relationships, by failing to account for the “multi-dimensional and multi-directional” nature of causation in the social world, that are fundamental to social work interventions. Opportunities to broaden the agenda of enquiry to examine variables in the broader socio-political context, such as gender, culture and socio-economic status, have generally not been taken up. The knowledge that has emerged from clinical trials has resulted in the development and support of a manualised approach to treating adolescent AN. Whilst this is useful, it also has limitations in terms of guiding social work interventions.

One example of a blind spot limiting enquiry into AN, is evident in a study conducted by Pereira et al. (2006) with 28 participants, on the role of the therapeutic alliance in family therapy for adolescents with AN. The purpose of the research was to ascertain whether an alliance with the therapist made any difference to treatment outcome. While this research provided empirical support for therapeutic alliance as a determinant of effective outcomes, it failed to reflect on the significance of a homogeneous study population. While “the relatively high socio-economic status” of candidates “compared with the general community” (Pereira et al., 2006, p.683) was identified as a limitation in the research, it was deemed acceptable because “their socioeconomic status was fairly typical of other participants with AN who enter treatment studies” (Pereira et al., 2006, p.683). Failure to address the significance of the over-representation of a particular socio-economic group might misinform the ability to generalise research findings, and also contribute to the social construction of AN as a white, upper to middle class phenomena.
The lack of critical subjectivity of researchers within positivist research can, therefore, result in socially exclusive interventions that stand at odds with social work values and principles related to social justice as referred to in the Australian Association Code of Ethics (2010). Where study participants have been over-represented at the expense of those marginalised, the AASW Code of Ethics (2010) would direct social workers to pursue fairness in access to service by

... working with individuals, groups and communities, through both advocacy and policy reform initiatives, in the pursuit and achievement of equitable access to social, economic, environmental and political resources (AASW, 2010, p. 8).

A refocus on the social context provides an opportunity for social workers to consider effectiveness in broader terms outside of the treatment context, and into the community of the individual. A broader view of working with adolescent AN could include a social work focus on outcomes associated with the social consequences of AN, for example, determining how AN impacts upon family functioning and subsequent treatment attendance or adherence. In this way, effectiveness shifts to a socially inclusive measure of familial or the individual’s quality of life and how such a measure impacts upon accessing and maintaining treatment.

2.5. Qualitative evidence to guide practice

Much of the evidence to guide practice from qualitative studies relates to experiences of treatment and the impacts the illness has upon families. In building upon existing knowledge in the treatment of adolescent AN, it is essential to consider an integration of knowledge sourced from clinical trials, with the phenomena experienced by families in regard to caring and treatment. To view qualitative or quantitative studies as dichotomous denies the complexity of intervening factors within families who have been affected by the illness and the subsequent impact this has upon treatment. As discussed earlier, understanding the lived experiences of
parents through qualitative research is central to engaging with “participants in a holistic and meaningful way about their experiences of a particular intervention and its effectiveness” (Gray et al., 2009, p.36). By emphasising the experiences, views and meanings of participants, this thesis aims to fill a research gap. It draws on both qualitative and quantitative findings in order to better understand how the phenomena of care and treatment for adolescent AN is experienced and uses these insights to propose ways to enhance family based interventions.

Availability of evidence from RCTs is helpful in building knowledge about what works in treatment. Qualitative research compliments this evidence by building knowledge about experiences and how certain factors impact upon experiences. In particular for adolescent AN, qualitative research can yield better understanding of what engages young people and families from a variety of backgrounds in treatment, and what sustains this engagement. Social work intervention would benefit from a better understanding of how culture, for example, may impact upon fundamental skills in parenting that support recovery. There are clear imperatives in accounting for cultural determinants in research related to adolescent AN, given the growing empirical support for family-based interventions and Australia’s culturally divergent population, particularly where “one must also consider the Asian worldview and cultural values when determining a treatment method” (Kempa & Thomas, 2000, p.26).

What distinguishes social work in mental health from other disciplines is its analysis of the individual’s social context. Consideration of context allows social workers to account for the cultural background of our consumers. While this amounts to another complicating variable in research, it cannot be ignored in determining effectiveness from a socio-political perspective. An example of how the socio-political context is integrated in research is found in a series of qualitative studies conducted by Chan and Ma from the Social Work Department in The Chinese University of Hong Kong between 2002-2004. Chan and Ma adopted a case study approach (2002a; 2002b; 2004) to challenge and extend thinking in Hong Kong beyond the belief that AN arose primarily from a desire for slenderness or beauty (Lee, 1995; S. Lee, A.
Lee, Ngai, D. Lee, & Wing, 2001; Lee, Chiu, & Chen, 1989). One of their findings identifies the aetiologies of AN in Hong Kong as ‘multifactoral’ which shifted the focus of treatment from symptom reduction, related to biological factors associated with ‘slenderness’, to a “holistic treatment for the patients and their families” (Chan & Ma, 2004, p.184). These findings open the door to multidisciplinary work within an individual’s psychosocial and political context.

Chan and Ma’s qualitative research also challenges Western discourse about the importance of aetiology in the treatment of adolescent AN. The researchers claimed it is critical to understand the meaning associated with food refusal, as a primary cause of AN, and that this understanding is central to the recovery process (Chan & May 2004). The following quote from their (2002a) research provides a good example of why an understanding of factors related to causation of AN in Hong Kong is central to the recovery process:

Whenever I think about my parents, that they are old and about the financial constraints of my family, I do not want to eat because I am afraid that my family cannot survive ... (Chan & Ma, 2002a, p.183).

The cause of food refusal may be culturally bound, as in this case, by the concept of filial piety – a respect for parental financial circumstances.

Western researchers suggest a focus on aetiology distacts attention from the treatment process and can also lead to blaming the family (Le Grange & Lock, 2005; Lock & Le Grange 2005a, 2005b). Eastern thinking promoted by Chan and Ma suggests an understanding of aetiology is integral to the treatment process in Hong Kong (Chan & Ma, 2004). To simply refeed a Chinese girl with AN in Hong Kong without consideration of cultural context, where concerns about their parents’ financial hardship are a potential cause of the problem, may only serve to reinforce and maintain AN.
In terms of qualitative research into perceived effectiveness of family therapy for adolescent AN, only two studies were identified. One study was Krautter’s and Lock’s (2004) mixed-methods analytic approach to Maudsley, referred to in earlier chapters, and Ma and Lai’s (2006) qualitative research of perceived efficacy of family therapy for Chinese patients suffering from AN and their families. Both add insights into the processes involved in family-based interventions for treating adolescent AN in particular situations. Krautter and Lock (2004) suggested that adolescents and their families found Maudsley treatment effective and satisfactory. That research supported RCTs promotion of manualised treatment as acceptable and effective in recovery from AN by both adolescents and their families. However, Ma and Lai (2006) considered these findings inadequate to generalise to the Chinese context. The researchers preferred to undertake a qualitative study with patients and families who experienced other forms of family interventions, other than Maudsley, that they regarded had more relevance to the Chinese cultural context. As social work researchers, Ma and Lai contended the socio-cultural context of treatment provision was inextricably linked to helpful subjective experiences for families in recovery processes. Mai and Lai (2006, p.59) established “the importance of the therapist in being flexible and versatile in treatment” by, for example, being more direct with advice and support to parents in some situations and in other instances encouraging parents to share their pain with their child, as a way of attaining common ground against AN.

Adolescents who have AN and their families, have their respective cultures, views, values and developmental tasks either as a unit or as individuals. The time for contextuality (Fook, 2004) in research into adolescents with AN is upon us, as is our need to reflect upon the treatments in which we participate.
2.6. **Conclusion**

While there is considerable agreement about the value of family based interventions in the treatment of AN (NICE, 2004), the overall evidence base is limited (Keel & Haedt, 2008; Patel, Pratt, & Greydanus, 2003; Carney, Tait, Richardson, & Touyz, 2008). Social workers seeking guidance in their practice with adolescents with AN and their families can be informed by both quantitative and qualitative findings. While empirical knowledge from RCTs is useful in identifying components of family therapy deemed effective, it can also limit social work practice in this complex area, by focusing too narrowly on particular client groups and characteristics which are compatible with associated manualised treatment approaches. To address complexities associated with treating adolescent AN in a diverse socio-political context, social work practitioner can be guided by outcomes of RCTs, but should not have them define practice (Fook, 2002).

By challenging the dominant paradigm associated with clinical trials and scientific parameters, qualitative studies expand current ways of knowing by adding an interpretation of phenomena of illness interaction within families, culture and treatment settings. Inviting new knowledge into existing knowledge creates new possibilities for social work. This could prompt trialling new practice approaches that may in turn influence treatment outcomes and future research. How we think about what we know, and alternative ways of knowing will be explored in the following chapter.
Chapter 3. Rethinking knowledge on adolescent AN

As presented in the previous chapter, Western researchers and clinicians have endorsed particular family-based treatments for adolescent AN over the last 25 years. This knowledge has evolved in a context of privileging and legitimatising some practices identified through scientific methods as the only true way of knowing how to intervene. However, knowledge needed for daily practice may not match with knowledge generated from scientific approaches (Fook, 2012).

Over the last 30 years in Australia there has been a growing number of non-government organisations generating different kinds of knowledge in the area of AN. Organisations such as: The Butterfly Foundation of NSW; Eating Disorders Victoria; The Eating Disorders Association Inc. QLD; Eating Disorder Association of South Australia; and Women’s Health Works are dedicated to providing researched-based and general information to those affected by AN, and to treating clinicians. Alongside these organisations has been a growing number of useful websites that family members, parents, and carers access including: Around The Dinner Table (a moderated online forum); Families Empowered and Supporting Treatment of Eating Disorders (F.E.A.S.T.) (information, mutual support and treatment options); Maudsley Parents (online forum and information); and Eating With Your Anorexic (advice and support). These organisations and forums make a significant contribution to knowledge in lay and academic language for consumers, family members, general public, clinicians and researchers. A list of organisation and forum websites is provided in Appendix A.

Consumer-based knowledge, in combination with the growing research base for mental health disorders, helps social workers to make sense of the lived experience of the disorder for the client and their family members (Bland, Renouf, & Tullgren, 2009). This provides social work and other mental health practitioners with greater opportunities to maximise all potentials within
the context of the family, rather than simply treat a set of symptoms aligned to a diagnosis. It is additionally consistent with the domain of social work practice in mental health that requires attention be paid to the social context and social consequences of mental illness (AASW, 2008).

Using Fook’s (2012) postmodern and critical social work perspective, this chapter explores how reliance on dominant perspectives alone narrows the knowledge base, scope and vision of social work practice in mental health. It commences with a brief overview of social work in mental health, then explores a critical perspective on practice by considering the socio-political context and new narratives for practice. This section also acknowledges how a critical postmodern orientation to different ways of knowing, through multiple perspectives, shaped the approach of the study and the interpretation of findings. The chapter concludes with possibilities for new ways of knowing and understanding practice in adolescent AN.

3.1. Context for social work practice in mental health

In 1923, Lt. Col. J.R Lord, Secretary of the National Council for Mental Hygiene London, addressed the Society of the Crown of Our Lord on Social Workers and the Insane. He saw social workers as facilitators of social inclusion for the insane by linking community to mental hospitals.

... as much a necessity to the work of the psychiatrist as are professional nurses ...

to co-operate with medical men engaged in psychiatric work in and outside mental hospitals (Devine, 1924, p.304).

This construction of social work has remained fairly static, yet challenged, over time.

Historically, social work’s perspective in relation to helping people has not focused on individual work alone, preferring the consideration of social context and its impact on wellbeing
(Richmond, 1922; Addams 1910, 1990). In recent times, the complex interplay of factors in working with individuals, relationships between families, community and society has been encapsulated by the Australian Association of Social Workers (AASW) practice standards for social workers outlining a contextual knowledge base to guide practice (AASW, 2003). These standards were then build upon by the AASW and made specific to mental health social work (AASW 2008).

The interchanges within the multifaceted relationships between families, community and society need to be reflected upon and understood in working with individuals with mental health concerns in order to capture the unique circumstances of individual experience. It is within this context that a postmodern and critical social work perspective offers a domain of understanding and learning that can extend practice beyond what is held to be true in working with adolescent AN, because it challenges the divisions between thinking, practice and research associated with Maudsley.

Social workers in mental health settings have the opportunity to think and practice in empowering ways where:

… people affected by mental illness are among the most vulnerable and disadvantaged in our community. They suffer from widespread, systemic discrimination and are consistently denied the rights and services to which they are entitled (Burdekin, Guilfoyle, & Hall, 1993).

Addressing this discrimination is not an easy task given the complexities surrounding provision of social care to mental health service users within a practice domain heavily influenced and shaped by dominant scientific ideologies and paradigms. Nevertheless, the desire to seek socially just decision making in service delivery, devoid of a positivist approach to evidence-
based practice, proves to be a quest many social workers are willing to attempt (Gray et al., 2009).

3.2. A critical social work perspective

In order to understand how a critical social work perspective to practice may be of assistance in extending practice boundaries in adolescent AN, it is important to outline influences that have shaped critical social work practice and thinking. Critical social work practice has been informed by an evolution in thinking about and beyond critical social theory. Gray and Webb (2009, p.80) note “Critical social work tends to use postmodernism and Critical theory as strategies of thought rather than specific ideas” to engage a variety of intellectual debates in understanding how “dominant relations of power operate through and across systems of discourse”. With Karl Marx as the acknowledged founder of critical theory, it comes as no surprise that the original basis of critical theory rests with its critique of existing institutions and locates them as the sources of social problems and subsequent domination (Mullaly, 2007).

At a narrow level, critical theory has been influenced by a school of Western Marxism referred to as ‘The Frankfurt School’, where writers such as Habermas and Fromm advanced Marxist theories by drawing links between subjectivity or human agency to radical social change (Mullaly 2007; Briskman, Pease, & Allan, 2009). Individuals were viewed as having the capacity to make choices and impose those choices upon the world, rather than merely being subconscious beneficiaries of capitalist society, who were unaware of processes that alienate and exploit.

More recently, critical theory has evolved to better represent the differing political structures and intent of the global economy (Mullaly, 2007). A number of theoretical positions have been embraced within critical theory such as: emancipatory forms of feminism; anti-oppression; structural social work; and of most relevance in the Australian context, Jan Fook’s conceptual
framework of forged links between modernist theories and postmodernism known as critical postmodernism (Fook 2002, 2012). A critical postmodern perspective was adopted in this study because it promotes the value of different ways of knowing about the dimensions of parenting and treating adolescent AN that can contribute to the advancement of knowledge in this complex clinical area.

‘Critical theory’ therefore is not a term that describes a unified theoretical stance. It is a term used to describe a range of theoretical positions seeking to challenge dominant ideologies and social institutions impacting on people’s lives (Briskman et al., 2009). Briskman and colleagues suggest critical theory emphasises reflection on dominant ways of knowing and questions the place of existing social institutions, such as the family or health system, with a view to constructing a more just society. Critical theory, also known as critical social theory, seeks to analyse and challenge a society’s institutional governance, characterised by dominant exploitative and discriminatory ideological practices and processes, such as the construction of illness and treatment, to one that is emancipatory and free of domination (Mullaly, 2007).

Like critical social theory, postmodernism has also evolved to reflect the historical context. In broad terms, postmodern theorists intentionally add multiple reflections of relativity and uncertainty to debates about discourse and knowledge (Wood, 1997). Voices and experiences subjugated by dominant ideologies are respected and valued within discourse in preference to any certainty and absolution sourced and maintained through dominant dialogue and so-called experts (Fook, 2002). Postmodernism allows for different ways of viewing what can be known, as well as different ways of gathering what may be known (Fook 2002, 2012). Thus the movement from certainty to relativity; locality and agency constitutes a break from modernity and scientific enquiry as the basis of all truths. This poses a challenge to universal truths and knowledge.
This thesis adopts a critically reflective approach, informed by critical postmodernism, to allow disruptions in dominant understandings of treatment for adolescent AN and to provide space for other ways of thinking about intervening. By recognising that dominant ways of treating adolescent AN (Maudsley) may not be relevant to all presentations in CAMHS, treatment options may be expanded upon by embracing a range of perspectives on treatment, from parents and clinicians through a combination of research methods. In this study, this occurred through the use of a methodical design promoting multiple perspectives of parents and clinicians through their participation in different methods of inquiry, a survey (quantitative data) and/or interview (qualitative data). This approach captures different aspects of experiences of parenting adolescent AN in treatment because “multiple conceptual schemes can be used to describe the same reality” to expose the “dimensions of the phenomenon” (Fielding 2009, p.435). From a philosophical position, Fielding argues a connection between postmodernism’s interest in multiple perspectives and mixed-methods research designs through a shared belief in the notion that there is no single paradigm or way of knowing a ‘truth’. He contends postmodernism’s orientation is similar to methodological triangulation in so far as multiple perspectives provide many truths about the same reality in the same way as multiple methods complete and enrich our understanding of the phenomenon under inquiry.

Postmodern thinking in this study does not upend hierarchies; rather, it unsettles polarised constructions of treatment by postulating more complex ideas and thinking, thereby creating other avenues for knowledge creation (Fook 2002, 2012).

### 3.3. Use of critical social work principles in the current study

To achieve a postmodern and critical approach to service delivery in child and adolescent mental health, practice needs to be free of domination, exploitation and oppression (Fook, 2012). In addition, practice needs to be culturally sensitive and inclusive to build upon family capacity (Costello, 2009).
Fook’s (2012) conceptualisation of postmodernism and a critical approach to social work is demonstrated in this doctoral study by the way it challenges dominant ways of knowing how best to treat adolescent AN. Fook (2012, p.40) conceives postmodernism and a critical approach to social work as a challenge to scientific ways of knowing in the following ways:

*By asking ... why some forms of knowledge are valued over others*

*By focusing on how we know, as well as what we know*

*By drawing attention to different perspectives on what and how we know*

*By drawing attention to the perspective of the knower... (reflexivity)*

Fook’s ideas will be called upon to create new knowledge in treating adolescent AN by:

1. Considering why certain treatments such as Maudsley may be adopted by clinicians over other ways of working with families? Are other ways preferred in certain circumstances?

2. Exploring how parents’ and clinicians’ conceptualisations of adolescent AN influence how they parent or treat.

3. Eliciting the meaning of different experiences within participant groups, such as the different perspectives on parenting and treatment from parents with culturally diverse backgrounds, with Anglo-Australian parents, or between Maudsley and non-Maudsley trained clinicians.

4. Enquiring about how experiences in parenting or treatment have been shaped over time through reflection.

The synthesis of critical and postmodern perspectives generating a postmodern critical social work stance, where both the lived experience of the consumer (parent), and the knowledge of
the practitioner, in reflecting upon their interactions over time (Allan, 2009), will be called upon in this research to create new knowledge in working with families who experience adolescent AN. A critical postmodern approach to research and practice suggests that while understanding empirical knowledge leads to an appreciation of aspects of treatment proven to be effective, it acts as a guide to practice rather than defining practice (Fook, 2002). A critical postmodern perspective provides a useful framework to help open new possibilities for research and treatment.

3.4. The socio-political context for research practice

The dominant economic rationalist approach in our global economy brings challenges to social work practice settings where knowledge for practice is defined more by the intentions of neo-liberalism (Pease, 2009). In the current neo-liberal context for practice, policy makers assume that social workers practice in accordance with a managerialist agenda characterised by objective, positivist evidence-based interventions, where effectiveness is deemed through measurable outcomes and cost-effectiveness (Pease, 2009). The inherent worth of value-based social work skill and knowledge has been devalued in favour of objective measurements for outcomes producing sustainable cost-effective interventions in the free market (Fook, 2002). While Bland and colleagues (2009, p.42) argue social workers need to “be able to respond positively to the demands of managers … to support a social worker’s position on the value of specific interventions” they additionally state social workers “don’t just do things to people”. In a neo-liberal context for practice; however, social work in Western countries has become technocratised for ease of measurement (Dominelli & Hoogevelt, 1996). Furthermore, professional social work practice becomes more program based, with skills and knowledge promotion targeted to specific intervention programs (Fook, 2012). Such an approach fits well with the scientific RCT approach to research discussed in the previous chapter, which relies on standard, manualised treatments that aim to produce measurable outcomes.
The overall impact of knowledge creation generated by a managerialist agenda, for social work and many other professions, is that interventions are represented in managerial terms rather than within professional discourses. Efficiency and effectiveness in service provision have become defined, as Fook (2012, p.23) states, through a “purchaser-provider split”. Under such an arrangement, components of knowledge, skill and service provision are fragmented, specialised and goal orientated to produce “more efficient use of resources and more effective outcomes” (Pease 2009, p.48). Those who fund and administer services have the power to make decisions about interventions. In this context, Plath (2009, p.173) states “social workers are expected by management and funding bodies to provide evidence demonstrating effectiveness of their practice”.

The type of knowledge most aligned within the neo-liberalist context views facts as objective realities, constituting a truth. Positivistic methodologies such as RCTs support positivist assumptions about objective realities where interventions become standardised and people are viewed as units, independent of context or relational influences (Pease, 2009). Knowledge that translates positivistic methodologies become ‘gold standard’ and appeal to managers more than skills and knowledge associated with interpreting meaning, despite the fact that knowledge may not always suit different contexts (Smith, 2004).

There is no doubt such forces are also at play in the context of treating adolescent AN. Initiatives for service delivery for adolescent AN have been objectified and measured in an effort to demonstrate effectiveness and efficiency aimed at treating a disorder that can have the objective finite reality of death, if left untreated (Le Grange et al., 1992; Lock et al., 2001; Lock et al., 2005; Lock et al., 2006; Lock et al., 2010; Krautter & Lock, 2004; Wallis et al., 2007). As promising as the knowledge gleaned from these RCTs may be, they are devoid of relational or contextual factors that may also have some bearing on outcome, outside of the experimentally designed environment. Current discourse on parenting provides one example of how contextual factors may impact upon a parent’s ability to participate in manualised treatment determined
through RCTs. Coveney (2008) suggests that post war discourse in Western society on what is perceived to be good parenting, is characterised by negotiation rather than direction, with children included in decision making related to food and meal times. He suggests this has an impression upon parents’ perceptions of their responsibilities in the provision of food to their children. The belief that the basis of ‘good’ parenting rests with negotiation with children around meal times may either compromise parents’ willingness or ability to undertake sequential tasks associated with re-nourishment outlined in RCT evidenced, manualised Maudsley treatment, or may, alternatively, assist parents to re-nourish in ways other than those proposed by manualised treatment programs. With limited evidence base for adolescent AN, it is somewhat surprising there continues to be a specific, standardised way of working with families. A socio-political analysis helps to explain how manualised Maudsley or Maudsley-type approaches, reinforced by RCT evidence, have gained and maintained dominance.

Knowledge in the area of treating adolescent AN has been influenced by managerialism and positivism much more so than by the experiences of either families or clinicians. Decisions about service delivery options are made largely on the basis of cost-effectiveness. A good example of this is findings of Gowers and colleagues who conducted a large multicentre RCT of adolescent AN in the UK comparing various forms of treatment (described earlier). This RCT concluded:

*Outpatient care...may be a preferable approach. The health economic analysis and user views both support NICE [National Institute for Clinical Excellence] guidelines, which suggest that anorexia nervosa should be managed in specialist services that have experience and expertise in its management. Comprehensive general CAMHS might, however, be well placed to manage milder cases. Further research should focus on the specific components of outpatient psychological therapies* (Gowers et al., 2010, p.1)
On the basis of economies of scale suggested by Gowers et al. (2010), generalist CAMHS service provision is deemed limited in its ability to work with adolescents who have more than mild AN. A hierarchy of treatment settings, defined by economic imperatives, creates a devaluation of generalist service provision and treatment. The absence of knowledge in positivist research such as Gowers and colleagues or Lock and colleagues about the agency of client, family and service provider; however, creates some space for critical social work to contest the meanings of this evidence, and contributes to new knowledge and practice in working with young people with AN and their families, beyond treatment setting and manualised approaches.

3.5. The narrative in research and practice

Individuals’ narratives about their experiences of treatment can broaden thinking about treatment possibilities as they provide “a key avenue to identifying and understanding how they construct their ‘realities’ and how they might then be changed for therapeutic purposes” (Fook 2002, p.67). This type of knowledge can be sourced from qualitative studies and reflections within a critical theoretical framework of qualitative enquiry.

Central to critical social work is the recognition of the multiple meanings from participants’ own subjective experience and discourse on treatment (either received or provided). Meaning making or making sense of what is experienced or said is, as Ife (1997, pp.130-31) suggests, an “interpretative stance to social science”. Within this context, meanings are viewed as knowledge that changes over time and does not exist independently of the reader or researcher. Meaning is made by the interaction of reader or listener and teller.

Looking at practice from a critical postmodern perspective, Fook (2002, p.69) contends that “formal theories act as intellectual tools not rules”. Fook (2002) suggests theories act as sets of languages and discourses that help us communicate ideas; theories act as a frame of reference to
help us make sense of situations. Fook (2002, 2012) cautions against ascribing theoretical frameworks to practice that does not support the concept of multiple meanings derived from people’s lived experiences because it limits the possibility of new knowledge. Consumers can act as informants to practice and practitioners’ own reflection and theorising. The potential impact on practice of a dominant discourse is the subjugation of experiences outside the language of formal theory. For example, knowledge sourced from personal accounts or reflections upon culture and context fail to influence practice, thereby limiting potential strengths and resources within families in treatment. When the evidence base is limited, as it is with adolescent AN, practice knowledge should not be limited in a way that restricts access to resources, possibilities and new insights for practice options. Well-researched narratives can enhance understandings and appreciation of different experiences of AN, that can in turn inform approaches to practice.

3.6. Construction of knowledge

The 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), (2013), is published by the American Psychiatric Association (APA). The DSM has influenced ideas about knowledge as it relates to mental illness since it was first published in 1952. DSM-5 is a modernist construct in the way it classifies and defines mental disorders as objectified realities. To practice in mental health services, social workers are “expected to have a working knowledge of the system of classification used in mental health services” such as the DSM-5 (Bland et al., 2009, p.98). Alongside other mental health professionals, Bland and colleagues (2009) contend a working application of knowledge sourced from the DSM is necessary for sharing of tasks with other members of the multidisciplinary team, such as those associated with assessment and treatment, in addition to understanding how disorders impact upon the lived experience of the consumer.
The DSM, under constant revision, provides baseline knowledge arising from ongoing research generated by scientific findings primarily by the medical profession of psychiatry (Dziegielewski, 2002). This knowledge is interpreted and produced by members of taskforces and working groups deemed to have expertise in the field of psychiatry (APA, 2013). A website created by the APA in 2012 for the DSM user community proclaims “professionals from the mental health and medical communities, patients and members of the public have had a strong voice in DSM-5” (APA, 2012). The APA recruited 160 clinicians and researchers from a range of medical and mental health professions including social work, psychiatry, psychology, paediatrics and nursing to ‘Work Groups’ such as the Eating Disorders Work Group, to review scientific literature and propose draft criteria for respective diagnostic presentations (APA, 2012). However, whilst all of these groups may have participated in the construction of the DSM-5, knowledge represented in the DSM is subject to the powers and influence of argument of members in each committee (Bland et al., 2009). Further, Dominelli (2005) warns that a reliance on research lead by experts in their field can be used to discredit the contribution of service users by silencing or subjugating their experienced-based knowledge in an effort to privilege, reinforce and maintain expert knowledge. Dominelli states:

... the privileging of expert knowledge, particularly those forms that adopt the supremacy of natural science paradigms can carry intellectual arrogance as a by-product. This approach holds sway in the social sciences and disinherit social work research with service users Dominelli (2005, p.24)

Knowledge derived from the DSM is subject to cultural and contextual bias, having the potential to represent the voice of those with more power and influence in Western society. The DSM does not acknowledge this social construction of knowledge. Nevertheless Bland and colleagues (2009, p.101) argue that knowledge sourced from the DSM helps social workers and other mental health practitioners share “a common language for research and for treatment of
people with mental disorders”, that helps with engagement in person-centred practice with colleagues and consumers.

Knowledge attained through a critical postmodern stance allows for different ways of viewing what can be known as well as different ways of gathering information about what may be known (Fook, 2002). In treating adolescent AN, knowledge relating to effectiveness of treatment may come from parents’ direct experience within a particular context and specific circumstances, in addition to findings from the evaluation of discreet programs obtained using ‘objective’ measures and experimental designs, because “recognising different ways of knowing” can create new knowledge (Fook 2012, p.51). Knowledge gained through a critical postmodern perspective allows for a deeper appreciation of effectiveness based on individual differences in treatment, rather than by relying solely on the measurement of effectiveness of a particular treatment for every instance.

The development of professional knowledge through social work research in Australia has gathered momentum with the growth and interest in debates related to an evidence base for practice in social care (Pease & Fook, 1999; Fook 2002, 2004; Smith, 2004; Plath, 2006, 2009; Gray & McDonald, 2006; Gray et al., 2009). At one level, practitioners and academic staff members participate in research to enhance and advance reflective practice and consequently optimise service outcomes for consumers (Fook 2002, 2004; Pease & Fook, 1999). Other researchers, such as Gray and McDonald (2006) emphasise the importance of the value base of social work research in the interpretation of research findings as an alternative to narrow scientific views sourced in positivist research. Internationally, there are social work researchers such as Thyer (2002), who argue the need for social work to evidence efficiency in service delivery to remain relevant in a competitive market for funding of programs and subsequent positions. However, Plath (2006) believes it is possible to blend critically reflexive methods with research findings from a range of methods because “evidence-based practice in social work seeks to value evidence gained from experience and understanding of contextual factors, as well
as research evidence” (Plath 2006, p.70). This study supports the view held by Plath (2006) as it seeks to add to the existing knowledge base in treating adolescent AN by integrating findings sourced from scientific quantitative and critically reflective qualitative methods.

3.7. Conclusion

This chapter has argued that new knowledge in the area of adolescent AN can be informed by adopting a postmodern and critical social work perspective that asserts there is no single ‘truth’ to knowledge in this area. There is an important place for description of experiences and events as they are interpreted. This study reports the dynamics of power within the researcher-participant relationship is disrupted in order to create knowledge that de-privileges the claims acquired through positivist paradigms and invests in subjugated knowledge of participants. From this perspective, research and knowledge have to be enacted from a moral and political standpoint where the participant is viewed as a person with agency, and an active contributor to the research, so that there is a direct link between the outcomes of the research and the participants’ contribution.

Knowledge acquisition that respects and privileges the voice of consumers and practitioners in the interest of promoting reflective practice still has to locate a legitimised methodology to respectfully carry the voice and intended meaning of participants. One such methodology is Interpretive Phenomenological Analysis. The methodological approach to the research is presented in the next chapter.
Chapter 4. Methodology

This chapter outlines the methodological approach to the research. It commences with ideas and concepts associated with phenomenological philosophy, which informs the interpretive approach to the research, and then examines the theoretical framework for the mixed-methodological research design. The chapter discusses some of the benefits and challenges of Interpretative Phenomenological Analysis (IPA) and a mixed-methods design. It concludes with an overview of two embedded studies. The first study examines the views and experiences of clinicians and the second, the views and experiences of parents. Each study used self-report questionnaires and in-depth semi-structured interviews, to generate quantitative and qualitative data to address the research question and aims.

4.1. Theoretical framework for methodology

4.1.1. A phenomenological approach

This study considers the phenomenology of parenting a child with AN who is receiving family-based treatment in a community-based mental health team, and explores how parents and clinicians explain these phenomena. Given participants had experienced family-based treatment for adolescent AN, the researcher thought that parents and clinicians were likely to have given consideration to aspects of treatment they found helpful or not and to have multiple explanations for their experiences. To make sense of what was considered helpful in treatment, a phenomenological method of analysis - IPA was chosen, because it permits a focus on the subjective experiences of participants in the context of their personal stance and perception (Greene, Larkin, & Sullivan, 2009). Through the use of rigorous methods of analysis, this approach also allowed for a movement beyond subjective descriptions to an interpretation of how participants made sense of their experiences and then, how the researcher makes sense of
these experiences, from different perspectives (Smith et al., 2009). The IPA approach complements a critical social work perspective as both recognise a diversity of experiences and that interpretations of these experiences are shaped over time. As this study set out to examine practices both within and beyond those located in Maudsley, it was important to consider experiences of all family-based treatment received and provided from multiple perspectives. This enabled the researcher to understand the contextual relationships between participants’ experiences and treatment processes and, through the processes of interpretation, develop a phenomenological account of the participants ‘experiential claims’ (Smith et al., 2009).

The IPA approach to qualitative research was first argued by psychologist Jonathon Smith (1996). While its core concerns are with psychological aspects of the experiential, it has been used by many other disciplines interested in psychological questions related to personal experiences (Ajjawi & Higgs, 2007; Macdonald, Murray, Goddard, & Treasure, 2011; Whitney, Currin, Murray, & Treasure, 2012; Sternheim, Konstantellou, Startup, & Schmidt., 2011; Chow, 2010). Although IPA is a relatively new method of inquiry, it has drawn on concepts and manifested ideas from theoretical ideas that have a longer history, such as phenomenology and hermeneutics (Smith et al., 2009). A brief outline of phenomenology and hermeneutics is provided to help clarify some of the key concepts and ideas associated with IPA.

Smith et al. (2009, p.11) states “Phenomenology is a philosophical approach to the study of experience”. It is essentially the study of lived experience or the life world (van Manen 1997). Phenomenology searches for meanings in human experiences through the systematic, reflective and inter-subjective study of the lived experience (Smith et al., 2009). Its focus of inquiry is on the world experienced in the consciousness of the individual, rather than the world or reality as something that is distinct from the person (Laverty, 2003). Phenomenological inquiry asks what a particular experience is like in order to reveal meanings experienced in the consciousness of individuals’ everyday existence, produce rich textual descriptions of that experience, and
connect with others’ experiences of similar phenomena. Its contribution to qualitative research is constructionist in nature, as it involves a detailed description and analysis of the lived experience “to understand how meaning is created through embodied perception” (Starks & Trinidad, 2007, p.373). The intention of a phenomenological approach to inquiry is to return and re-examine taken-for-granted experiences, and expose new or subjugated meanings (Starks & Trinidad, 2007; Laverty, 2003).

The German mathematician and philosopher, Edmund Husserl, set some of the foundational principles of phenomenological inquiry that have since been developed by other phenomenological philosophers (Smith et al., 2009; Larkin, Watts, & Clifton, 2006). Smith et al. (2009), suggest that Husserl was interested in finding a way in which someone might understand their own experience of a phenomenon with a depth and rigour that allowed the essential qualities of that experience to be identified. If this could be achieved, then the features of this experience would transcend pre-existing ways of knowing what is observed and understood in that instance, to a more reflective stance that links the experience to the subconscious. Connecting lived experiences to reflective subconscious processes creates the phenomenon that is beyond the taken-for-granted activity (Larkin et al., 2006). Husserl developed a phenomenological method to “identify the core structures and features of the human experience” that has contributed to qualitative research methods (Smith et al., 2009, p.13). This method requires us to consider the consequences of everyday taken-for-granted experiences and try to set them to one side in order to concentrate on our and others’ perception of the experience. By using ideas from mathematics, Husserl suggested we bracket or place to one side the taken-for-granted world and replace it with the world as we perceive it (Smith et al., 2009). Smith and colleagues suggest the taken-for-granted approach is not lost; rather, it is managed through a series of reductions where the inquirer is taken through different ways of thinking and reasoning about the phenomenon at hand, in order to get to the essence of the experience of a given phenomenon. For example, a parent’s experience of parenting their child.
with AN in treatment will involve drawing upon their past experiences of parenting their child, imagining what it might be like for their child to receive help, and what it is that makes undertaking treatment helpful or not. The aim of the process is to get to the essence of seeking help, and attend to what treatment for adolescent AN means to parents, including the practical and emotional components of parenting.

Alternatively, Husserl’s views of phenomenological inquiry through individual psychological processes were largely conceptual. One of his students, Martin Heidegger, developed Husserl’s views by being more concerned about “the ontological question of existence itself” (Smith et al., 2009, p.16). Heidegger’s developed hermeneutic phenomenology, a concept used to address the experience of ‘being-in-the-world’ (Vis, 2008). Laverty (2003, p.7) contends that, while Husserl focused on understanding phenomena through psychological processes such as perception and consciousness, Heidegger focused on the “situated meaning of a human in the world”. Heidegger emphasises a contextualised phenomenology. He suggested our thoughts are a derivative of our worldly experience, and as such, the person is always a ‘person-in-context’ (Larkin et al., 2006). Conceptually, Heidegger extends the phenomenological approach by suggesting people and the world are inextricably related in cultural, social and historical contexts. People are therefore thrown into a “pre-existing world of people and objects, language and culture, and cannot be meaningfully detached from it” (Smith et al., 2009). Therefore

… meaning is found as we are constructed by the world while at the same time we are constructing this world from our own background and experiences (Laverty 2003, p.8).

From Heidegger’s perspective our relatedness to the world is a fundamental part of who we are, and that being-in-the-world involves “practical engagement with the world … self-reflection
and sociality, affective concern” and importantly a “temporal existential location”, meaning lasting for an unknown, finite time (Smith et al., 2009, p.17). In this way a human’s interpretation of every encounter is influenced by their own history or background for that moment (Laverty, 2003). Heidegger draws the attention of the inquirer to our contextualised relational engagement with the world and their relational experience to the process of inquiry. He was particularly interested in the process of interpreting the meaning of human existence, as one experiences it. His concept of interpretation, influential IPA, is based on the understanding “that how one sees the world depends on how one interprets it” (Vis, 2008, p.4). Heidegger’s hermeneutic-phenomenology provides an investigative model that is interpretive of both content and method so that:

... when the researcher and the researched are engaged in understanding the meaning or experience of a certain phenomenon, they are not free from previous influences of others ... our interpretations are not entirely our own, but influenced by shared and historical experiences (Vis, 2008, p.4).

Husserl’s and Heidegger’s work has informed IPA’s approach to qualitative inquiry (Smith et al., 2009). Smith and colleagues cite Husserl as helping IPA researchers to focus on reflection, by systematic examination of the content of the consciousness, through techniques of bracketing and reduction. A focus on reflection of the lived experience together with a sequencing of reductions, aimed at reconsidering content from different ways of thinking and reasoning, helps the researcher move away from their own assumptions and towards the essence of the phenomenon. Heidegger’s hermeneutic phenomenology brings IPA researchers to an understanding of the person-in-context “by exploring person’s relatedness to, or involvement in, the world” (Larkin et al., 2006, p.117). IPA’s approach to “capture something of the claims and concerns of the person-in-context with the more speculative development of an interpretive account” is consistent with Heidegger’s ‘contextualised’ position (Larkin et al., 2006, p.117).
An interpretative phenomenological perspective was chosen for this study because it focuses on what can be learnt from meanings constructed through dialogue; in particular, what is learnt, from shared meanings that are enacted in the talk of interviews and how the context of this dialogue informs those meanings. This approach allowed the exploration of participants’ experiences with interpretation by the researcher based on the researcher’s theoretical and professional knowledge. Similar to a critical social work approach, IPA emphasises that a reflective process is required in order to reveal relationships between an individual’s inner world, contextually constructed meanings and their agency. Yet, one of the challenges of undertaking an IPA approach to analysing qualitative data has to do with the role of subjectivity in research (Frost et al., 2010). Subjectivity in qualitative research, as represented by the living knowledge of an individual, is re-authored through the co-construction of the meaning of an experience by researcher and participant, with the aim of capturing multiple meanings of narratives across several dimensions (Reason & Riley, 2008). Subjectivity does not exist “as a rigid and bounded entity or process”; it can only be revealed in part to an outsider as it occurs in temporal moments (Frost et al., 2010, p.454). It therefore raises the question of transparency and control, and how much the researcher chooses to reveal of the participant’s interior world (Frost et al. 2010).

Quantitative researchers regard subjectivity as a variable to be controlled to safeguard against bias in the study, in the pursuit of an absolute knowledge about the issue under investigation (Drapeau, 2002). Smith (2004) acknowledges the subjective element in the data transformation process in IPA research, and suggests it is attended to through modes of hermeneutic engagement in the analysis; empathic reading then qualified by more critical and speculative reflection. Smith et al. (2009, p.32) argue the idiographic commitment of IPA which views participants in their contexts, exploring their personal perceptions, and “starting with a detailed examination of each case before moving on to more general claims”, demonstrates sensitivity to context and validity in qualitative research.
The researcher had experiences in providing both Maudsley and non-Maudsley family therapy to adolescents with AN in one of the study sites and, as discussed in the introduction chapter, the initial idea for this research arose from those experiences. In adopting a critical social work perspective these experiences allowed for a questioning of why some forms of knowledge related to treatment, namely Maudsley, was valued over other ways of knowing that could also be useful in treating adolescent AN. Previous experiences offered a depth of understanding of the practice context and methods. It allowed the researcher to grasp terms and concepts discussed in interviews with participants such as ‘the family meal’ or ‘Phase 1’ of treatment. Care was taken to draw a distinction between myself as a researcher and as a practitioner for the purpose of this research, to safeguard against any experiential bias in the study. This was achieved by close attention to the qualities of an IPA researcher such as: “open-mindedness; flexibility; patience; empathy; and the willingness to enter into, and respond to, the participant’s world” (Smith et al., 2009, p.55). Use was also made of the supervisory team in reviewing findings and interpretations, in order to offer alternative viewpoints and to strengthen the validity of interpretations.

4.1.2. Mixed-methods design

Conceptual interest in mixed-methods, as a process of social inquiry, has been gaining momentum over the past 30 years (Tashakkori & Cresswell, 2007). Social scientists have been seeking new and innovative ways of understanding complex phenomena in a manner that attends to both the rigours of research design as well as lived experiences (Greene, Caracelli, & Graham, 1989; Morse, 1991; Hanson, Creswell, Plano Clarke, Petska, & Creswell, 2005; Greene, 2008; Castro, Kellison, Boyd, & Kopak., 2010; Dures, Rumsey, Morris, & Gleeson, 2011). In recent years, combining quantitative and qualitative data, and consequently drawing on both positivist and interpretivist paradigms within a single study, has become acceptable within research designs. This is a way for researchers to tackle complex phenomena by integrating data of different types from different sources to strengthen the quality of the research
findings and offering different perspectives on the phenomena under investigation (Hanson et al., 2005; Walter, 2007; Sarantakos, 2005; Johnson, Onwuegbuzie, & Turner, 2007; Tashakkori & Cresswell, 2007; Morgan, 2007; Bryman, 2007; Greene, 2008; Castro et al., 2010; Mertens, 2010). An increasing articulation of mixed-methodology research designs has some researchers asserting that it is the third major research paradigm: quantitative research, qualitative research and mixed-methods research (Johnson et al., 2007; Denscombe, 2008; Dures et al., 2011).

While scholars often refer to a mixed-methods project as “one that includes a qualitative and a quantitative substudy” (Tashakkori & Creswell, 2007, p.3), a distinction needs to be made between mixed-methods as the combination of two types of data (qualitative and quantitative), and mixed-methods as an integration of two approaches to research methods (qualitative/interpretive and quantitative/positivist). The latter focuses on methodology whereas the former has its focus on the type of data generated. Tashakkori and Creswell define mixed-methods methodology as “research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches and methods in a single study or program” (Tashakkori & Creswell, 2007, p.4).

Traditional debate surrounding mixed methods relates to philosophical stance and methods of inquiry. Fundamental differences in approaches to studying the social world exist, where “assumptions about the nature of reality (ontology) and ways of knowing and understanding (epistemology)” render a divide between positivist (quantitative) and interpretive (qualitative) paradigms (Dures et al., 2010, p.2). A puristic stance asserts traditional paradigms are essentially incompatible and therefore it is not possible to mix paradigms in a single study (Lincoln & Guba, 1985; Brewer & Hunter, 1989; Morse, 2003). This view maintains an ontological divide where reality is either: universal, objective and quantifiable, (quantitative framework) or socially constructed by the person’s experience, (qualitative framework). From a purist’s perspective, methods of enquiry into the social world should support, value and uphold the ontological and epistemological underpinnings of each respective paradigm and as such, it is
not possible to mix paradigms in the same study. An alternative is the a-paradigmatic stance, that views paradigms as helping only in thinking about practice, as opposed to guiding practice, and epistemologies can therefore be mixed and matched in varied combinations (Patton 2002; Reichardt & Cooke, 1979).

Within the mixed methods research community, deliberations about how paradigms should be mixed or integrated in the process of enquiry “remain one of the most disputed areas in the theory of mixed methods” (Greene, 2008, p.10). For instance, mixed-methods researchers who adopt a dialectic stance suggest traditional paradigms are historical social constructions that differ in important ways; knowledge is attained through an appreciation and exploration of paradigm differences (Greene & Caracelli, 1997; Maxwell & Loomis, 2003). The exposition and engagement in paradigm diversity brings about new knowledge and understandings. Alternatively, other mixed-methods researchers such as Teddlie & Tashakkori (2003) and Mertens (2003) promote the value of the integration of qualitative and quantitative strands throughout the research process, opposing the illumination of differences. This latter approach reconciles any philosophical incommensurability among paradigms to enhance findings about research problems, rather than using either qualitative or quantitative approaches alone. Particular attention to the notion of integration is inherent in this approach, where the incompatibility of research paradigms is rejected, claiming research paradigms can remain separate but they can also be mixed together into another research paradigm to “provide superior research findings and outcomes” (Johnson et al., 2007, p.129).

In this study, a mixed-methodological approach has facilitated the integration of findings regarding experiences of participants and therapeutic processes with the assessment of outcomes. This has entailed both an inferential qualitative approach and a quantitative survey approach. The function of mixed-methodology in this research is to facilitate a full appreciation of an approach to knowledge that links theory and practice, through considering multiple points of views, perspectives, positions and standpoints, by integrating qualitative and quantitative
approaches in one study (Bryman, 2007; Johnson et al., 2007). As a research design, mixed-methodology is used when the principal aim is to generate a deeper explanation of phenomena through the integration of qualitative and quantitative data that is “above and beyond the sole use of a qualitative or quantitative approach” (Castro et al., 2010, p.345). A mixed-methodological approach in this research helped to synthesise knowledge gained from qualitative and quantitative methods to present meanings of those participants in the sample.

The issue of paradigm-method suitability in seeking research evidence has generated considerable debate within the social and behavioural sciences for decades (Reichardt & Cooke, 1979; Guba & Lincoln, 1989; Smith, 1983). A bridging of strengths within each approach brought new meanings to this study. Mixed-methodology allowed inferences to be drawn about efficacy and experience of treatment for adolescent AN through the process of integrating knowledge and data from two approaches.

4.2. Bringing together quantitative and qualitative data in this study

In exploring the phenomena of treating adolescent AN, a combination of qualitative and quantitative data are triangulated in this research design, to maximise the benefits of each (Denzin, 1978). A fusion of quantitative and qualitative data provides an integrated analysis that enriches research findings associated with the small sample size. A mixed-methods research design was chosen to incorporate and integrate specific information, such as elements of effectiveness and experiential phenomenon in treatment, to facilitate an understanding of meaning behind experience and the degree to which meanings are shared between study participants.

The value of qualitative data in exploring phenomena associated with clinicians’ and parents’ experiences of treatment for adolescent AN was as follows:
• it provided a way to explore social meaning (Travers, 2007)
• it permitted consideration of thoughts and feelings that were “highly pertinent” to treatment (Busfield, 2006, p.221)
• the methods (interviews) and data collection (text and explanation) were closer to the reality of the lived experience of participants (Alston & Bowles, 2003)
• it provided insight to the “importance and relevance of interventions in people’s lives” (Plath, 2006, p.64)
• it endorsed an interpretive stance by the researcher, where phenomena were understood from the inside, focusing on how people experience and interpret meanings in their life, in a non-objectifying manner (Shaw, 1999) and
• “its respect for people as active agents in meaning construction relative to their social action coincides with the growing recognition of the need for incorporation of a consumer’s perspective in the knowledge development of clinical social work” (Ma & Lai, 2006, p.62).

The value of quantitative data in this study was as follows:

• it captured a snapshot overview of attitudes
• it provided a means to collect large amounts of data accurately and quickly (Sarantakos, 2005)
• it offered capacity to conduct group comparisons and the extent of association between clinician and parental variables (Castro et al., 2010)
• the use of a standardised scale also provided for comparisons to prior research pertaining to the helpfulness of manualised family treatment for adolescent AN, (Krautter & Lock, 2004).
To enhance validity, a sequential implementation of methods was chosen as the study’s design. Quantitative survey data, relating to parents’ and clinicians’ levels of perceived experiences of treatment, were followed by qualitative interviews. The interview data was then used to corroborate, refute, explain and expand upon findings from the survey. This design gives voice to diverse perspectives under examination “where phenomena may be changing as a result of being studied” (Hanson et al., 2005).

The quantitative component of the study asked parents and clinicians to rate their perceptions of how important and effective particular elements of treatment were in the management of AN. The qualitative component of this study explored parents’ and clinicians’ attitudes and experiences of engagement in treatment, processes in effective treatment, and recovery from AN. This data was used to gain insight into, and understandings of, perceptions of effectiveness in treatment. The phenomenon of effective treatment of adolescent AN, from parents’ and clinicians’ perspectives, was therefore explored by linking and sharing the aims of qualitative and quantitative data within this research.

Bringing quantitative and qualitative findings together throughout the research process has the potential to “offer insights that could not otherwise be gleaned” (Bryman, 2007, p. 9). One of the most important considerations within mixed methods research is an appreciation of what each component of the data contributes and how that may illuminate information and data already provided. Merging the analyses of quantitative and qualitative data is mutually informative. In this study, mixed methods research was about developing a negotiated account of the findings that brings together both components of the conversation.
4.3. **Benefits and challenges in the use of Interpretative Phenomenology Analysis and mixed-methods**

The benefit of utilising an interpretative phenomenological approach to inquiry in this study rests with its aim to provide a “detailed analysis of divergence and convergence across cases, capturing the texture and richness of each particular individual examined” as opposed to “developing accounts of commonality in experience” (Smith et al., 2009, p.200). This is important in this thesis, because IPA’s idiographic aim of a detailed description of what each participant’s experience was like and what sense they made of what happened for them, captured diversity and congruence that is vital in understanding contextualised processes that optimise treatment experiences for parents. For example, what was it about Maudsley treatment that was useful and helpful for some parents and not others, or what were important considerations for clinicians that resulted in modifications to treatment? Further, when multiple perspectives of parents and clinicians are considered, IPA’s idiographic commitment allows a more detailed and multifaceted account to be developed of the phenomena of parenting, and of treating adolescent AN. This was particularly useful given the small, purposively-selected number of participants in this study; not uncommon in research associated with treating AN because “the relative rarity of anorexia nervosa makes recruitment challenging” (Watson & Bulik, 2013, p.2478)

Hunt (2009, p.1290), points out one of the challenges in adopting an interpretative approach, suggesting interpretative researchers may risk not developing the interpretation sufficiently and therefore limiting “the usefulness of the research findings for their intended practice application”. This, he suggests, can be offset by pursuing a degree of interpretation that yields useful insight to guide practice (Hunt, 2009). In this research this is realised by pursuing practices that help parents engage in meaningful treatment, and conceptualised by probing and “picking up on important cues from the participant and digging deeper” for thoroughness and generalizability (Smith et al., 2009, p.181). Another challenge for interpretative research is often
posed by quantitative researchers who question the validity and reliability of IPA (Smith et al., 2009), however, “qualitative research is what quantitative research is not” (Sarantakos, 2005, p.44). Sarantakos (2005) suggests it is merely different to quantitative research, not inferior.

The value of a mixed-method design in this study is in its use of more than one investigative approach representing different types of paradigms, each with their own values and techniques guiding the research process, to achieve a higher degree of validity and credibility (Creswell, 2003). In research designs for mental health services, qualitative methods compliment quantitative research methods because qualitative methods offer more than a consumers’ perspective; they are “ideal for generating formative contextual data for intervention” because “a protocol that works in a controlled trial may simply not be feasible in real-world settings” (Robins et al., 2008, p.728). In this way, designs for research including qualitative and quantitative components help uncover previously unrecognisable factors affecting service use and delivery (Robins et al., 2008). Data collection and analysis procedures from each paradigm, used in survey and interviews, resulted in a “thick description” of the phenomenon that would not have been possible if only one paradigm was employed in this study (Johnstone, 2004, p.264). This is essentially “the case of all the data being necessary but insufficient on their own to explain a phenomenon in a rigorous and credible manner” (Johnstone, 2004, p.264).

A challenge in adopting mixed-methods research pertains to representation and the difficulty in capturing the lived experience of participants using text and numbers (Collins, Onwuegbuzie, & Jiao, 2007). Collins and colleagues suggest the issue of representation can be overcome by the sampling decisions made in the study to generate adequate data pertaining to the phenomenon which is subject to inquiry. An example of this is the purpose of a study and purpose for mixing quantitative and qualitative approaches to recruit participants. In this study, the use of a methodological approach valuing the contribution of quantitative and qualitative paradigms provided a means to maximise participation, where participants could chose to either participate in a survey only (incorporating open-ended questions) or additionally, a semi-structured
interview. Given the high levels of burden in caring for a child with AN and time constraints on clinicians, a mixed research design offered the flexibility to participate in a manner respectful of time constraints in caring and treating, to elicit meaningful and contextual data. This increased the amount of research data and subsequent knowledge, cited as one of the primary reasons for adopting a mixed-methods approach (Sarantakos, 2005).

4.4. Overview of the two studies – parents and clinicians

Adolescents with AN rely on their parents to determine the type of treatment they will receive and where it will occur. It is important that parents seeking treatment, and mental health professionals working in this area, see themselves as part of a team relying on the expertise of each member to offer insight and direction to recovery (Lask & Bryant-Waugh, 2013).

Parents and clinicians were chosen as participants for this study because they form the basis of the team in a family-based approach to treating adolescent AN (Lock et al., 2001). The engagement of parents, at varying levels, is fundamental to ongoing treatment whether it be in the form of their active participation in the treatment process or by supporting their adolescent to attend (Ma & Lai, 2006). Partnering with the family is fundamental to the dominant Maudsley approach used in treatment for adolescent AN as discussed in the previous chapters. A clinician’s skill in engaging parents is therefore crucial to treatment acceptance and retention.

This research is aimed at understanding the experience (phenomenology) of parenting a child in treatment for AN and how parents and clinicians made sense of the treatment (interpretation of meanings). An exploration of this phenomenon through interpretation helps to construct an understanding of parents’ experiences and consequently possible strategies to engage them in elements of effective treatment for adolescent AN. Exploring and comparing parental experiences with the perspectives of the clinicians, who work with both the young person and the family, was used to determine points of agreement (convergence) and variance (divergence)
regarding the impact that AN has upon the family. It is anticipated that an understanding of points of convergence and divergence will assist in the enhancement of the therapeutic alliance and thus contribute to the process of recovery. Investigating attitudes and experiences of parents and clinicians of treatment efficacy, importance and helpfulness, aims to contribute further knowledge about working with families in the field of family-based treatment for adolescent AN. Furthermore, an exploration of parents’ and clinicians’ experiences of treatment may provide insights into the essential ingredients required within a service to support treatment processes. This may then help to identify underlying principles in working with families of adolescents with AN that move beyond current approaches.

Participants in this study had experience in either receiving or providing family-based treatment for adolescent AN through CAMHS. The following chapter presents the methods used to engage parents and clinicians in the study, and describes the data collection instruments and analysis processes, all of which are underpinned by the mixed-method, phenomenological, interpretative and critical postmodern stance on inquiry, described earlier.
Chapter 5. Research methods

This chapter outlines the methods used for the study of clinicians and the study of the parents. Each study comprised four parts:


2. Demographic information pertaining to either parents and their adolescents, or clinicians.

3. Qualitative data sourced through short answer questions.


5.1. Clinicians’ study

Clinicians engaged as participants in the study were employed by the CAMHS; a child and adolescent mental health service located in a designated health region of NSW. Clinicians were either: psychiatrists; social workers; psychologists; dietitians; nurses; occupational therapists; or Aboriginal counsellors. Clinicians were purposively sampled on the basis of their expertise in providing family-based therapy for adolescent AN.

Clinicians were advised of the nature and purpose of this research through CAMHS team meetings or through an annual CAMHS planning day in 2009. Clinicians experienced in treating AN were identified by the researcher through discussions with clinical leaders and by the CAMHS general email list. Thirty CAMHS clinicians were approached as potential
participants across the geographical region covered by the health service and CAMHS. This number of clinicians represented all of the clinicians working with AN, as identified through discussions with clinical leaders in CAMHS. Hunter New England CAMHS provides services to families across seven rural, remote and regional sites in NSW. Three of the study sites were not available for this study. Although approximately 60 clinicians are employed in Hunter New England CAMHS in various roles across these sites, only 30 clinicians work therapeutically in generalist teams with families presenting for treatment for underlying mental health concerns in their children. Services to families for treating adolescent AN are provided in conjunction with other therapeutic services to families.

Letters of invitation (Appendix B) were sent to clinicians along with the survey questionnaire and a consent form (Appendices C & D), outlining the nature of the study and inviting participation (Stage 1). Clinicians could consent to participate by answering part or the entire questionnaire. They also had the choice of participating in a semi-structured interview (Stage 2). Clinicians were invited to discuss what participation would entail with the researcher prior to providing consent. Each invitation to participate was placed in an internal Hunter New England envelope addressed to the identified clinician, and handed directly to clinicians or placed in their workplace pigeon holes. Clinicians were asked to return completed consent forms and questionnaires to the researcher. Those clinicians who declined were followed up, where possible, via email or phone, to explore any concern regarding the invitation to participate.

Clinicians who participated in interviews were sent a letter of invitation, with a consent form, to participate in a brief follow-up interview (Stage 2-2) (Appendices E & F) to examine issues emerging from the initial analysis of the interview data in more detail. In particular, this focused on the ways in which clinicians adapt Maudsley. Twenty clinicians participated in the survey questionnaire and first round of interviews and 16 participated in the brief follow-up interview.
5.2. Parent study

Clinician identified and recruited parents of young people who met study criteria shown in Table 5.1. The study’s participants had experience in some form of family-based treatment, such as the Maudsley approach, where the family was seen as a conjoint unit. Partners of parents were also included but only if they had attended treatment through CAMHS. Clinicians were asked to consider their current clients and additionally recall discharged clients who met the study criteria. There is no existing database of clients within CAMHS allowing for the reliable identification of clients diagnosed with AN, and hence clinician recall and records from June 2006 to June 2009 was used as a more effective way to identify potential parental study participants.

Adolescents, who were no longer clients of the service, were identified by their former treating clinician through a review of their discharged CAMHS clients, from June 2006-June 2009. In that period, 848 clients from 27 clinicians were discharged. An additional 425 current clients were identified through review of client listings by 30 clinicians. Although 1273 clients were identified through this process, there was no way to accurately identify all those diagnosed with adolescent AN. Clinicians subsequently identified 22 sets (18 discharged and 4 current) of parents who met the criteria for inclusion as potential study participants (Figure 5.1). Whilst it was not possible to be certain, due to the limitations of the patient data system, the researcher was reasonably confident that the identified group of potential participants constituted the majority who met the inclusions criteria, based on feedback from clinicians.
Table 5.1 Criteria for inclusion and exclusion in the parent study

Inclusion Criteria

- Parents and their partners had received family-based intervention for adolescent AN from CAMHS. Note parents were defined as one or two individuals dependent on family configuration.
- Adolescent aged between 12-18 years at the time of diagnosis
- Adolescent body mass index was within the healthy weight range (18.5 – 24.9 kg/m²)
- Duration of illness was less than 3 years from CAMHS diagnosis
- Adolescent was either currently receiving treatment from CAMHS or was recently discharged

Parents excluded from the study were:

- Parents who had received treatment by the researcher

Parents and their partners who were current clients of CAMHS and who met the study criteria were advised by their primary clinician in a treatment session of the nature and purpose of this research. The clinician explained that they were not directly involved with the research. Parents were offered a mail out pack containing an information letter, consent form and survey questionnaire (Appendices G, H & I) or were handed this pack if they consented during a session.

Potential participants identified from the discharged CAMHS clients were sent a letter of information and consent form with a reply-paid envelope outlining the nature of the study and an invitation to participate in the research. Parents could choose to participate, by consent, to only the survey questionnaire or additionally provide consent to a semi-structured interview. Participants were invited to contact the researcher by phone for further information prior to their decision to participate.
The recruitment procedure is detailed in Figure 5.1. Twelve sets of parents agreed to participate in the study (by survey or interview or both survey and interview). Five sets agreed to the survey only, one set to interview only and six sets to both the survey and semi-structured interview. For some parent sets, one parent only participated whilst two parents participated for other parent sets. This resulted in 13 returned surveys and nine individuals participating in interviews, representing 15 individual parents participating.

The small sample size attained in this study is appropriate for a mixed-methods research design seeking a more intense and in-depth method of data collection. Although the sample for survey meant that analysis of relationships between variables was not possible, the intent of a mixed method design is about a depth of understanding and therefore a sample is appropriate.
Figure 5.1: Recruitment of treated families to participate in the parent study - survey and interviews.
5.3. **Data collection instruments**

5.3.1. **Survey questionnaires for parents and clinicians**

A self-administered survey questionnaire was used to measure parents’ and clinicians’ attitudes regarding effective and helpful components of treatment and to gather demographics pertaining to parents, adolescents and clinicians (Appendix I for parent version & C for clinician version). The questionnaire was a version of the Outcome Effective Scale (OES) used in a Stanford University California study that measured parent and child satisfaction with manualised treatment for AN (Krautter & Lock, 2004). The questionnaire was adapted with the permission of the author, Dr James Lock. Data analysis was conducted to produce descriptive statistics using SPSS version 18. Open-ended questions were also included in the questionnaire. Participants responded to them in writing.

Self-administered written surveys were employed with 28 items for parents and 16 items for clinicians (Appendices H & C). Five point Likert scales were used to measure perceived elements of important and effective family-based therapy in the treatment of adolescent AN, ranging from ‘not at all important’ and ‘not effective at all’ through to ‘extremely important’ and ‘extremely effective’. The same survey layout and design was employed for both surveys which asked parents and clinicians to provide background socio-demographic data. Parents were asked their gender, age, relationship status, education, employment, cultural background, and information about their child in treatment. Clinicians were asked their gender, profession, education, employment in CAMHS, cultural background, experience with family based treatment for AN, and whether they had used Maudsley family therapy. These questions were asked to gather data that could inform comparisons with groups identified in other family-based research in AN, and to see if there were any associations between socio-demographic data and treatment, either received or provided.
Both parents and clinicians were asked to rate their perception of the importance of aspects of care for the effective treatment of adolescent AN. Respondents were asked to identify the nature of the treatment received or provided: Maudsley or non-Maudsley. They were asked to rate the importance of:

- the therapeutic relationship
- parents receiving information
- parents being active in treatment
- seeing the adolescent as separate from AN (separating the illness from the child)
- parental refeeding
- parents negotiating with the adolescent over food consumption once healthy and
- empowering parents.

Parents were additionally asked to rate how effective their experiences of the same components of family-based treatment were in the CAMHS service they received. Clinicians were not asked to rate effectiveness of treatment provided, because they would be rating their own treatment. The type of questions asked were to help make comparisons with other research in subjective experiences of family based treatment for AN such as Krautter & Lock (2004), Ma & Lai (2006) and also to explore differences and similarities between experiences of treatment in accordance with the type of therapy received: Maudsley or non-Maudsley, in line with the research aims and objectives.

The main difference between parent and clinician surveys were that parents were asked: a) specific questions rating overall treatment experience; b) information about family configuration and duration of illness in their child; and c) three open-ended questions relating to their experiences of parenting and treatment. The clinicians’ survey comprised: a) rating the
experience of treatment in terms of importance only; and b) a specific open-ended question asking about aspects of treatment parents may find unhelpful.

5.3.2. Semi-structured interviews

The in-depth semi-structured interviews were designed to generate detailed, qualitative information about experiences and meanings of treatment from parents’ and clinicians’ perspectives. The interviews sought to understand, as far as possible, how participants made sense of their personal psychological and social world in relation to adolescent AN. A second interview was held with clinicians when sufficient depth and breadth of data on family-based treatment was not obtained in the initial protocol. Analysis of interviews was undertaken using (IPA), (Smith, 2008; Smith et al., 2009) as described in Chapter 4.

Questions were posed in an attempt to understand what experiences were like for participants when reflecting on their involvement with the treatment of AN. Questions used in the interviews were framed broadly and openly with the aim of exploring flexibly, and in detail, parents’ and clinicians’ experiences of treatment for AN. Participants (parents, partners and clinicians) had a choice of either face to face or telephone interviews. Interviews were conducted with sets of parents or individual interviews with a parent, according to participants’ choice. All sets of parents chose face to face interviews. These were conducted in their workplace (n=2), home (n=2) or CAMHS’s (n=3) site. The length of interviews ranged from 45 to 120 minutes. Clinicians had a choice of either a face to face interview conducted in their workplace, or a telephone interview. All clinicians chose face to face interviews. Interview length ranged from 45 to 90 minutes.

The semi-structured interview design was in line with a phenomenological schedule that seeks to illicit the meaning of experiences. Participants had the opportunity to do this through a facilitated conversation that permitted them to “tell their own stories, in their own words” (Smith et al., p.58, 2009). Interactions with participants occurred through a deep engagement
around their concerns, where active listening and probing sought to learn more about their lifeworld (Smith et al., 2009). The schedule was also informed by a critical social work perspective that is interested in moving beyond dominate ways of understanding experiences. Reflective questions were used to encourage participants to make and remake “the meaning of their experiences in relation to ever changing contexts” (Fook, p.179, 2012). Enquiring about the use of subjugated knowledge, such as the role of values and beliefs in families over time, allowed multiple and hidden perspectives about care and treatment to be uncovered. Questions were based on issues identified from a review of relevant literature about caring for, and treating, an adolescent with AN. These included the burden of care, adjustments to family lifestyle when caring for an adolescent with AN, experiences of family-based treatment, and socio-cultural factors impacting upon care and treatment. The type of questions asked of parents related to their experiences of: parenting an adolescent with AN; cultural issues within their family that may impact upon care; CAMHS treatment for adolescent AN; and perception of elements of helpful and effective treatment, in addition to unhelpful treatment (Appendix J). The type of questions asked of clinicians related to experiences of: engaging parents in effective treatment; parental care of an adolescent with AN; cultural issues within the families; and helpful and unhelpful elements of treatment (Appendix K).

A brief follow–up interview was conducted with clinicians who participated in the initial interview, to further clarify if and how adjustments were made to manualised treatment in practice. Findings related to clinician modifications to treatment did not emerge in detail from data collected in the initial round of interviews, but was identified as an important issue in the context of other emergent themes from the other data sources and review of literature. As with the initial interviews, all clinicians were interviewed in their workplace for the follow-up interviews. Interview length ranged from 30 to 45 minutes. This interview schedule focused on variations to standardised treatment offered for adolescent AN and the rationales for the modification of treatment schedules (Appendix L).
In order to engage in a critically self-reflective process, in line with critical social work theories, questions posed in the interview schedule were pilot-tested prior to implementation on research supervisors and social workers employed outside of CAMHS and the interview schedule was appropriately revised. The revisions were designed to ensure that the questions were linked to critically reflective processes and the intent of phenomenological enquiry. This ensured that the translation of aspects of participant’s experiences could create new knowledge through transparent means of investigation. Revisions were intended to optimise participants’ subjective experiences and facilitate a comfortable interaction, enabling a detailed account of experiences of parenting, or treating a child with AN.

Initial interactions with participants were designed to place them at ease. For parents, this occurred by advising of my interest in working with young people with AN and their families and with clinicians, through sharing an interest in enhancing outcomes for the families we treat. Participants were advised that while the interview schedule acted as a guide to outline areas of interest to be discussed, the interview itself would be led by the opinions they wished to express, if they were relevant to the research question. Participants were also advised they were considered to be the “experiential expert” on parenting or treating adolescent AN, and as such they could be prompted to expand on experiences to take the interview to “the thing itself”; the essence of their experience (Smith et al., 2009, p.58).

The interview schedule was thus not prescriptive. It allowed for questions to be adapted to the specific context, and for clarifying and probing questions to follow on from the main questions in order to elicit detail and examples (Osborn & Smith, 1998). The sequence of questions in the interview schedule differed for parents and clinicians in order to assist with transitioning to more evaluative and reflective areas. The parents’ interview schedule commenced with questions about parenting their child with AN to ease into the interview process through descriptive accounts of recent and current experiences. This encouraged each parent to talk openly, and at length, about parenting experiences, before becoming more analytical or
evaluative about CAMHS treatment experiences, which occurred at the end of their interview schedule. Conversely, the clinicians’ interview schedule commenced with questions about the context of treatment, to place them at ease with a known topic, before moving them gradually towards more sensitive topics associated with placing themselves in the shoes of parents.

The interview style was non-directive with a process of reflecting and probing upon key issues (Minichiello, Aroni, Timewell, & Alexander, 1995) to gain an insider’s perspective (Conrad, 1987). In order to explore experiences of parents and clinicians, the semi-structured interview was regarded as a dynamic process between the participant’s account of phenomena and my own conceptions of the account provided (Smith, 2008). In engaging each participant to give their account of their experiences, it was important to disclose to both clinicians and parents, that as a clinician working with adolescent AN, my interest was in creating new knowledge in the area of treating adolescents with AN. This assisted in building rapport and establishing trust with parents and clinicians allowing them to expose their inner world to either an outsider or colleague. This is particularly important in collecting data for IPA, as the interviewer and interviewee are active participants in the process (Smith et al., 2009). Sense is made of the participant’s world through the active, interpretative activity of the interviewer reflecting to participants their understanding of responses, in order to help shape understanding (Smith et al., 2009). Trust and rapport were also important to establish early in the process to place participants at ease for the recording of each interview.

Each interview was digitally recorded with participant consent and fully transcribed. All participants were offered a copy of their transcription for correction and additions and only one clinician requested a copy of their interview.
5.4. Analysis of data

5.4.1. Survey questionnaires

The data set generated from scanned teleform questionnaires was entered into an Excel database and then into the statistical software package for social science (SPSS version 18). SPSS was used to generate descriptive statistics (frequencies and percentages) for participants’ responses to each question. The sample size (13 parents and 20 clinicians) was not large enough to examine relationships between variables beyond descriptive analysis. This is a limitation of the quantitative component of the research.

A phenomenological-type content analysis was employed for analysing this data. Participants’ written responses about their experiences were grouped thematically by the process of phenomenological reduction (Marshall & Rossman, 2006).

5.4.2. Semi-structured interviews

Data was analysed using IPA (Smith et al., 2009) employing QSR-NVivo 9 (QSR International 2011) to help facilitate the analytic process. The intent of data collection using IPA was not to test a hypothesis; rather the aim was to discover meanings of a given phenomenon. The purpose of an IPA in this study was to understand the content and complexity of meanings within the story conveyed by the participants rather than measure the frequency of such meanings (Smith, 2008; Smith et al., 2009). As this study’s researcher, I was engaged in an interpretative relationship with the transcript, through a sustained relationship with the text, and a process of interpretation. In engaging with the transcript, from a critical social work perspective, I was additionally influenced by a reflexive way of thinking, by seeking and valuing the interpretations from research supervisors, to ensure “being open as possible to the unexpected, keeping the bias of one’s own vision to a minimum” (Fook, 2012, p.139).
Following transcription, in the spirit of free textual analysis, the transcript was read a number of times so that I became as familiar with the text as possible (Smith et al., 2009). A margin was drawn next to the text and text was divided into meaning units with a comment assigned for each unit. I then returned to the beginning of each transcript, created another margin next to the text and documented emerging themes’ titles. These titles were generated through the process of engaging with a descriptive core of comments assigned to meaning units in the text with a phenomenological focus. In this phase, notes were transformed into “concise phrases which aimed to capture the essential quality of what was found in the text” (Smith, 2008, p.68). Where similar themes emerged through the transcript, the theme titles were combined. This formed an initial list that was compiled in the chronological sequence in which the themes emerged.

The next stage in analysis involved more analytical ordering. By reference to an iterative analysis involving a close interaction between myself and text, emergent themes were listed and connections made between them. Some themes were grouped. As each clustering theme emerged, it was checked against the transcript to ensure the connections applied to the primary source material. At this stage, I was involved in making sense of what the participant was saying and constantly checking the sense of the meaning about what I deduced against what the participant actually said. Clustering occurred through the use of QSR-NVivo 9.

The next phase involved producing a table of themes which captured, as best as possible, participants’ views on the topic. Clusters of themes were then given a name that represented superordinate themes. The table listed themes under each superordinate theme. QSR-NVivo 9 was used to help with the organisation of material and the location of original source through this process. Through the use of key words, QSR- NVivo 9 was also used to extract instances of each theme from the transcripts.

A continuing process of analysis was employed with the interview transcripts. Themes from the first interview transcript were used to help orient subsequent analyses. The discipline required
in using themes from previous participants was in respecting convergence and divergence in the data by recognising similar patterns, while acknowledging new issues and themes. Once each of the transcripts had been analysed, a final table of superordinate themes was constructed.

Reporting of participants’ meanings, inherent in their experiences, involved translating themes into a narrative account. The table of themes was the basis of the participants’ accounts of experiences and took the form of narrative argument supported by verbatim extracts from the transcripts. The table of themes does not stand alone as long extracts were also used to capture the narratives and contexts of participants’ perspectives and to avoid a reductionist approach to analysis. The results section presented in Chapters 7 and 8 contains emergent thematic analysis through the presentation of quotations and by the use of thematic tables. A separate discussion section links these qualitative findings to the literature on AN.

To maintain anonymity of participants, the researcher chose pseudonyms, used in interview data and in the presentation of this data in the findings section.

5.5. Ethical considerations and approval

There were ethical considerations in this study that required attention. The first related to my being, a senior social worker in CAMHS, and a clinician having professional oversight for some clinician participants. To offset concern held by clinicians who had professional responsibility to me, it was made clear that participation was voluntary and that non-participation had no adverse effects on professional responsibilities within CAMHS. To address any discomfort in participating in a semi-structured interview, these clinicians were offered the option of an interview with a co-researcher. None took up this offer.

As researcher, I was able to refer a parent to an appropriate professional within or outside of the service if a situation arose during the course of their participation in the research where they
required counselling. The study received ethical approval from Hunter New England Human Research Ethics Committee, application number 08/12/17/5.05 and University of Newcastle Human Research Ethics Committee in 2009 application number H-2009-0057 in Appendices M and N.

The following chapter reports the findings from the surveys parents and of clinicians that produced both quantitative and qualitative data. These findings are summarised in tables and illuminated through a fusion of quantitative and qualitative data to achieve a higher degree of validity. The subsequent chapters report findings from the interviews.
Chapter 6. Findings from surveys

This chapter documents the findings from 13 parents’ and 20 clinicians’ self-administered questionnaires. The chapter commences with quantitative findings on: demographic characteristics of parents and clinicians; characteristics of the adolescent’s illness; treatment experienced; clinicians’ and parents’ perceptions of the levels of importance of treatment components; and clinicians’ and parents’ perceptions of effectiveness of treatment components. Frequency data are presented and trends are identified. The findings on parents’ and clinicians’ experiences of parenting or treating adolescent AN, from analysis of answers to open-ended questions, are then presented.

Using the mixed-methodological approach, the chapter concludes with a fusion of qualitative and quantitative data from these questionnaires, to illuminate the phenomenon of parenting adolescent AN through treatment in CAMHS. In-depth qualitative findings from the semi-structured interviews are provided in the following two chapters. Those findings offer an in-depth exploration of meanings and experiences that build upon the survey data findings presented in this chapter.

6.1. Characteristics of participants

As shown in Figure 5.1 in the previous chapter, 11 parent sets, from the 22 potential sets identified by clinicians, participated in the survey. This represents a 50% response rate. In two cases, both parents separately completed and returned the survey questionnaire, bringing the sample size to 13 for the survey. Table 6.1 provides background characteristics of the 13 parents who completed the survey. Six of these parents also participated in the in-depth interviews, which are reported in the next chapter. Given the small sample size, there were no discernible differences between those who were interviewed and those who were not. The majority of parent study participants were well-educated, white women within nuclear families, and with
daughters in treatment. This is consistent with sociodemographic data found in RCTs examining family-based treatment for adolescent AN (Eisler et al., 2000; Robin et al., 1995; Lock et al., 2006; Gowers et al., 2010).

Just over half of the parents were employed on a full-time basis, but over one third had experienced changes to their employment status following their child developing AN. The impact of AN on employment status is an issue investigated in more detail in the qualitative interviews. Four participants had a cultural reference point which differed from the dominant Anglo-Australian culture. This provided opportunities to explore meanings and knowledge of AN that differed from the perspectives of the dominant white, middle class in Western societies. The influence of culture was explored in qualitative interviews and these findings are discussed in Chapter 7. This recognition of different cultural perspectives and meanings demonstrates how the research was influenced by the critical social work perspective (Fook, 2012).

Table 6.2 provides information on the illness and treatment characteristics of the children whose parents completed the survey. Maudsley and non-Maudsley types of treatment identified by parents did not fall neatly into two categories, because some parents started with Maudsley and then withdrew. This is also explored in the qualitative findings reported in Chapter 7. Approximately two-thirds of parents indicated that AN had been in the life of their child for less than two years. Most had been diagnosed within the last three years and in treatment with CAMHS for less than two years.
Table 6.1: Characteristics of thirteen parents who completed the survey

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Interviewed % (n)</th>
<th>Not interviewed% (n)</th>
<th>All % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28.6 (2)</td>
<td>16.7 (1)</td>
<td>23 (3)</td>
</tr>
<tr>
<td>Female</td>
<td>71.4 (5)</td>
<td>85.3 (5)</td>
<td>76.9 (10)</td>
</tr>
<tr>
<td><strong>Age:</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&lt;30</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>30-39</td>
<td>14.3 (1)</td>
<td>16.7 (1)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td>40-49</td>
<td>85.7 (6)</td>
<td>66.7 (4)</td>
<td>76.9 (10)</td>
</tr>
<tr>
<td>50+</td>
<td>0 (0)</td>
<td>16.7 (1)</td>
<td>7.7 (1)</td>
</tr>
<tr>
<td><strong>Relationship Status:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>14.3 (1)</td>
<td>16.7 (1)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td>Married</td>
<td>85.7 (6)</td>
<td>66.7 (4)</td>
<td>76.9 (10)</td>
</tr>
<tr>
<td>Divorced</td>
<td>0 (0)</td>
<td>16.7 (1)</td>
<td>7.7 (1)</td>
</tr>
<tr>
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<td>61.5 (8)</td>
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<td>100 (13)</td>
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<td>53.8 (7)</td>
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<tr>
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<td>46.2 (6)</td>
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Table 6.2: Illness and treatment characteristics of children whose parent participated in the survey

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<tr>
<th>Illness and treatment characteristics</th>
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<th>Not Interviewed % (n)</th>
<th>All % (n)</th>
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<td><strong>Perceived duration of illness:</strong></td>
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<tr>
<td>0-6 months</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>6-12 months</td>
<td>14.3 (1)</td>
<td>66.7 (4)</td>
<td>38.5 (5)</td>
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<tr>
<td>12-18 months</td>
<td>42.9 (3)</td>
<td>0 (0)</td>
<td>23.1 (3)</td>
</tr>
<tr>
<td>18m-2 yrs</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>&gt;3 yrs</td>
<td>28.6 (2)</td>
<td>33.3 (2)</td>
<td>30.8 (4)</td>
</tr>
<tr>
<td><strong>Time since Diagnosis:</strong></td>
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<td></td>
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<tr>
<td>0-6 months</td>
<td>14.3 (1)</td>
<td>0 (0)</td>
<td>7.7 (1)</td>
</tr>
<tr>
<td>6-12 months</td>
<td>28.6 (2)</td>
<td>33.3 (2)</td>
<td>30.8 (4)</td>
</tr>
<tr>
<td>12-18 months</td>
<td>28.6 (2)</td>
<td>0 (0)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td>2-3 yrs</td>
<td>14.3 (1)</td>
<td>33.3 (2)</td>
<td>23.1 (3)</td>
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<tr>
<td>&gt;3 yrs</td>
<td>14.3 (1)</td>
<td>16.7 (1)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td><strong>Treatment duration with CAMHS:</strong></td>
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<td></td>
</tr>
<tr>
<td>0-6 months</td>
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<td>7.7 (1)</td>
</tr>
<tr>
<td>6-12 months</td>
<td>57.1 (4)</td>
<td>0 (0)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td>12-18 months</td>
<td>57.1 (4)</td>
<td>10 (3)</td>
<td>53.8 (7)</td>
</tr>
<tr>
<td>18m-2 yrs</td>
<td>14.3 (1)</td>
<td>0 (0)</td>
<td>7.7 (1)</td>
</tr>
<tr>
<td>2-3 yrs</td>
<td>14.3 (1)</td>
<td>0 (0)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td>&gt;3 yrs</td>
<td>14.3 (1)</td>
<td>16.7 (1)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td><strong>Type of treatment</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Maudsley</td>
<td>57.1 (4)</td>
<td>16.7 (1)</td>
<td>38.5 (5)</td>
</tr>
<tr>
<td>Non-Maudsley*</td>
<td>42.9 (3)</td>
<td>83.3 (5)</td>
<td>61.5 (8)</td>
</tr>
</tbody>
</table>

* includes those parents who commenced Maudsley and withdrew

Twenty (20) CAMHS clinicians, experienced in providing family-based therapy for adolescent AN, participated in the study. This represents 66% of the 30 clinicians providing family-based treatment for adolescent AN in the health area at the time of the research. Table 6.3 shows characteristics of the clinicians. The majority of CAMHS clinician participants were white, educated women. Although there was a range of professions represented in the sample, the most common was psychology. More than half of the sample was employed full-time and more than half had over three years’ experience in CAMHS, indicating a reasonable degree of experience in working with families with mental health concerns. Whilst 14 of the 20 of clinicians indicated in their survey that they are trained in Maudsley family therapy, and continued to use this as an intervention for treating adolescent AN, the qualitative interviews revealed that aspects of Maudsley family therapy have influenced all clinicians. Non-Maudsley clinicians,
who utilised more generic family interventions, revealed in interviews that they also integrated principles and practices from the Maudsley model into their systemic and narrative family based interventions. This is discussed in the qualitative findings presented in Chapter 8.

Table 6.3: Characteristics of the twenty CAMHS clinicians

<table>
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<tr>
<th>Demographics</th>
<th>% ( n )</th>
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<td>Gender:</td>
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<tr>
<td>Female</td>
<td>75 (15)</td>
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<tr>
<td>Male</td>
<td>25 (5)</td>
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<tr>
<td>Profession:</td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td>40 (8)</td>
</tr>
<tr>
<td>Dietitian</td>
<td>20 (4)</td>
</tr>
<tr>
<td>Social Worker</td>
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</tr>
<tr>
<td>Psychiatrist</td>
<td>10 (2)</td>
</tr>
<tr>
<td>Nurse</td>
<td>10 (2)</td>
</tr>
<tr>
<td>Aboriginal Counsellor</td>
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</tr>
<tr>
<td>Occupational Therapist</td>
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</tr>
<tr>
<td>Highest Education:</td>
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<tr>
<td>Postgraduate qualifications</td>
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<td>Undergraduate Degree</td>
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<td>Employment status CAMHS:</td>
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<td>Full-Time</td>
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<tr>
<td>Part-Time</td>
<td>35 (7)</td>
</tr>
<tr>
<td>Casual</td>
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<td>Aboriginal or Torres Strait Islander:</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>95 (19)</td>
</tr>
<tr>
<td>Yes</td>
<td>5 (1)</td>
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<tr>
<td>Australian Born:</td>
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<tr>
<td>Yes</td>
<td>80 (16)</td>
</tr>
<tr>
<td>No</td>
<td>20 (4)</td>
</tr>
<tr>
<td>Parents Born Overseas:</td>
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</tr>
<tr>
<td>No</td>
<td>70 (14)</td>
</tr>
<tr>
<td>Yes</td>
<td>30 (6)</td>
</tr>
<tr>
<td>Duration Employment with CAMHS:</td>
<td></td>
</tr>
<tr>
<td>&gt; 3yrs</td>
<td>60 (12)</td>
</tr>
<tr>
<td>&lt; 3yrs</td>
<td>40 (8)</td>
</tr>
<tr>
<td>Experience with Family-Based Treatment for AN</td>
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</tr>
<tr>
<td>&gt;3yrs</td>
<td>55 (11)</td>
</tr>
<tr>
<td>&lt;3yrs</td>
<td>45 (9)</td>
</tr>
<tr>
<td>Treatment using Maudsley family therapy:</td>
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<tr>
<td>Yes</td>
<td>70 (14)</td>
</tr>
<tr>
<td>No</td>
<td>30 (6)</td>
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6.2. Importance of aspects of treatment

Parents were asked to rate how important various aspects of treatment were in treating adolescent AN in CAMHS. Table 6.4 presents data according to type of therapy received: Maudsley (n=5) or non-Maudsley family therapy (n=8). Parents rated nearly all aspects of treatment as of high importance. The only aspect of treatment for which there was a possible difference between those who underwent Maudsley and those who did not, was in regard to the category ‘Separation of Illness’. Whilst the sample size is too small to test for significance, there is some suggestion that Maudsley clients regard externalisation of the illness in treatment as more important than those who did not undergo Maudsley treatment. This issue was explored in more depth in the qualitative interviews and is discussed in Chapter 7.

Table 6.5 shows data on clinicians’ ratings of importance of various aspects of treatment, according to the type of therapy the clinicians usually provide. There was no apparent difference between Maudsley and non-Maudsley therapists in terms of what they perceive as important in treatment, with all clinicians rating most aspects of treatment as reasonably or very important. This suggests that clinicians in CAMHS, who provide family-based therapy for adolescent AN, support similar principles and aspects of treatment regardless of whether or not they use or were trained in Maudsley.

Tables 6.4 and 6.5 demonstrate the general agreement between parents and clinicians on the importance of aspects of treatment in family-based therapy for adolescent AN. Some difference of opinion is noted with regard to the importance of ‘separation of the illness from the child’. Parents appear to regard this as less important than clinicians do, particularly those parents receiving non-Maudsley treatment, but it was not possible to determine a statistically significant difference due to the small sample size. Parental refeeding was another apparent point of
difference, with clinicians rating this aspect of care as being less important than parents did, but again the small sample size means that strong conclusions cannot be drawn.

Both the parents’ and clinicians’ ratings of importance of aspects of treatment for adolescent AN is shown in Table 6.6. The data suggests there was again congruence between parents and clinicians about the importance of most aspects of treatment, irrespective of treatment modality undertaken or provided. Divergence of opinion occurred with regard to the importance of separating the illness from the child and parental refeeding, which was investigated further in qualitative interviews (Chapter 9).
Table 6.4: Parents’ views on importance of aspects of treatment according to type of therapy received (13)

<table>
<thead>
<tr>
<th>Aspect of Treatment</th>
<th>Maudsley % (n)</th>
<th>Non-Maudsley % (n)</th>
<th>All % (n)</th>
</tr>
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<tbody>
<tr>
<td><strong>Relationship between parent and therapist:</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Very Important</td>
<td>100 (5)</td>
<td>100 (8)</td>
<td>100 (13)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Receiving information from therapist:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>100 (5)</td>
<td>100 (8)</td>
<td>100 (13)</td>
</tr>
<tr>
<td>Reasonably Important</td>
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<tr>
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<tr>
<td><strong>Therapist including parent as active in treatment:</strong></td>
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<td></td>
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<td>100 (5)</td>
<td>100 (8)</td>
<td>100 (13)</td>
</tr>
<tr>
<td>Reasonably Important</td>
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<td>0 (0)</td>
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<tr>
<td><strong>Separation of illness from child:</strong></td>
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<td>87.5 (7)</td>
<td>92.3 (12)</td>
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<td>12.5 (1)</td>
<td>7.7 (1)</td>
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<td>0 (0)</td>
<td>0 (0)</td>
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<tr>
<td><strong>Handing back decisions to child once healthy:</strong></td>
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<tr>
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<td>80 (4)</td>
<td>100 (8)</td>
<td>92.3 (12)</td>
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<td><strong>Learning how to stand up to AN:</strong></td>
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<td>100 (8)</td>
<td>100 (13)</td>
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<td>87.5 (7)</td>
<td>76.9 (10)</td>
</tr>
<tr>
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<td>12.5 (1)</td>
<td>23.1 (3)</td>
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<tr>
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<td>0 (0)</td>
<td>0 (0)</td>
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<td>100 (8)</td>
<td>100 (13)</td>
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<td><strong>Treatment in enhancing parental ability:</strong></td>
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<td>100 (8)</td>
<td>100 (13)</td>
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</table>
Table 6.5: Clinicians’ views on importance of aspects of treatment according to type of therapy provided (20)

<table>
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<tr>
<th>Aspect of treatment</th>
<th>Maudsley % (n)</th>
<th>Non-Maudsley % (n)</th>
<th>All % (n)</th>
</tr>
</thead>
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<td><strong>Relationship between parent &amp; therapist:</strong></td>
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<td></td>
</tr>
<tr>
<td>Very Important</td>
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<td>100 (6)</td>
<td>95 (19)</td>
</tr>
<tr>
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<td>7.1 (1)</td>
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<td>5 (1)</td>
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<tr>
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<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Providing information to parents:</strong></td>
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<tr>
<td>Very Important</td>
<td>92.9 (13)</td>
<td>83.3 (5)</td>
<td>90 (18)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>7.1 (1)</td>
<td>16.7 (1)</td>
<td>10 (2)</td>
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<tr>
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<td><strong>Therapist including parent as active in treatment:</strong></td>
<td></td>
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<tr>
<td>Very Important</td>
<td>100 (14)</td>
<td>100 (6)</td>
<td>100 (20)</td>
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<tr>
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<tr>
<td>Not Important</td>
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<tr>
<td><strong>Separation of illness from child:</strong></td>
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</tr>
<tr>
<td>Very Important</td>
<td>100 (14)</td>
<td>100 (6)</td>
<td>100 (20)</td>
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<tr>
<td>Reasonably Important</td>
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<td>5 (1)</td>
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<tr>
<td><strong>Handing back decisions to child once healthy:</strong></td>
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<td></td>
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</tr>
<tr>
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<td>85.7 (12)</td>
<td>100 (6)</td>
<td>90 (18)</td>
</tr>
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<td>10 (2)</td>
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<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
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<tr>
<td><strong>Teaching how to stand up to AN:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>100 (14)</td>
<td>83.3 (5)</td>
<td>95 (19)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>0 (0)</td>
<td>16.7 (1)</td>
<td>5 (1)</td>
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<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
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<tr>
<td><strong>Treat adolescents issues once child healthy:</strong></td>
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<td></td>
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<tr>
<td>Very Important</td>
<td>92.9 (13)</td>
<td>100 (6)</td>
<td>95 (19)</td>
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<tr>
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<td><strong>Enhancing parental ability:</strong></td>
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<td>92.9 (13)</td>
<td>100 (6)</td>
<td>95 (19)</td>
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<td>Reasonably Important</td>
<td>7.1 (1)</td>
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<tr>
<td><strong>Active parenting in treating AN:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>92.9 (13)</td>
<td>83.3 (5)</td>
<td>90 (18)</td>
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<tr>
<td>Reasonably Important</td>
<td>7.1 (1)</td>
<td>16.7 (1)</td>
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Table 6.6: Parents’ and clinicians’ views on the importance of aspects of treatment.

<table>
<thead>
<tr>
<th>Aspect of Treatment</th>
<th>All Parents (n=13)</th>
<th>All Clinicians (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship between parent and therapist:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>100 (13)</td>
<td>95 (19)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>0 (0)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Receiving information from therapist:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>100 (13)</td>
<td>90 (18)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>0 (0)</td>
<td>10 (2)</td>
</tr>
<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Therapist including parent as active in treatment:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>100 (13)</td>
<td>100 (20)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Separation of illness from child:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>76.9 (10)</td>
<td>100 (20)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not Important</td>
<td>23.1 (3)</td>
<td>0 (0)</td>
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<tr>
<td><strong>Given the task of parental refeeding:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>92.3 (12)</td>
<td>70 (14)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>7.7 (1)</td>
<td>25 (5)</td>
</tr>
<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>5 (1)</td>
</tr>
<tr>
<td><strong>Handing back decisions to child once healthy:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>92.3 (12)</td>
<td>90 (18)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>7.7 (1)</td>
<td>10 (2)</td>
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<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
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<tr>
<td><strong>Learning how to stand up to anorexia:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>100 (13)</td>
<td>95 (19)</td>
</tr>
<tr>
<td>Reasonably Important</td>
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<td>5 (1)</td>
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<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
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<tr>
<td><strong>Treat adolescent issues once child healthy:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>76.9 (10)</td>
<td>95 (19)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>23.1 (3)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Assuming active parenting in treatment:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>100 (13)</td>
<td>95 (19)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>0 (0)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Treatment in enhancing parental ability:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Important</td>
<td>100 (13)</td>
<td>90 (18)</td>
</tr>
<tr>
<td>Reasonably Important</td>
<td>0 (0)</td>
<td>10 (2)</td>
</tr>
<tr>
<td>Not Important</td>
<td>0 (0)</td>
<td>0 (0)</td>
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</tbody>
</table>
6.3. Effectiveness of treatment components

After rating the importance of aspects of treatment, parents were also asked to rate the effectiveness of these treatment components. Table 6.7 shows the parental ratings of effectiveness of aspects of treatment for adolescent AN according to type of therapy received. Parents who received non-Maudsley family therapy tended to rate effectiveness of treatment lower than those who received Maudsley for all aspects, except for handing back decisions to the child once healthy. It appears from the survey results that parents who received Maudsley family therapy viewed treatment as more effective than those parents who did not complete the Maudsley program. Although most clinicians reported adhering to similar practice principles in treating AN, non-Maudsley parents show greater degrees of uncertainty toward aspects of treatment received than do Maudsley parents. This difference was explored in the qualitative interviews and findings are discussed in Chapter 7.
Table 6.7: Parents’ views on effectiveness of treatment components according to type of therapy received (13)

<table>
<thead>
<tr>
<th>Aspect of Treatment</th>
<th>Maudsley % (n)</th>
<th>Non-Maudsley % (n)</th>
<th>All % (n)</th>
</tr>
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<tbody>
<tr>
<td><strong>Relationship between parent and therapist:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>100 (5)</td>
<td>37.5 (3)</td>
<td>61.5 (8)</td>
</tr>
<tr>
<td>Reasonably Effective</td>
<td>0 (0)</td>
<td>37.5 (3)</td>
<td>23.1 (3)</td>
</tr>
<tr>
<td>Not Effective</td>
<td>0 (0)</td>
<td>25 (2)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td><strong>Receiving information from therapist:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>40 (2)</td>
<td>25 (2)</td>
<td>30.8 (4)</td>
</tr>
<tr>
<td>Reasonably Effective</td>
<td>60 (3)</td>
<td>62.5 (5)</td>
<td>61.5 (8)</td>
</tr>
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<td>0 (0)</td>
<td>12.5 (1)</td>
<td>7.7 (1)</td>
</tr>
<tr>
<td><strong>Therapist including parent as active in treatment:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>100 (5)</td>
<td>50 (4)</td>
<td>69.2 (9)</td>
</tr>
<tr>
<td>Reasonably Effective</td>
<td>0 (0)</td>
<td>25 (2)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td>Not Effective</td>
<td>0 (0)</td>
<td>25 (2)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td><strong>Separation of illness from child:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>100 (5)</td>
<td>0 (0)</td>
<td>38.5 (5)</td>
</tr>
<tr>
<td>Reasonably Effective</td>
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<td>75 (6)</td>
<td>46.2 (6)</td>
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</tr>
<tr>
<td><strong>Given the task of parental refeeding:</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>100 (5)</td>
<td>50 (4)</td>
<td>69.2 (9)</td>
</tr>
<tr>
<td>Reasonably Effective</td>
<td>0 (0)</td>
<td>25 (2)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td>Not Effective</td>
<td>0 (0)</td>
<td>25 (2)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td><strong>Handing back decisions to child once healthy:</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>20 (1)</td>
<td>57.1* (4)</td>
<td>41.7 (5)</td>
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<tr>
<td>Reasonably Effective</td>
<td>60 (3)</td>
<td>14.3* (1)</td>
<td>33.3 (4)</td>
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<td>Not Effective</td>
<td>20 (1)</td>
<td>28.6* (2)</td>
<td>25 (3)</td>
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<tr>
<td><strong>Learning how to stand up to anorexia:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>80 (4)</td>
<td>37.5 (3)</td>
<td>53.8 (7)</td>
</tr>
<tr>
<td>Reasonably Effective</td>
<td>20 (1)</td>
<td>37.5 (3)</td>
<td>30.8 (4)</td>
</tr>
<tr>
<td>Not Effective</td>
<td>0 (0)</td>
<td>25 (2)</td>
<td>15.4 (2)</td>
</tr>
<tr>
<td><strong>Treat adolescent issues once child healthy:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>60 (3)</td>
<td>28.6* (2)</td>
<td>41.7 (5)</td>
</tr>
<tr>
<td>Reasonably Effective</td>
<td>40 (2)</td>
<td>42.9* (3)</td>
<td>41.7 (5)</td>
</tr>
<tr>
<td>Not Effective</td>
<td>0 (0)</td>
<td>28.6* (2)</td>
<td>16.7 (2)</td>
</tr>
<tr>
<td><strong>Assuming active parenting in treatment:</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>100 (5)</td>
<td>50 (4)</td>
<td>69.2 (9)</td>
</tr>
<tr>
<td>Reasonably Effective</td>
<td>0 (0)</td>
<td>37.5 (3)</td>
<td>23.1 (3)</td>
</tr>
<tr>
<td>Not Effective</td>
<td>0 (0)</td>
<td>12.5 (1)</td>
<td>7.7 (1)</td>
</tr>
<tr>
<td><strong>Treatment in enhancing parental ability:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Effective</td>
<td>100 (5)</td>
<td>50 (4)</td>
<td>69.2 (9)</td>
</tr>
<tr>
<td>Reasonably Effective</td>
<td>0 (0)</td>
<td>37.5 (3)</td>
<td>23.1 (3)</td>
</tr>
<tr>
<td>Not Effective</td>
<td>0 (0)</td>
<td>12.5 (1)</td>
<td>7.7 (1)</td>
</tr>
</tbody>
</table>

* missing data for one participant therefore valid percentages are reported
* rounded up .1
6.4. Open response questions

6.4.1. Parenting a child with AN

Eleven (11) parents, (6 non-Maudsley and 5 Maudsley) and thirteen (13) CAMHS clinicians, (6 non-Maudsley and 7 Maudsley trained) provided responses to open questions in the questionnaire about their perception of parenting or treating a child with AN. Table 6.8 shows three main themes derived from analysis of parents’ responses to what it has been like to parent a child with AN, along with some illustrative quotes.

It is evident from the survey responses summarised in Table 6.8 that most parents described their lived experience as a tough and unremitting journey. This is characterised by fear and loss, which tested their willpower and spirit.

Table 6.9 shows three main themes extracted from clinician responses to the questions about their perception of the experiences of parenting adolescents with AN. The general perception was that parents of children with AN would experience a gamut of diverse and distressing emotions that lay behind the daily tasks of helping their child recover.
Table 6.8: Parents’ responses – what has it been like for you to parent a child with AN?

<table>
<thead>
<tr>
<th>Themes Identified</th>
<th>No. respondents</th>
<th>Illustrative Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on parents psychological wellbeing</td>
<td>9</td>
<td>“A living nightmare every day.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It’s more painful than death of a parent. It’s gut wrenchingly difficult.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“To me anorexia is hell and the journey to recovery is heaven on earth.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I am a single parent dealing with this on my own. I have to work full time due to financial restraints. So working and dealing with this has been tough.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I felt a sense of helplessness.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Anorexia leaves you feeling lost, (not knowing what to do), it leaves you empty.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“To be a parent of a child with anorexia is the hardest test of your life. Anorexia in your life tests and questions your mind (sanity), body (health) and soul (beliefs).”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It has been a difficult journey I would say! It took a long time to understand the timeframe of treatment.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“A very hard journey, hard to describe, you never think it can happen to your child.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Anorexia places enormous amounts of stress and strain on a family. It tests the strength and relationship of all family members.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It can be a very frustrating disease and it not only destroys the anorexic child, but damages everyone concerned with him or her.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Constant battle over food and quantities – constant supervision of meals and mind set with nothing seeming to work for long periods of time.”</td>
</tr>
<tr>
<td>Impact on family system</td>
<td>4</td>
<td>“Watching your child starving themselves, trying to talk to her about eating disorders and my daughter telling me she doesn’t have it, where as a mother I knew she was sick and wasting away to nothing.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“A terrible fear and helplessness as your child’s body is starving but they are angry at you for encouraging them to eat.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“All you can do is love and support the child with anorexia, unconditionally (even when love and support is not wanted).”</td>
</tr>
</tbody>
</table>
Table 6.9: Clinicians’ responses – can you comment on common experiences of parenting a child with AN?

<table>
<thead>
<tr>
<th>Themes Identified</th>
<th>No. respondents</th>
<th>Illustrative Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact upon psychological wellbeing of parent</td>
<td>10</td>
<td>“Parents are shocked, it’s difficult to understand, and they’re out of their depth, confused, helpless, anxious, angry, and responsible. They experience distress around what is happening to their child (severity and potential outcome).”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Anxiety, fear, helplessness, hopelessness, self-blame, confusion and frustration with accessing services.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Self-doubt of parental efficacy that often leads to feelings of guilt.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Parents are often isolated and disempowerment by the illness.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Parents experience anger, isolation, guilt and a sense of powerless.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Parents are frustrated; have feelings of disempowerment, guilt and isolation.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“The biggest challenge is feeling that the ED* is in charge of parenting decisions about food and health at home. So feeling pushed around by the ED* – that it can’t be approached or challenged.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It’s a very difficult experience managing the distress of the young person (particularly during recovery) and also of the rest of family.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“They face very difficult challenges in confronting the illness at home. This frequently results in strong feelings of guilt or inadequacy, frustration and fatigue that affect everyone in the home.”</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>“The difficulty starts with parents fully comprehending that anorexia is a mental illness not simply behavioural.”</td>
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<td></td>
<td></td>
<td>“Parents find it hard to separate the teenager from the illness.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It distorts normal aspects of adolescent/parental opposition (often around food and eating). Anorexia has a powerful impact on relationships/power base (parents are afraid to take normal stances on general issues). It impedes normal “adolescent developmental processes.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Enmeshment with child or relationship breakdown with child.”</td>
</tr>
</tbody>
</table>

*ED=Eating Disorder

The data from open response questions suggest there is consensus that a parent’s sense of agency is compromised in parenting a child with a mental illness due to the need to focus on behaviours leading to weight loss and those interfering with weight gain. This is consistent with findings in the literature review.
6.5. Aspects of helpful treatment

Table 6.10 shows aspects of treatment parents found helpful. The two most frequently mentioned aspects of helpful treatment according to the parents were, firstly, learning how to view their child as someone who has been impacted upon by an illness that drives behaviour and, secondly, receiving encouragement and validation from CAMHS’s clinicians about their parenting. It is important to note that separation of illness from the child was still important for some non-Maudsley parents, despite the trend identified earlier in this chapter in quantitative findings. Table 6.11 provides data on clinician perception of aspects of treatment they perceive helpful to parents. The two most helpful aspects of treatment clinicians commented on were the need to provide information to parents about AN and the process of separating the illness from the child. Both parents and clinicians perceived receiving education and information about the nature of AN as the most helpful aspect of treatment. Parents were helped to understand the complexity of AN by clinicians separating the illness from the child and by providing education and information. In addition, clinicians indicated that systemic work with the family and active parenting was helpful in treatment, whereas parents identified being understood and validated as being helpful.
### Table 6.10: Parents’ responses – what have you found to be helpful in the treatment process?

<table>
<thead>
<tr>
<th>Themes Identified</th>
<th>No. respondents</th>
<th>Illustrative Quotes (Maudsley or non-Maudsley parent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding the nature of AN as distinct from child.</td>
<td>5</td>
<td>“To be made aware of the deception of anorexia really helped me do my job.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Helping my daughter to see that anorexia was robbing her of all of the things that she really wanted in life. Mental strategies and metaphors to combat anorexic thoughts was very helpful to us both.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It was helpful to be able to distinguish between anorexia and the child.” (non-Maudsley)</td>
</tr>
<tr>
<td>Encouragement and Support</td>
<td>3</td>
<td>“We worked as a team and both I and my daughter were supported. The team aspect of supporting both of us.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“The reassurance that what I was expecting and doing with my daughter was the right thing and what I was doing was the best I could do. What I have found helpful is the reassurance to be a stronger person around anorexia.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“To be able to talk to someone who knows what is going on and what myself as a parent and my daughter was going through, understanding what anorexia actually is.” (Maudsley)</td>
</tr>
</tbody>
</table>
### Table 6.11: Clinicians’ responses – could you comment on aspects of treatment you think parents find helpful?

<table>
<thead>
<tr>
<th>Themes Identified</th>
<th>No respondents</th>
<th>Illustrative Quotes (Maudsley and non-Maudsley clinicians)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psycho-education</td>
<td>6</td>
<td>“Empowerment strategies and guilt minimisation approached through psycho-education, with regard to eating disorders.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Psycho-education and strategies for standing up to the power of anorexia.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Information that enables parents to think about anorexia differently.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Information about severity of illness.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Education about treatment processes and expectations, as well as recovery.” (non-Maudsley)</td>
</tr>
<tr>
<td>Externalisation</td>
<td>5</td>
<td>“Separating out anorexia from the adolescent encourages parents’ confidence in taking a firm stand with anorexia whilst loving their child.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“A process of externalisation, illness is not their young person, helps attack the illness whilst supporting the young person.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Externalising the problem helps with ways to step back from conflict over food. It helps to develop ways of maintaining a positive relationship with the teenager at other times that are not about food.” (Maudsley)</td>
</tr>
<tr>
<td>Systemic work with family</td>
<td>4</td>
<td>“Building respectful relationships with parents and their child/adolescent.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Support with language that model healthy relationship with food and body within the family.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Explore how the family can work together more effectively; facilitate family cohesion and working together assists families to manage difficult situations.” (Maudsley)</td>
</tr>
<tr>
<td>Enhancing parental capacity</td>
<td>3</td>
<td>“Parental engagement as critical players in the treatment process and validation of the active role as parents is important.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Helping parents to stand up to the ED and take back the territory it has claimed at home. We are empowering parents in decision making and empowering parents in their ability to trust their instincts re food and exercise is the most important thing we can do.” (Maudsley)</td>
</tr>
</tbody>
</table>

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6.6. **Parents’ and clinicians’ suggestions for how treatment could be improved**

Four main themes were identified on the aspects of treatment that parents felt could be improved (Table 6.12). These themes have been termed: *access; quality of information about treatment; relationship with therapist; and tailored treatment*. Difficulty accessing specialist treatment was cited by many parents as a barrier to recovery, especially for those residing in rural areas. Some parents expressed the need to clarify expectations about therapies, such as Maudsley, to avoid dissonance in treatment with clinicians about anticipated parental responsibilities.
Table 6.12: Parents’ responses – are there aspects of treatment which could be improved?

<table>
<thead>
<tr>
<th>Themes Identified</th>
<th>No. respondents</th>
<th>Illustrative Quotes (Maudsley or non-Maudsley parent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>5</td>
<td>“Only difficulty was that it is difficult to get into the service. We were desperate as we were paying a private dietitian and running out of money.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“The hardest thing for my family during treatment was all the travelling to and from Newcastle for weekly appointments.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“There really isn’t a lot of places around for treatment of this disease, there needs to be a lot more facilities around more remote areas, very taxing on families that have to do a lot of travelling.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Long distance travel for treatment weekly appointments caused more stress and fatigue.” (Maudsley)</td>
</tr>
<tr>
<td>Quality of information</td>
<td>2</td>
<td>“We were given options of Maudsley or individual therapy but not told what they involved.” (Maudsley)</td>
</tr>
<tr>
<td>about treatment</td>
<td></td>
<td>“Overall we found this treatment (Maudsley) to be very depressing and felt it worsened the condition. The atmosphere was dark and oppressive and the therapists were not open with us.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Attachment with the therapist and the patient could have been better. This aspect of treatment seems to be the most important factor in treating anorexia” (non-Maudsley)</td>
</tr>
<tr>
<td>Relationship with therapist</td>
<td>2</td>
<td>“Try different methods of getting into anorexia headspace than Maudsley. Not repeating things that don’t work or don’t get them to think.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Every child needs to be treated individually (not pigeon – holed).”(Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Treat the person with anorexia as a person not just a number, be treated as an individual.” (Maudsley)</td>
</tr>
<tr>
<td>Tailored treatment</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Clinicians’ comments on aspects of treatment method perceived to be unhelpful are shown in Table 6.13. Lack of attention to engaging parents in transparent treatment processes were cited by clinicians as being most unhelpful for parents. Some clinicians conveyed parents’ sense of judgement from their treating clinician also interferes with helpful treatment process.

The survey results provided in Tables 6.12 and 6.13 suggest that while there are some areas of agreement between parents and clinicians regarding a need for clarification of expectations in treatment and meaningful engagement of parents, only parents commented on the need to improve access to CAMHS for treatment. Parents were also concerned about the visibility of
their child in the treatment process, while clinicians did not refer to the potential to alienate the child in treatment.

Table 6.13: Clinicians’ responses—what are your comments on aspects of treatment parents may find unhelpful?

<table>
<thead>
<tr>
<th>Themes Identified</th>
<th>No. respondents</th>
<th>Illustrative Quotes (Maudsley or non-Maudsley clinician)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor engagement of parents</td>
<td>7</td>
<td>“Therapist alignment with child/adolescent, as seen by parents, can be viewed as opposing their wishes or perception of the issues. This often happens when parents feel excluded or not consulted.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Being excluded from the plans in treatment gives the impression that it is their fault.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Judgement and disempowerment comes from exclusion in care planning and intervention.” (non-Maudsley)</td>
</tr>
<tr>
<td>Inconsistencies in treatment approach</td>
<td>5</td>
<td>“Not having a chance to clarify expectations of nutrition and weight change means the child can remain unwell.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Inconsistency within treating team and approach discrepancies in communication of therapies is unhelpful.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Moving on with treatment before the family is committed and had a clear understanding of illness, severity and treatment expectations create confusion and tension between therapists involved and parents.”(non-Maudsley)</td>
</tr>
<tr>
<td>Lack of attention to psychological wellbeing of parent</td>
<td>5</td>
<td>“Lack of co-ordination of treatment – different approaches, different advice from professionals involved puts us on different pages.” (Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Split approaches by therapists/medical involved means we are not working together as we need to with this powerful illness.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Covert blaming.” (non-Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Perceived blame.”(non- Maudsley)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Being blamed.” (Maudsley)</td>
</tr>
</tbody>
</table>

6.7. Conclusion

The quantitative and qualitative data from the surveys showed parenting adolescent AN was perceived by both parents and clinicians as a journey characterised by fear, despair and frustration. In open responses, parents tended to describe their experiences as a test of emotional
and physical endurance, whereas clinicians conceptualised parenting as a series of challenges to and from AN, throughout treatment. There was a shared sense between parents and clinicians that helping to understand the phenomena of AN a empowered parent to help their child recover.

Other points of convergence were:

1) The importance of the relationship between parents and clinicians in treatment, although only parents valued support and re-assurance. Clinicians tended to focus on attainment of skill to build resilience in parents.

2) Separating the illness from the child. However, there was a specific concern from some non-Maudsley parents who felt the uniqueness of their child was lost in this aspect of treatment, and there was a suggestion in the survey results that this aspect of treatment was regarded as less important by those who did not complete the Maudsley treatment in comparison to those who had.

Parents and clinicians identified different aspects of treatment that were perceived to be unhelpful. Parents expressed difficulties in accessing specialist services, particularly those in rural areas and also identified the alienation of their child in treatment as a concern, yet neither was mentioned by clinicians. The following chapter contains emergent thematic analysis from interviews with parents which further illuminate data presented in this chapter.
Chapter 7. Findings from interviews with parents

This chapter documents the findings from seven in-depth interviews with nine parents of adolescents who underwent treatment through CAMHS for AN. Four interviews were held with six parents who participated in Maudsley family therapy. Two of these interviewed parents chose not to complete the survey reported on in the previous chapter. Three interviews were held with three parents who participated in other forms of family therapy. One of these parents commenced Maudsley treatment but chose to move to another form of treatment. In keeping with interpretative phenomenological analysis (IPA), the study reported in this chapter explored the personal meaning parents made of parenting an adolescent with AN and how they attempted to make sense of the illness in their lives.

Four primary metaphoric themes about AN emerged from participants’ experience: fear and denial; living with the foe; making sense of the struggle in treatment; and the quest for meaning. Table 7.1 provides a summary of these themes. The themes revealed in the data analysis were explored to help illustrate how parents conceptualise their experiences of parenting their adolescent with AN and the sense they made of their experience of receiving treatment. An exploration of each theme was undertaken where participants’ quotes were used to convey the personal meanings and experiences of the parents in relation to each theme.

The chapter commences with a discussion about the ways in which AN was first realised by the parents through the emergent theme: fear and denial. This includes their conceptualisations of initial suspicions and experience of seeking confirmation of diagnoses. The chapter then explores the impact of adolescent AN upon the parent in their social contexts and then how the parents’ social context impacts upon their management and experience of treatment, in the themes living with the foe and making sense of the struggle in treatment. Attention is also given to secondary themes related to the emotional response provided by parents as they recounted
their stories. Whilst all struggled to parent, and suffered under the tyranny of an exhausting and unrelenting disorder, many found a resilience within which helped withstand what one parent described as ‘the wild ride of emotions’. The chapter concludes with an exploration of how parents made sense of the phenomenon of AN through the theme *the quest for meaning*. 
### Table 7.1: Themes and subthemes from parent interviews

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
<th>Key Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Fear and Denial</td>
<td>1.1 A growing awareness</td>
<td>“… the last thing you’d expect was anorexia. So it takes a while to realise there is actually a problem.”</td>
</tr>
<tr>
<td></td>
<td>1.2 No-one says the word</td>
<td>“… the GP said is it anorexia? I said well that’s what’s on the request form!”</td>
</tr>
<tr>
<td>2. Living with the foe</td>
<td>2.1 The family context</td>
<td>“It’s had an enormous impact on the whole family.”</td>
</tr>
<tr>
<td></td>
<td>2.2 Adjustments to paid work</td>
<td>“I had to organise my work and all my rosters around Mitchell’s eating disorder.”</td>
</tr>
<tr>
<td></td>
<td>2.3 Social networks</td>
<td>“My existence, my social life, and my home life, my work life, in every aspect came to a stop.”</td>
</tr>
<tr>
<td></td>
<td>2.4 Challenges and reactions</td>
<td>“We have a temple … and we do bring in the values from it to help.”</td>
</tr>
<tr>
<td>3. Making sense of the struggle in treatment</td>
<td>3.1 Differing experiences of treatment delivery</td>
<td>“… every week you’d go there and there’d be this one more step.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“… with Maudsley therapy it’s treatment, they don’t really care about the person that’s at the core of it all.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“… it was totally inflexible.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“… it was mainly supportive.”</td>
</tr>
<tr>
<td></td>
<td>3.2 Negative perceptions of treatment</td>
<td>“I think the clinicians are role playing.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“… they were trained what to say in Maudsley without caring.”</td>
</tr>
<tr>
<td></td>
<td>3.4 Positive experiences of treatment</td>
<td>“They helped us to learn and deal with it, to be stronger and fly on our own.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“They helped us separate anorexia from her … that was helpful … It really helped me face up to really hard things that I probably wouldn’t have faced up to in my parenting.”</td>
</tr>
<tr>
<td>4. Quest for meaning</td>
<td>4.1 Making sense of AN</td>
<td>“… in a lot of ways anorexia brought us closer.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It has no meaning; how long can you tolerate this.”</td>
</tr>
</tbody>
</table>
7.1. Fear and denial

Most parents reflected on their initial suspicions as an apprehensive time because the gradual and secretive nature of the disorder contradicted their view of their child and their child’s usual behaviour. The measured nature of change most parents witnessed was embedded in the context of their daily routines, thus masking the true intent of illness-driven behaviours. Initial suspicions were raised when clustered or paired with other behavioural anomalies in their child rather than a single change in behaviour.

7.1.1. A growing awareness

Most parents’ suspicions commenced in the context of their child’s heightened activity around food. Parent Sabar commented on his 15 year old daughter:

*I think the first time we picked up and noticed that there’s a problem is when she started to like cooking a lot. Every opportunity she had she wanted to cook and most of the ingredients that she usually used, she reduced levels of food, which we never picked up on because she’s trying to be health conscious. We never paid any attention to this before. That’s the beginning of the thing.* (Sabar)

Ruth illustrates how the illness gained momentum in her 14 year old daughter who combined carefulness in intake with what appeared to be healthy exercise with her mother:

*We used to go for walks and talk about points. I hate speaking about it now you know what it led to. At the beginning it started with a friendly diet between us both, so we both decided to, just for fun. I suspected things were going bad, probably after about three months when she seemed to be getting a bit obsessed with food.* (Ruth)
Kabir, mother of a 15 year old girl, illustrates her reflection on how AN grabbed onto innocent healthy activities to disguise its intent:

_This is the beginning; she would love to go for a walk with me and her sister. It never occurred to me, it was great to keep seeing her every day. I didn’t really see the change in her physical body because we were all going for a walk. Then one day a lady picked up on it and said, darling why is your body getting skinny. That woman triggered it for us. We became aware that there was something else happening here._ (Kabir)

Both extracts illustrate how the child’s behaviours were initially conceptualised as behaviours which promoted healthy relationships, including walking together as a family, or dieting. The extracts also made reference to the parents’ sense of regret in unwittingly being complicit in the early stages of the illness. The accentuated behaviours hid behind the norms of adolescence and family relationships which made early identification of AN particularly difficult. Parents did not understand that they were dealing with a force beyond that of their child.

The gradual emergence of the power and influence AN has over the child and within the family, is further illustrated in comments by Trevor and Michelle.

_So she gradually became, this is a thirteen year old child, very proficient in the kitchen but then it gradually got more power. Her influence over what we were doing such as buying the goods for the family meals, preparing the family meals, entertaining our friends._ (Trevor)

_Then she just gradually got fussier and fussier about what she would eat, smaller portions, and smaller variety and then wouldn’t eat with the family._ (Michelle)
Trevor and Michelle illustrated how heightened vigilance around food, coupled with authority over decision making related to food preparation and consumption rose as a powerful force in their family. They recognised an emerging set of behaviours that gradually shaped not only the child’s behaviour, but that of all of those around them, also. Almost by stealth, parents and family members become caught in a complex web of behaviours and relationships designed to transfer the authority over decision making from the parent to the child. Ruth also provided a good illustration of the progression of suspicion of the illness, from secretive but noticeable behaviours to overt authority over intake:

*I mean it wasn’t obvious really. If she’d eat a sandwich she wouldn’t make any fuss about me putting grated cheese in it but I could see her with her finger trying to pick it out, whereas now if she did that she would just outright go, no way, no I’m not having cheese, so it was more secret I guess, at that point. (Ruth)*

The evolution of protest, related to intake and authority over decision making, combined with a fierce determination to exercise seems be to the catalyst for some parents seeking confirmation of their suspicions. Ruth said:

*It was when I realised she was doing like seventy push-ups and skipping for ten minutes at a time that I said to her ‘that’s not a sensible thing to do, you have to stop that.’ So she stopped. It was when I found her doing it in her bedroom that I knew we had a problem. (Ruth)*

Other parents made similar comments:

*She spent more time getting dressed and then in her bed. When she was reading in bed she also did leg exercises. That was very unusual but when you asked her why*
she said, ‘oh this is just my leg exercises and I just want to just try and get a good
B-test (school test), get good marks. She said to me, ‘you can check it out.’ (Kabir)

Parents’ growing suspicions that their child’s altered behaviour were grounds for serious
concerns were matched by parental bewilderment and fear of the unknown. In this context it
was very difficult for parents to make sense of the unfolding phenomena of AN taking hold of
their child and family. Parents could see their child changing, both physically and
behaviourally, but lacked a known framework to help turn suspicions into a defined problem to
be managed. Although suspicious, parents were confused about what they were seeing. Ruth
spoke of her confusion:

… she used to come home and make herself snacks with a lot of cheese and
biscuits and fried sausage and all sorts of things. Well that stopped abruptly. The
last thing you’d expect was anorexia. So it takes a little while to realise that it is
actually a problem …. I was still bewildered at that time, I didn’t know about
anorexia so if she had a problem with anorexia, I wouldn’t have known how bad it
was going to be. I just felt a bit lost. (Ruth)

Sherry, mother of a 15 year old girl, added understanding to this by suggesting that betrayal and
denial also made it difficult to realise one’s initial suspicions were true:

… the hardest thing to deal with is that you couldn’t trust your child anymore. In
my case it was something that was gradually happening for a long time. I’d had
suspicions but ask questions, I’d ask and probed and checked up on her but the
lying to you in the face for so long was the hardest part to deal with. (Sherry)

Some parents, however, did not notice behavioural changes in their child. For some parents,
their busy lifestyles, combined with the secretive nature of AN, kept the focus away from their
child’s behavioural changes. This was particularly the case for parents who provided the sole
source of income to the family. Balancing competing priorities in work and home sadly paved a
path for the illness to thrive in the life of their child. For these parents, awareness that something
was wrong with their child occurred after the child had experienced a physical deterioration
requiring medical attention. The following extracts illustrate how two parents regretfully
reflected upon their awareness of their child’s deterioration in the context of their busy lifestyles:

*I was really busy going to university and as well as work. I would cook the food
and put it on the table. I had never ever noticed that she wasn’t eating her food
because you just expect that people eat; it’s a natural thing. So when I realised that
she wasn’t eating, that was just a shock; I just felt guilt. How it happened was that
she was getting dizzy and blacking out and so she started going to the doctors. The
doctor said, ‘what have you eaten today’ and when my daughter listed what she’d
eaten it was barely anything at all! Up until the doctor’s appointment not in my
wildest dreams would I think that my daughter had anorexia.* (Alison)

For Alison, completing priorities to keep her family functioning, diffused her reality from that
of her daughter. In doing so she experienced guilt associated with causing the opposite effect to
her actual intent. In this instance, and from what we have seen in previous extracts from parents,
AN took full advantage of the fact that it could go unnoticed and subsequently unchallenged. A
combination of a busy lifestyle and secretive behaviours provided the means by which AN
gained more power than would ever have been anticipated by Alison.

Diane, mother of a 15 year old boy, added further insights to the process. Diane drew attention
to similar experiences in parenting an adolescent male with AN, where significant harm to
health and wellbeing occurred before the realisation of an eating disorder was recognised.
We went the whole week that we were in hospital where nobody could tell me anything; no-one could tell me what was wrong with my son. They were getting physios in because he lost mobility of his legs and his arms, then a dietician came in one day and asked me what was Mitchell’s normal eating. I was there twenty-four hours a day and I still didn’t know that my son had an eating disorder.

(Diane)

As with other parents, neither Alison nor Diane had thought an eating disorder was a possibility in their child’s life, and both suspected other illnesses as the cause of their child’s altered physical status. Diane’s reflections also raised the difficulties parents face in talking with health professionals about their concerns.

In realising the emergence of AN within their child, parents described a gradual progression of the illness gaining momentum over time. Carefulness around intake progressed to restraint, restriction and protest. Some parents’ suspicions were raised by a clustering of behaviours in their child, such as, hyper-vigilance around food, secrecy, and denial of a problem despite the evidence of an emaciated state. These parents witnessed their child’s usual pattern of relating morph into something gaining a life of its own and they suspected AN. For other parents, busy lifestyles provided the perfect environment for the illness to thrive undetected.

7.1.2. “No-one says the word”

With no frame of reference for dialogue with health professionals about their child’s bewildering and challenging behaviours, the path to confirmation of suspicion is almost as perplexing as the illness itself. In seeking diagnostic clarity, Diane’s extract below describes her experience of a lack of direct dialogue with health professionals in circumstances where her son had been disabled by a then unnamed condition. Her extract illustrates how the absence of dialogue between parents and health professionals can disempower parents. For example:
In hospital I was feeding information and not getting anything coming back to me. I didn’t know what was going on ... we finally went home, I got the letter that said he’d been diagnosed and that people were going to call me and make arrangements; obviously that’s when they got CAMHS involved. But there was a period there when I didn’t know what I was doing. (Diane)

Diane’s reference to feeding information is an interesting description of a process that she felt benefitted professions, over her. She was providing information yet receiving no validation by way of direct discussion or assessment details. Her feedback came via a statement in a letter that only clarified diagnosis. There was no opportunity to discuss implications of the illness, or management in the period leading up to treatment at CAMHS. For some parents, power differentials between parents and health professionals commenced from the moment they placed their child before a professional, seeking clarification of concerns.

Trevor and Michelle spoke of taking their 13 year old daughter to health professionals, seeking help and confirmation. Their extract is further testimony to the power differentials parents experience when their concerns are undermined by a seeming lack of identification, dialogue and action in the face of the declining health of their child:

… for about two years we took her to the GP fortnightly and also took her to a dietician to try and help get meals for teenage vegetarians but she just kept getting thinner and thinner... the day she collapsed our GP had actually called another GP into the office, ‘saying what do you think we should do?’ and I’m thinking, oh my gosh please... (Michelle)

We didn’t know what was happening. There was nothing of her. Fortunately they said she had pneumonia so she was taken away in an ambulance and you think, ‘thank god’. (Trevor)
... I called the GP to let them know what was happening and the GP said, ‘is it anorexia?’ I said ‘well that’s what’s on the request form here!’ Like no-one says the word. (Michelle)

Parental experiences of health professionals failing to name the illness and confirm concerns, left parents directionless and frustrated. For Michelle and Trevor, the experience of presenting their gaunt child to the General Practitioner for regular monitoring left them perplexed regarding the lack of knowledge about the disorder. They could see their child becoming thinner and fussier but needed a medical practitioner to diagnose the illness for a treatment plan to follow. It was somewhat astounding for these parents to witness their doctor call another doctor into their consultation, seeking advice on management, and additionally then having that same doctor ask them what diagnosis had been given to their child once admitted. The multilayered challenges faced by parents in seeking diagnostic clarity for AN and subsequent help for their child and family is evidenced by Michelle’s and Trevor’s joy at their daughter’s diagnosis of a tangible and manageable illness (pneumonia). Whilst AN was not recognised at this point, it did set off a process for treatment. This extract also highlights the undeclared and powerful nature of the illness. This is evidenced by a lack of recognition of the illness at multiple points of presentation. It also provides another illustration of indifference to parents when they are left to read the diagnosis on a form and, in this case, relay it back to their health care provider.

Most parents experienced power differentials in the encounters with health professionals when seeking confirmation of their suspicions. The following extract from Sherry’s interview describes how she felt she was treated. Where an emerging serious problem required respectful and engaging dialogue, she felt alienation and a berated sense of self:

*I took her to a GP, he didn’t laugh at me but he more or less laughed it off, saying ‘yes she’s a little underweight’... so I took her to Emergency, they didn’t believe me either. He (doctor) said, in front of my daughter and me, ‘oh what’s this I hear*
about you having this eating disorder; you don’t want one of those!’ He said ‘I think she’s got pneumonia’... she did have a cold, but it wasn’t pneumonia that was her problem at the time, it was that she was too skinny and that dehydrated; they didn’t even re-hydrate her. So if you can’t get the hospital system to take notice of you, who can you? (Sherry)

In some respects Sherry’s recollections suggest that the doctor at the hospital had thought an eating disorder was likely to be present. Sherry’s primary concerns were not, however, explored or discussed. In fact her concerns were trivialised by one doctor and re-defined by another, in front of her daughter, undermining the serious nature of her suspicions. She sought corroboration for a serious concern and received invalidation. Sherry’s final comments in the extract suggest the anger she felt about this experience which had the potential to undermine her ability to trust future health professionals.

Parents wanted to hear the words, ‘anorexia nervosa’, from a health professional to confirm suspicions and guide treatment. Once spoken, or in some instances read, most experienced intense emotional reactions. The need to receive confirmation of a diagnosis of AN meant parents could begin to make sense of their child’s behaviour and establish a way forward. Despite their shock and realisation they were now dealing with a life threatening mental illness, there seemed to be somewhere to head from here. As Ruth recounted:

*I remember when my GP said it ‘anorexia nervosa’, and he said, ‘I want you to go to the Mental Health Team’. That was probably the biggest shock I got; we were now full scale into it ... it was disappointing. I thought, here’s my daughter that I expected to grow up happy and everything go right and now it was just a real turn around now we’ve got a mental illness to cope with. It was just really big for me to cope with, the fact that I had a child with a mental illness.* (Ruth)
In this extract, Ruth’s referral to the mental health team helped her gain some perspective on an illness. Now defined by a referral for treatment as a mental illness, Ruth projected a life of unhappiness for herself and daughter while ever AN is present. A sense of burden is also suggested in Ruth’s extract by having to cope with, and come to terms with, caring for her child’s mental illness. This was something she perceived as demanding on her, and substandard to expectations held in life for all.

Alison also described the intensity of her emotional reactions to being told that her daughter had AN:

> When I first found out that my daughter had anorexia it was like a huge shock. You never in your wildest dreams think this can happen to you. So I suppose shock is your first reaction. When they won’t eat, and that if they don’t eat, they could die, fear is a huge factor, and shame is another. So shame is a really big thing because you think what have I done in my parenting that has contributed to my child having this disease? (Alison)

Although shock seems to be an initial reaction for most parents, Alison expressed deep seated fear and shame that was inextricably linked to her sense of contributing to the development of AN in her child’s life. She also experienced dread that her child could die if the progression of the aggressive illness did not cease.

This provides a complex and confusing canvas of emotions for parents. It is complicated by a sense of impotency in the face of a life threatening illness that could be remediated by resources readily at hand - food. This will be explored in more depth later in this chapter.

Most parents experienced invalidation from health professionals in their journey to confirming their suspicions or concerns about their child’s health. Parents said that they felt disregarded or
undervalued by health professionals. Such statements from parents indicate the influence of power inequalities between consumers and providers in the health system. For those who were suspicious of AN, presenting to health professionals was at times a demeaning and perplexing experience. Some parents discovered health professionals did not readily recognise a presentation of AN, were reluctant to diagnose or name it, and seemingly did not know how to treat it. In fact, many parents were unexpectedly confronted by the experience of driving the process for treatment with little direct assistance from health professionals. Generally, parents ‘fed’ information to ascertain diagnostic clarity and treatment, and for the most part received a disappointing response.

7.2. Living with the foe

Once participants’ children had been diagnosed with AN and referred for treatment to CAMHS, all parents were exposed to a key concept in treatment: separating the illness from the child. This concept was central to all parents’ articulation of their experience of parenting adolescent AN and its subsequent impact upon their social circumstances. Conceptualising AN as an entity, allowed parents to describe phenomena in a way that helped them step back from notions of guilt and self-blame. Externalising illness-driven behaviours also provided parents with a common language with which to communicate concerns and achievements with professionals, between themselves as parents, and most importantly with their child. Generally, separating AN from their child helped parents focus on the cause of their child’s distress and in doing so, propelled them to the frontline of the battlefield with the illness. For example one parent said:

> It’s funny before I learnt how to separate anorexia from my child it was just in her and then after I knew it wasn’t her, it was the enemy; it was the enemy out there I had to defeat. (Alison)
The theme, *living with the foe*, explores how the battle with the enemy, AN, tested the wellbeing and safety of all. Determination to “beat it” (Michelle) was a vital factor in coming as close as possible to, as Diane said, “*becoming functional again*”.

### 7.2.1. The family context

Parent’s interpretation of the impact of AN upon family life was initially understood in terms of a description of their child’s current behaviour, as distinct from their former behaviours which were driven by AN, and those that pre-dated AN. This helped parents describe the phenomena in an objectified manner and allowed them to see their child struggling, as much as they were, under the duress of an unrelenting and uncompromising illness. Ultimately what came to pass were accounts of how parents perceived all family members caught, in some way, in a “*dark tunnel with their child.*” (Trevor)

Parental alienation featured in all accounts. This was initiated by the intrusion of AN into the identity of their child and consequently on family dynamics and momentum. Diane spoke of how her son had succumbed to a powerful force that robbed him of his own sense of self and of their usual pattern of relating:

> ... *my son became like an alien to me. He wasn’t the son I used to know. He became a totally different person, and that was really very hard emotionally.*
> *Suddenly seeing that this person wasn’t your son, and you couldn’t relate to him in any aspect. He couldn’t see that what you were trying to do was to keep him alive.*
> *It was really, really hard.* (Diane)

Diane’s son became unfamiliar and, perhaps more importantly, odd to her. She could not find a way to relate to the stranger that he had become. Their relationship had been substantially altered. Prediction of his usual behaviour, based on years of parenting, could no longer be relied upon. Diane’s grief for her son and the loss of relationship is evident in her extract, as are her
efforts at trying to reach out. Trust had been compromised and her exhaustion at efforts to “keep him alive” were overshadowed by the illogical quest and influence of the illness.

Parental unfamiliarity with their child’s behaviour, influenced by AN, is well described by Ruth as follows:

“Some days I would sit with her all day because it would take three hours to get one meal into her and she would throw her food around. She’s always been pedantic about neatness and cleanliness. She’d never make a mess but she was prepared to just spit food all down her front to get rid of it. When she would drink something she’d just let it all run out the front of her mouth. It just took her away totally. It was every minute of the day; it was every meal … it was absolutely constant. You could think of nothing else because it was there with you all the time. (Ruth)

Both Diane’s and Ruth’s extracts illustrate how the foreignness of their child’s behaviour estranged them from their child. They provide a description of the relentless thoughts, worries and efforts all parents shared in trying to help their child to recover. Their children were otherwise predisposed to the goals of AN. Parents’ sense of their child’s mortality provided the motivation to battle with the disorder that tested family norms and wellbeing.

The parents interviewed knew that they were up against something much more forceful and influential in their child’s life than anything they had previously encountered. They were most challenged around meal times and had to find ways to keep their child alive, whilst trying to maintain a level of functioning for the whole family. In trying to sustain some normalcy around meal times, some parents experienced their child’s attempts to control any activity associated with food preparation as abusive. Ruth provided an account of meal times in her home:
I would just dread cooking an evening meal because she would stand at my elbow, pinching me or kicking me or swearing and she was always such a gentle girl. It got to a point where you would make meals that you knew were going to cause the least injury to yourself... sometimes if my husband was home he’d try and hold her off but she used to claw the skin off his arms. It was just horrible for the boys to have to watch ... if she was bashing into me I could think, this is not my daughter, this is the other thing; it helped me cope knowing that she didn’t really hate me.

(Ruth)

Meal preparation was the primary battleground for physical abuse of parents. Many parents described devolution of power from parent to child in decision making about food preparation and delivery.

Meal times were often filled with a sense of ‘dread’ for most families, with siblings exposed to the dominance, confusion and burden created by AN affecting their brother’s or sister’s behaviour. Ruth commented further on this pressure:

We always bought tea on Saturday night and we decided we were not going to give that up... the whole family tensed as soon as we got in the car because we knew there was going to be a terrible outburst at some point. It just makes for a lot of tension ... the boys would say ‘why can’t you be normal?’ And if anyone watched her eat there’d be a huge fight because they [sibling brothers] stared at her. It was just extremely tense twenty-four seven. (Ruth)

Ruth illustrates the strain families experience when anticipating an adverse response from the adolescent with AN when trying to keep to family routines around eating out. Siblings in this extract are unrestrained in their emotional response to their sister, as they are adversely affected by something they do not understand and have little patience for. They struggle as they watch...
their parents combat an unknown entity that is outside of what they would consider usual and expected for an adolescent, and indeed their sister, prior to AN. Their reactions to their sister’s behaviour reflect resentment and embarrassment.

Some parents described parenting adolescent AN as an experience of parenting someone with infantile behaviours:

*It was exhausting and just constant, like it was worse than a new born baby, you know, you just had to watch every, every bit.* (Michelle)

Other parents described the experience as a completely unrecognisable human behaviour:

*You felt like you might feel when you’re given a baby animal to care for; you’ve got no idea what to give it to eat. I just felt like I can’t look after this thing because I don’t know what to do with it.* (Ruth)

Ruth and Michelle described their experience of their adolescent with AN as ‘growing down’ in their family, becoming someone who required a level of concentrated parenting far greater than that required for a newborn. They were dealing with high levels of tension, conflict and control that were infantile in nature yet emanating from an adolescent. Such incongruence perhaps resulted in Ruth’s comments about her child being more like a baby animal with behaviours that are unanticipated from any human being, let alone her own daughter.

Sherry’s comments in the extract below parallel the vulnerabilities in parenting adolescent AN to those of parenting new born babies:

*If someone could come to me with a book and said read that, this is what anorexia is, that would be fantastic because you’d know. It’s like having a baby for the first
time. You want it to come with an instruction manual but it doesn’t. You’ve got to figure it out as you go along, you know, and it’s different. (Sherry)

Perceiving their child’s behaviours as infantile helped parents to locate a time in their own past experience that assisted them in conceptualising the role they had to assume in their current parenting. This also highlighted the current neediness of their child. Sherry’s extract additionally refers to her experience of trial and error in parenting as she attempted, like many others, a range of methods to keep her child safe and well. Experimental parenting was realised after parents acknowledged the competition AN posed to parenting.

Kabir illustrates parental awareness of the push and pull in communication between parents and their adolescent with AN:

Parents should understand it’s the sickness talking, not them. They will believe the opposite to what you say, they will do opposite. So you’re trying to find, as a parent, a little of your own child and you need a lot of selective hearing. It is very important to recognise what they have said so you quickly think, oh that’s not her or that is her. (Kabir)

Parents described relearning to parent their adolescent. They became more forthright in their parenting of their child with AN and began to predict that objection and disharmony in their child was a feature of challenging the illness. While this caused burden and distress in parents, they realised they could build separate relationships with both their child and AN. They did this by being transparent in acknowledging behaviours influenced by the illness in contrast to those of their adolescent’s usual behaviour prior to the onset of illness. This realisation occurred throughout the course of their involvement in treatment.

Parents practiced conceiving the illness as something that they had to engage with directly rather than having to referee or mediate family discord. Parents commented on their experience
of understanding their foe as AN, and learnt that it sustained a life in their child while ever they were disengaged from the battle. Some parents felt engaging in battles with AN provided opportunities to move away from vulnerability in parenting. For example, Alison said:

... before it was like anorexia was sort of this big shameful thing in our family and treatment put it outside; like it was a foe that we were working together to defeat. When Abby let anorexia win and take away from the things that Abby really wanted, it gave me something helpful to do. I could help her get what she wanted. (Alison)

It was an empowering moment for Alison to feel she could continue to have a relationship with her daughter whilst managing AN. While ever AN prevented her child from attaining other goals, outside of thinness, Alison was able to forge a wedge between AN and her child to pave a way to a relationship again. In this extract we see Alison regain her sense of parenting through connecting with the goals of her daughter, not AN. She had an opportunity to do something when AN had let her child down. Although Alison was dealing with loss and grief, which came with her child being robbed of age appropriate opportunities, she illustrated how important it was for her to seize any opportunities to parent the child she knew.

Parents’ recollections of regaining a relationship with their child are also evident in Diane’s extract below. Diane conveyed how her increased understanding of AN in her child’s life empowered her to focus on managing the illness and re-establishing a relationship with her son. Diane described how her son, in a therapeutic session, explained his experiences of AN in a manner that helped her understand that her son had not truly left her:

We called Mitchell’s eating disorder Tex... Mitchell described Tex like a cat one day. He drew it on the board and said that cats can be very manipulative, they can purr when you stroke them and then they’ll suddenly turn. And the moment I just
went, “oh my god what you have drawn on the board that’s how it is!” ... once I understood that, it took the focus away from Mitchell; it was the eating disorder. That helps a parent to see that it’s not their child and not take it personally. I blamed myself for his eating disorder and finally I had to get over that blame and say, “OK this is how it is, what we are going to do to fix it. (Diane)

Parents like Diane described having to manage the emotional overload of seeing their child become something unknown while also feeling, at the same time, responsible and disempowered by the experience. Diane’s ability to sideline her emotions to deal with the battle ahead was common to many parents. Appreciating the phenomena was not enough to help parents undertake the quest of reclaiming their child and their future. Sidelining particular parental emotions, such as guilt and shame, were significant in enhancing their capacity to battle with AN within their child.

Kabir’s and Sabar’s conversation about focusing on the content of what their child was saying, rather than connecting with their own emotional reactions, allowed them to move forward in their family:

You’re dealing with two different individuals. When you focus on your child you give love, when you focus on anorexia, you deal with anorexia and be strict as where possible. (Sabar)

Firm with love. (Kabir)

Some parents concluded that when their emotions were at the forefront of decision making they tended to be more reactive to their child’s behavioural outbursts and less able to help their child or others in the household. In the following extract, Alison also spoke of having to push guilt and shame to one side because it was succeeding in undermining her ability to remain focused on what she felt she needed to do. She also identified that decisions based on guilt and shame
unintentionally created an environment where she became complicit in maintaining the illness in the life of her child. Her feelings of guilt were making her do things that she would not normally do as a parent, in the same way AN had shaped her child’s behaviour:

... guilt doesn’t help, if you’re doing things because of guilt, you’re focusing on you and you’re not focusing on your daughter... it gets in the way ... if you feel guilty then that emotional force of anger comes with it and you get really forcefully frustrated yelling ’you have to eat!’... if you take the guilt out of it then the way you react can be different because it’s not personal ... her not eating isn’t a reflection of your parenting. (Alison)

Here Alison spoke about the way she persevered with her relationship with her daughter during times that were highly anxiety provoking for parents and their child. Alison could identify her own unhelpful behaviours emerging through her frustration. This allowed her the opportunity to distinguish the guilt-driven behaviours that reinforced AN from those that kept her on track and able to adopt a calmer approach with her daughter, required to challenge the eating disorder.

Although parents managed their emotions in order to focus on actions that they felt helped their child recover, abuse of parents continued. Helping a child reclaim their life was not a linear process characterised by compassion and a series of gains in parental authority. Parents struggled with their child’s emotional responses and the distress caused by the demands of AN. As a result they found themselves moving in and out of their own distress:

Sometimes it was ok and we were fine, it just took a long time to eat, but one time he had a break down; he was throwing plates and smashing the house, and I was cowered in the corner. (Diane)
Being available to their child was a particularly difficult thing for parents to do, both physically and emotionally. Michelle’s extract below, tells us about the ongoing determination required by parents to face the emotionally eroding experience of parenting adolescent AN. For Michelle, focused determination was critical in the journey with her daughter.

_Well I guess I was looking at wanting Grace to be healthy again, so anorexia was like my enemy, like I didn’t think it was Grace doing it. It was anorexia I was battling with. That’s what I kept telling myself, ‘I’m going to beat this’, like I gave myself that challenge. I hated anorexia and I love my daughter; for all her faults._

(Michelle)

The central points that parents expressed when asked to consider how AN impacted upon family life related to how they made sense of the illness in their child’s life and how they rebuilt a relationship with their child whilst battling the illness. In order to begin to understand and manage AN, parents had to develop a clearer sense of self. Parents knew they had to deal with their own emotional reactions to living with their child, who was subject to the forceful nature of AN, before they went into battle with the illness. To do this, parents separated behaviours of the illness from behaviours of their child. This allowed parents to have a relationship with both their child and the illness, as they learnt more about illness driven behaviours.

Many parents found themselves experimenting with new methods of parenting that assisted in having a dual relationship with their child. All discovered that AN thrived while ever they did not engage in the battle with the illness. Battling with the illness meant parents had to reorganise their time. This necessitated adjustments to work.
7.2.2. **Adjustments to paid work**

Parents found that helping their child to recover absorbed most of their time. They allocated additional time to parental responsibilities and adjusted work patterns in order to parent a child who did not want help. Differences were noted in parents’ abilities to adjust work schedules and in the level of support they received from employers.

Differences were noted between couples and those parents who provided the sole source of income to the family. For example Michelle, owner of a small business with her husband, reflected upon her ability to make adjustments to paid work:

*I had six months off work; so we just got extra staff. If we weren’t working for ourselves, I don’t know how you’d do it. Like I really had to put being at home with our daughter number one, then the rest of the family and work was last. I think for a lot of people it would be hard.* (Michelle)

Economic considerations associated with adjustments to work featured less in Michelle’s thoughts than it did for other parents. Michelle could prioritise her care without the worry of significant financial strain on the family. Her empathy for other parents less able to finance time away from work to care for their child was linked to her own knowledge and experiences of time required to care. For example Michelle said:

*I’d given up work but that involved standing outside the shower, watching every mouthful she took and then, when she was well enough to go back to school, I’d get morning tea and take her to the school and get lunch and take it to the school ... this is the whole day.* (Michelle)
The nature of work required to care for their children altered the structure of parents’ lives. Care for their child meant that in any day, parents worked in either a paid or unpaid capacity most hours of the day. While the costs of caring for an adolescent with AN were multilayered, the added financial burden for some was far greater than others. Single parents were particularly economically vulnerable.

Diane’s extract below, illustrates similar levels of care referred to by Michelle; however, with the additional stress of being a single parent. Diane expounded on the stressors of care, together with having to work out how she would adjust her work schedule in order to care for her son on her own:

*I had to organise my work and all my rosters around Mitchell’s eating disorder. I had to be here for his breakfast and well as his dinner. I would then organise supervision for his lunch … I could not afford to give up my job. Financially I had commitments and I couldn’t go on to benefits, as a carer, due to my personal circumstances.* (Diane)

Although Diane could not afford to give up her paid work completely, like most parents she had to take a period of full time leave from work to organise her management of the illness at home. To do this, Diane exhausted all available work related entitlements:

*I gave up work for six weeks. I used all my sick leave and all my annual leave, and then it would have crept into leave without pay. I couldn’t even think how I was going to deal with this.* (Diane)

For many parents, adjustments to paid work created more stress at work and at home:
I shared shifts with other people. So it just didn’t impact me it impacted the personal lives of everybody else that I worked with. ... sometimes it would take two to three hours for Mitchell to eat his lunch. I’d be sitting there thinking, ‘I’ve got to get back to work; somebody’s doing my job’. Then dinner time I’d come home he’d be sitting there separating grains of rice from the meat and vegetables saying, ‘You’ve put something in it!’ I’d be sitting there thinking, ‘I’m in a dream, I’ve got to get back to work, I’ve got to get back to work’. With all this stress I thought that I was jeopardizing my job; I’m going to have to give it away.’ (Diane)

In Diane’s case, although she had a clear support network at work, evidenced by her work colleagues adjusting their rosters, she recounts the duress of continual monitoring and supervision required to ensure her son was eating appropriate amounts of food during the day. Diane describes the twenty-four-seven nature of paid and unpaid work, which was a common experience for most of the parents interviewed. Diane’s extract also highlights high levels of distraction caused by the oscillation of worry about their child when they are at work, and worry about their paid work when they are at home. This tension creates a level of exhaustion in parents that interfered with their ability to undertake either task adequately. Inevitably, something had to give to allow parents enough space to care. For some, responsibilities in paid employment were often compromised, leaving some parents feeling less functional at work:

*I almost sacrificed my position with this condition. I didn’t leave my work, I’m still working but I could not think properly. I did not take care of my responsibilities at work.* (Chakor)

While distraction at work occurs when parents are thinking and worrying about their child, some managed a balance between being at work and providing a level of care at the same time. Sabar described balancing work and sharing a level of care with his wife:
… they [employer] said to me, ‘if you’re sitting in a meeting everybody should have the phone off but you can have it on; leave the room when your child calls.’

Some issues I would talk through and try to sort it out in five or ten minutes, sometimes it could be forty minutes. I will be walking around and talking saying ‘calm down O.K.’ … I have also taken her to Sydney with me just to break the cycle with mum at home. I’d say, ‘now you’re staying with dad, come to my office and we’ll go to lunch.’ (Sabar)

Although this was not the norm for parents interviewed, Sabar raises the possibility of greater flexibility associated with care under circumstances where parents in paid positions have some power or authority in the workplace. Sabar’s reference to having an office and being able to move in and out of meetings meant his position, although demanding, had elements of autonomy and independence allowing for flexibility. This enabled him to incorporate the needs of his child into his routine.

Alternatively other parents, such as Sherry, experienced little support in her workplace. Her experience of judgement and isolation, upon returning to paid work from a period of care for her child, came as somewhat of a surprise:

_I had to have time off work and I have a supervisor who wasn’t very understanding; she was very nasty … it challenged my sanity that someone could be so hurtful to someone going through the most tragic thing of my life and then having to deal with that as well._ (Sherry)

Sherry’s description of her experience of parenting her adolescent as a tragedy implied she had anticipated warm regard from her employer upon returning to work. Her confusion and almost disbelief that she could be judged for trying to manage this tragedy was a truly astounding moment for her. Her sense of isolation, judgement and separateness from others in the
workplace was an experience other parents also noted. This will be discussed further in the next section.

Parents’ experiences of adjustments to work in order to care for their child varied. Parents who were self-employed or held positions with a degree of autonomy and authority had more positive experiences with employers and experienced less stigma than those who provided the sole source of income to the family. All parents experienced high levels of distraction at work and home in the period their child was most unwell. Many took time away from paid work or adjusted work patterns in order to care for their child. All parents experienced high levels of exhaustion and burden in order to become involved in the work that was required of them all hours of their waking days.

7.2.3. Social networks

Parental isolation and fatigue were reported by most parents as common features of parenting adolescent AN. Dividing hours between paid work and caring for their child, meant little time to meaningfully relate to friends and extended family members. For some parents, attempting to connect with their friends proved to be a painful experience. For example, in the following extract, Alison reflected on her ability to talk with her friends about parenting her daughter:

… it was very lonely. I did sort of try and tell a few friends but it was almost like you were telling them you had an S.T.D … I felt such shame and guilt about it. It’s hard to say anyway; I don’t blame anyone and if someone doesn’t know what to do with it, you don’t really try again. (Alison)

Alison provided a very powerful illustration of alienation in attempting to share her experience of parenting with people she felt she could trust. In doing so, she experienced unanticipated reactions that served to further silence her, and reinforce her feelings of shame and guilt. Diane had a similar experience in talking with one of her work colleagues about parenting:
I had issues at work where someone would say something and then I thought, ‘oh you know, you shouldn’t be saying that, you don’t understand what I’m living with.’ It’s not their fault, they just don’t understand, because they’ve never had to experience this. (Diane)

Although Diane had a supportive workplace, where colleagues had adjusted their shifts to accommodate her parenting, she also experienced the isolating effect of judgement from others. Despite parental isolation being reinforced by misconceptions, some parents accepted and forgave the reactions toward them, recognising that only those who have lived the experience could really understand it. Diane continued to explain her isolation:

I became very introverted because my whole world just became Mitchell. I had to give up work, because I’m a single parent. I was encouraged not to include other family members because it was a one on one; they needed to teach me mainly to deal with it, so I got very isolated ... I couldn’t do anything with friends because I always had to be there for Mitchell ... Mitchell and I became one. (Diane)

Diane linked her isolation from her family to the guidance given in treatment, where she was encouraged to be the sole source of support at home. It is as if this fused her with her son, while reinforcing her isolation and exhaustion.

Variability, however, occurred in the parents’ experience of isolation. For example although Kabir described their family’s isolation as:

… self-sacrifice we did as her parents. There were a lot of parties we would have missed, a lot of events, a lot of festivals, a lot of things we have missed.
Kabir later described how she and her husband created a community of care, out of existing networks, to assist them parent. This network did not involve family members. The network Kabir and Sabar describe in the extract below, was one where they called upon parents of their child’s friends to help monitor behaviour when their child was visiting. In this way Sabar and Kabir created a network where they could keep track on their child’s eating patterns outside of the family, while sharing parental experiences with other parents:

So what we did is ring her two best friend’s parents. I explained to them our daughter had anorexia nervosa and we just wanted to monitor her...we asked them to do it for us when she was with them. (Kabir)

So when we came to get our daughter we asked certain information from the parents. (Sabar)

In many ways Kabir and Sabar drew other parents closer to their experiences. Although Kabir and Sabar undertook similar tasks to Diane, they created a broader network of support. They made the best use of the resources within their networks but limited it to only those who needed to know, thus reducing the possibility of gossip and judgement. For example Kabir said:

Even though the close family knew, we certainly didn’t tell them. There’s a reason for it; we didn’t want talk about our family. (Kabir)

In reflecting upon the value of the network they created, Sabar added it gave him a sense of achievement:

Now I’m beginning to think that the success of this really depends on the network that you create, and most importantly the trust that you put on your friends. Not too many to friends, but close friends ... that is where the friends are important.

(Sabar)
Parents had to find a means to navigate this “rare experience” (Chakor). Misjudgements and misunderstandings by others can cause parenting AN to be more painful that it already is, as seen in Alison’s and Diane’s extracts but it can also elicit willing help from others, as seen in Kabir’s and Sabar’s experience. Either way, parents have little option but to make the best use of available resources. While some of those resources are attached to new learning through the treatment process, some are realised through the internal world of parents’ guiding beliefs and values.

7.2.4. Challenges and reactions

When faced with major challenges in parenting, some parents in this study re-examined and connected with their personal value or belief system to help guide behaviour. Some were guided by spiritual or religious beliefs and values, others by the belief system of their family of origin. Making use of personal values or beliefs helped parents shape their responses to their child and proved be a useful adjunct to strategies discussed in treatment.

Connecting with a spiritual belief system helped some parents manage their emotions in very stressful periods and retrieve a sense of potency to help their child. For example, Alison described how she used her spiritual beliefs to sidelonge guilt and help her focus on helping her child:

*I had to come to a point where guilt wasn’t what drove me and how we were going to deal with it ... the Christian belief of finding forgiveness in God and also his strength was really a big thing for me that really helped me. This let me make a decision to go; O.K. this guilt isn’t helping us.* (Alison)

Alison sought forgiveness in herself through religion for what she perceived to be her own failings. In doing so, she could move to a point where she could shift the focus from her in
dealing with her own guilt, that she commented on earlier in this chapter, and refocus on the tasks at hand of helping her child become well. This was a significant turning point for Alison in her experience of parenting. Below, Sabar and Kabir described how they made use of their spiritual beliefs and values to relate to their daughter during meal times and manage food throwing:

*We have a Temple and she has been to classes there as a little child. She still goes and she knows the teaching of it and we do bring in the values from it to help stop food throwing.* (Kabir)

*We say ‘you know what Baba says about throwing food.’* (Sabar)

In this example Sabar and Kabir illustrate how they reminded their child of who she was prior to AN entering her life, and the values that are important to her. In this way they helped her to self-manage, as well as reconnect with her former sense of self. In the next extract Kabir describes how she and her husband apply the values of their spiritual beliefs to all behaviours they feel are alien to their child:

*The lying, the anorexia will lie .... she never lied before. So when she lies we use our values. They are: the proof, love, non-violence, peace and the right conduct.*

*These five values we bring to every moment of a tantrum, every moment of shouting ... to get rid of abuse, you really need these five human values.* (Kabir)

The use of a clear value system in this family provided a set of norms for the parents to refer to at all times. These values were familiar to their child prior to the onset of the illness and gave these parents a source of strength to inform their approach. When not knowing what else to do, Kabir and Sabar drew upon a fundamental value and belief system that could be relied upon for all scenarios presented.
Other families, such as Ruth’s, made use of foundational childhood values to help in times of great stress. The following extract highlights Ruth’s use of her childhood experiences in helping her reaffirm a clear stance around meal times:

*When I was a child we had to eat everything on our plate. Absolutely, no questions asked and I guess I tended to bring my kids up a bit the same … it helped because my daughter knows she has to eat everything on her plate still. The serving wasn’t easy of course because once it’s on the plate she knew it had to be eaten but if it got there she knew she had to eat it.* (Ruth)

Here we see a norm that stemmed from Ruth’s family of origin helping her to embrace expectations around meal times. Ruth was able to maintain her resilience through the stress of mealtimes by linking her stance to known and accepted family values. Although her daughter may have resisted, by attempting to push food from the plate, her daughter was equally familiar with the stance of her mother. This was understood as a family norm.

The value base of parents became a useful tool, in providing a frame of reference for managing complex behaviours within their child. It also helped parents reconnect with their child by reminding them of a common set of beliefs or values that predated the evolution of the illness. Values and beliefs provided a common ground for the parent-child relationship and anchored parents in times of distress. Parents’ reflection upon their use of values and beliefs in helping them parent was transformative in nature as it allowed for a reworking of the experience of parenting in a more empowering way. As parents reflected upon their experiences, the influence of treatment were apparent in the language they used to describe their lives, as well as the actions they undertook. The next section will explore parents sense of what was helpful and unhelpful in treatment at CAMHS.
7.3. Making sense of the struggle in treatment

Understanding parental experiences of helpfulness in treatment is presented in three sections. It commences with experiences of how treatment was delivered, and then explores some negative perceptions of treatment. This section concludes with positive experiences of treatment. Parents’ experiences of key concepts of treatment will be discussed in all sections. While all parents participated in family based treatment, some aspects of treatment were more helpful than others. For some, Maudsley built new learning into a pre-existing value base that seemed congruent with this approach. For others, the experience was demeaning and impersonal. Those who did not receive Maudsley also experienced varying degrees of helpfulness in treatment. Regardless of treatment approach, all parents referred to the style of the clinician as central to their experience, irrespective of treatment received.

7.3.1. Differing experiences of treatment delivery

There were several components of treatment that parents commented upon. Parents remarked on the type of treatment provided, and processes within treatment. Parents who were treated with Maudsley had a clearer sense of the type of treatment provided than parents undertaking other forms of family based treatment. They understood they were taking part in a particular type of treatment approach to adolescent AN and could articulate both the treatment type, as Maudsley, and convey clear concepts associated with Maudsley treatment. While some parents engaged well with the structure of Maudsley, others felt it distanced them from an alliance with the therapist and what they believed was the intent of treatment. Parents who undertook other types of family based treatment also reported variance in their experiences of helpfulness and engagement in the process.

Parents participating in Maudsley family therapy were aware that this treatment placed a series of expectations upon them to help their child recover. This meant an attainment of skills or
reconnection with existing skills in therapeutic sessions. For example, Diane commented on the
delivery of Maudsley family therapy in this way:

_The whole idea of the program was laid out to me very up-front. They said we_  
cannot have someone there at home with you, we cannot keep you in hospital to_  
have this twenty-four hour support but this is what we’re going to do for you …_  
_and what they train you to do is to keep putting the focus back onto the food,_  
keeping it consistent and keeping it calm._ (Diane)

Diane had a clear sense that she was part of a program that emphasised her responsibility for her
child’s wellbeing. To undertake this responsibility, she received training to help her child
recover. Similarly, Sabar and Kabir had clarity that they were part of structured program
designed to help them, as a family, parent adolescent AN:

_We were all in treatment for one year… six months with effective family treatment,_  
_like once a week at first, then once a month when she started to get better._ (Kabir)_  
_with the whole family; we had Maudsley._ (Sabar)

Sabar and Kabir were aware that the approach undertaken to treat their child was targeted at all
household family members to help in the recovery process. Similarly, Michelle was clear about
the intent of Maudsley treatment by saying:

_With Maudsley, you know each week it sort of just pushes you that bit further._

(Michelle)

There was an element of predictability associated with this approach where parents understood
it meant not only active participation of family members but also challenges along the way.
Maudsley parents knew each week in session they would be set a task associated with
challenging illness-driven behaviours, and in the following week session they would be expected to discuss their success or otherwise. Michelle said:

... every week you’d go and there’d be this one more step. (Michelle)

These pushes were anticipated, forming what parents understood as a treatment where momentum was essential. The following dialogue between Michelle and Trevor illustrate their understanding of this expectation within Maudsley:

It just pushed us to keep going, because we’d think, ‘oh phew we’ve eaten out’; that was such a big deal. (Michelle)

It helped with the momentum, like to give her and us something to manage.

(Trevor)

Ruth, who commenced with Maudsley but elected to move to another treatment outside of CAMHS, reflected differently to Michelle and Trevor upon Maudsley as a model of treatment:

with Maudsley therapy it’s treatment, they don’t really care about the person that’s at the core of it all ... she (daughter) used to come out saying ‘no-body cares about me at all, I’m just nothing, I’m worthless so kill me.’ She never got spoken to. They should really structure a treatment around the family rather than saying, ‘this is how we treat you’. (Ruth)

Ruth described the nature of Maudsley as impersonal and potentially harmful in its disregard for her child’s inner experience. Her comment “it’s treatment” implies that it is delivered in a manner where something is done to someone rather than an interactive process that respects the family working together with the child. Ruth also described the alienation of her child in a
treatment that seemed to be imposed, and that existed independently of the unique need or desire of the family. This created an atmosphere absent of care and hope for her and her child.

Parents also commented upon specific components of Maudsley family therapy, in particular ‘the family meal’. Parents recounted the family meal was a key component of treatment within Maudsley, and remarked on this focus in sessions at CAMHS. The following extract from Diane described her reflections on the process of the family meal:

Carla (clinician) was saying, ‘how are you going to get Mitchell to eat?’ and I just didn’t know and she said, ‘well do you think it might help if you actually pick the sandwich up and take it and put it in his hand?’ I said, ‘oh O.K. then.’ So then I picked the sandwich up and put it in Mitchell’s hand and Mitchell just squashed it all up in little pieces. I just went ‘right what do I do next’ and she said, ‘well what are you going to do next, how are you going to get the food into his mouth?’ and I said, ‘I could feed him like a baby?’ These are all the things that I would be trying to do at home, but I didn’t have the support on tap. That was so good; it made me think outside the square and think O.K this didn’t work, what are you going to do next? (Diane)

Here Diane described the family meal as a chance for new ways of learning to challenge the eating disorder. She was coached through the process, and the style of questioning by the clinician allowed her to experiment with thoughts and actions. The family meal presented an opportunity for Diane to practice further problem solving at home with a freedom to “think outside the square.”

Kabir had a similar experience to Diane where her ability to problem solve was strengthened through the process of undertaking the family meal:
So when Monica (clinician) said very calmly in the meal session ‘what are you going to do about it Kabir, what are you going to do?’ I had to come up with the idea to tell her, then she made me think, ‘yeah I’m the mother, I should be a mother.’ (Kabir)

While Kabir and Diane’s experience of the family meal paved a path towards greater problem solving and helped them gain a sense of mastery over the situation, other parents reflect on this aspect of treatment quite differently. Michelle and Trevor comment:

“I think they were trying to encourage us to force feed her... I’d rather just be really patient even if it took all day, negotiating rather than shoving a spoon in her mouth with her throwing food everywhere. It was such a foreign environment.

(Michelle)

We weren’t given the impression, that’s what we were supposed to do; force feed.

This just wasn’t our method at home (Trevor)

Just sort of stand up and put it in; like it was dreadful (Michelle)

We felt that wasn’t going to work anyway (Trevor)

I knew they wanted to see how we tried to operate. (Michelle)

Michelle and Trevor reflected upon the family meal as something that they knew placed all of them under pressure and scrutiny. Their experience of the family meal, as a component of treatment that compelled them to force feed their child, was something they did not feel had any benefit or transferability to their home. For Michelle and Trevor, this aspect to treatment was thought to be of little value and, rather, emphasised the differences in approach at home in comparison to expectations within Maudsley. Ruth made similar comments about the family meal as a component of treatment within Maudsley family therapy:
I believed in Maudsley one hundred per cent, definitely I did, I don’t know what went wrong. To say Maudsley is family therapy, a family is very flexible, it was totally inflexible; like even that meal they make you have. I thought, it’s not what we would do, like it’s just such a weird thing to do and it just took everything out of the grounds of being normal; we had to force her to have this and force her to have that, it just didn’t seem right. (Ruth)

Although Ruth could acknowledge she had some trust in Maudsley, she felt an unnatural tension with a treatment that forced her to undertake a private event, a family meal, in an atypical setting. This, coupled with the inflexibility of force feeding, proved to be a bizarre act for her to participate in. It undermined her confidence in the Maudsley treatment modality. For Ruth, the family meal stood out as a time where the mode of treatment seemed incongruous with not only her own family lifestyle but also for other families struggling with AN.

Parents were polarised in their views on the family meal within Maudsley family therapy. For some parents, being challenged to problem-solve and act differently at a meal time in a clinical setting raised opportunities to extend upon their usual style of parenting. For others, however, it was alien to their style of parenting and therefore not considered helpful or transferrable to the home environment.

Parents who received other forms of family-based treatment were less able to articulate specifics about the nature of treatment offered. For example:

*We had a team approach. I don’t know what method of counselling or anything Margaret (clinician) was, but it was mainly supportive. I don’t know what she said to my daughter. It involved counselling, information and diet, so it was a combination of counselling and information I suppose and support.* (Alison)
Alison’s description of treatment emphasised counselling, education and support. Unlike Maudsley, this form of treatment was presented as having no standardised format. Delivery of this treatment was, however, discussed in the context of a broader team. Alison expressed a sense of connectedness with and support from the treating team.

Chakor described his experience of family based treatment at CAMHS. His example supported an experience of learning about the illness in treatment, as suggested in Alison’s extract, but added he expressed concerns that the treatment approach did not include important family members:

*I was the only one who attended mostly. But now I feel that the clinic should have been able to acknowledge the other parent somehow. I regret that my wife did not attend these clinics because if she did we could both have had the understanding that I now have. She does not have that understanding and cannot understand anorexia or our daughter.* (Chakor)

For Chakor, service delivery proceeded without an expectation that significant family members attend. This resulted in significant remorse because he became the sole source of valuable information to help parent his child. The absence of an expectation that both parents attend treatment reinforced a distance between Chakor’s wife and their daughter’s experiences.

Other parents who underwent non-Maudsley treatment also commented on participation of family members in treatment sessions:

*I mean it was about her, it was stuff that she had to deal with, and yes, I had to help her … she went in by herself, no-one talked with me though so she’d tell me stuff when she’d come out.* (Sherry)
Sherry was curious about the content of sessions to gauge the wellbeing of her daughter. Although Sherry felt the purpose of treatment was to help her child deal with the illness, there was a sense that Sherry would have appreciated time to discuss the illness with a clinician. Alison, however, was afforded an opportunity to have time by herself in non-Maudsley treatment:

Practically every time that we went there were two people, Kerry and Margaret (Clinicians) worked with us. At times Margaret would talk with Abby alone and then Kerry, with me alone, then we would all come together to work on ideas.

(Alison)

Unlike Sherry, Alison experienced a form of separated family therapy where she was given the opportunity to be heard without her daughter present and at other times had opportunities to raise ideas and concerns in sessions with her daughter. She described flexibility in the treatment received as being responsive to needs as they arose. Alison also referred to having two clinicians as points of reference in treatment, providing differing perspectives to help her parent her child to recovery.

The treatment model, to a certain degree, shaped parents’ experiences of family-based treatment but their experiences were still varied. Some found treatment informative and supportive whilst others found it inflexible and alienating. Parents who were offered Maudsley family therapy were able to offer a clearer explanation and critique of components of therapy received than were non-Maudsley parents. There was also a strong sense amongst Maudsley parents that they were receiving a structured form of treatment. This structure gave some parents a sense of predictability, yet others felt restrained by the inflexibility of the treatment. Non-Maudsley parents struggled to identify key aspects of treatment delivered, but identified that support and education were its aims.
One of the key differences between delivery of Maudsley and other forms of family-based interventions was the flow of information from clinicians to parents. In non-Maudsley therapy, information was imparted in a more direct manner to parents, whereas in Maudsley treatment guidance was inferred. Parents’ learning styles had a great deal of influence on what they found helpful in the delivery of treatment. Those who sought clear direction from their clinician fared less well in Maudsley than those who underwent non-Maudsley treatment.

7.3.2. Negative perceptions of treatment

There was a general sense of agreement from parents that treatment from CAMHS was helpful; however, some aspects of treatment were more helpful than others. The following section will explore parents’ experience of the type of family therapy received and elements of treatment they found unhelpful.

The style and manner of clinicians involved in treatment significantly influenced the experience of parents. Initial accounts of how parents felt about the treatment they received revealed early recollections of a lack of clinicians’ empathy for their lived experiences and desperation for help. For example, Alison, a non-Maudsley parent, reflected on her initial contact with a CAMHS clinician as follows:

*When we first came to this service one person wasn’t helpful. In some ways maybe she was trying to shock us into action when she said, ‘do you realise a number of people who have anorexia die of it?’ I did feel a little bit from that person that they were like a school teacher saying, ‘don’t you realise this!’ As if I didn’t, as if I wasn’t already in a state of high panic. She was a little bit superior. So I suppose the way that a person presents to you when you’re going through difficulties that they can’t perceive of is really important.* (Alison)
Alison’s initial engagement with CAMHS heightened her distress and worry. Although she graciously acknowledged the approach could have occurred to deliberately raise anxiety in parents and to facilitate an understanding of the serious nature of the illness, the way information was conveyed only served to create further panic. Alison also felt that the clinician behaved in a condescending manner; perhaps because that clinician had no idea of what she may have been dealing with in parenting.

Ruth, as a parent who attended treatment by herself, spoke of her perception of the remoteness of Maudsley therapists when she sought support and guidance to assist her with the anguish over her and her daughter’s pain:

*I told them a couple of times that she was hurting us and herself. She would sometimes scratch the skin off her face and pinch herself. She used to plead with me to kill her. I told them that and they just sat there as if it didn’t register. We were going through such terrible times, we needed a lot of help and they never once offered us support. I just felt like it was just so impersonal.* (Ruth)

Ruth’s description of the detached nature of clinicians, in times of great distress, left her feeling as though her lived experience was inconsequential and of little relevance. The absence of empathy by clinicians left Ruth with a feeling that her lived experience was not to be acknowledged.

Experiences like Ruth’s are highlighted by other parents who undertook Maudsley alone. A lack of empathy was experienced, particularly when parents attempted to proactively reach out to clinicians for more direct advice. Evidence of this comes from sole parent Diane, who felt that, despite Maudsley clinicians doing “*a damn good job... because they teach you not to allow the eating disorder to get the better of you*”, she experienced the isolating effect of a lack of time and compassion for carer experience:
Although Diane had found treatment and clinicians invaluable, her own unique circumstances could only be understood by providing time for her on an individual basis. This was not offered or received. Further, Diane felt Maudsley clinicians distanced themselves from carers because they mirrored the content of a package in sessions. For example:

*I think the clinicians are role playing. I’m not saying that they’re cold, they have a job at hand and they’re going through the motions. What they’re saying to me is probably exactly word for word to the next session they have with the other person but the more I think, we’re not all the same personality. What’s going to work for me may not necessarily work for that carer.* (Diane)

Here clinicians were perceived as experienced actors, playing a role designed to be replicated with others who parent an adolescent with AN. Diane speculated that the replication of content left no room for the unique contribution of each parent to shape the treatment process. This is an important perspective to note, particularly as Diane also referred to being the treating team at home. In order for her and others to make meaningful transitions from the treatment setting to home, Diane felt that the uniqueness of different carer experiences needed to be integrated into treatment that was tailored to actual lived experiences. This, she felt, would result in better self-management at home. For Diane, learning in treatment was a two way process where clinicians needed to learn about her as much as she needed to learn from them. The absence of this resulted in missed opportunities to strengthen treatment.
The experience of Maudsley being an impersonal ‘one size fits all approach’ was shared by other parents. For example, Ruth commented on the trained, measured clinician in Maudsley:

*I just always had the sense that they were saying what they were trained to say in Maudsley, without caring, it was just very impersonal. I wanted to understand anorexia and they seemed to know but wouldn’t say. I thought every visit they’ve gone by the textbook; they’ve known what they wanted to say but they haven’t taken in account our particular situation.* (Ruth)

Here, Ruth described her sense of a rote Maudsley clinician who saw no need to explore the uniqueness of her circumstances; something she felt would help her make more meaningful gains from treatment. For Ruth, treatment was a reflection of clinician memory of a learnt modality, rather than a response to need. Ruth sought answers to questions that seemed privileged to the clinician. Her extract tells us how she experienced a form of treatment happening to her, rather than one where she and her needs were fully engaged with. She did not feel listened to, and therefore was not helped to understand AN in a manner that made sense to her. She felt she received textbook treatment. The presence of the child in all Maudsley sessions also posed major challenges for Ruth in maintaining a relationship with her child outside of treatment. For example, Ruth said:

*It reached a point where she (daughter) distrusted us and that’s what I think was introduced by the treatment. They would sort of talk to us about what anorexia did in the home during the week and question whether I believed what she said was true and would tell me to do things without her knowledge, while she was listening. So it caused a lot of mistrust, she didn’t believe anything I said and I tended to not believe what she said because I thought it was just anorexia. I think that distrust was the worst thing that happened to us because we’re still paying for it now… I*
*just always had the sense that they were saying what they were trained to say.*

(Ruth)

In this extract, Ruth conveyed that there was also no room in treatment to manage trust which was compromised by openly speaking about her child’s behaviour in the combined sessions. For Ruth, the script that clinicians followed had no section on managing trust within relationships. Sessions were focused on the identification of deceit caused by the illness. Over-emphasis on the deceitfulness of the illness by clinicians occurred concurrently with Ruth’s daughter’s over-identification with the illness. The obvious suspicion created in each other’s behaviour, during this time of great mistrust, remained a cost incurred by Ruth and her daughter. This occurred because the intent of clinicians to help Ruth stand up to deceitfulness of behaviour, driven by AN, was not counter matched by an intention to help them maintain a trusting relationship.

Ruth further described the dissonance she experienced in reporting to clinicians how she made decisions about food that were in line with her values and logic:

*It was a supper time. I gave my daughter the choice of a muffin or a large Anzac biscuit because I felt they were equal. They said, ‘why did you do that, why would you give her that choice?’ implying I shouldn’t have done that. I was really upset because I would give my children a choice, so why completely change the way you operate. It just didn’t make sense to me. So we dreaded it, every time ... but the thing was they never told us what Maudsley therapy was, they just said, ‘it’s similar to what you’ve been doing’, because I’d always made her eat but it wasn’t similar. I just felt that what they said and what they did were different, that they didn’t really keep their word. So we stopped coming.* (Ruth)

Ruth described how she thought she was agreeing to participate in treatment that had similar ideals and values to her own. Instead she found little room for flexibility and that her previous
experiences of parental decision making regarding food, were invalidated. Ruth felt criticised and judged for the decisions she made that were in keeping with her beliefs about parenting. Circular questioning from the clinician for example “why did you give her that choice?” experienced by other parents as helpful in thinking outside the square, was experienced by Ruth as demeaning and authoritarian. It seems the style and purpose of questioning and the responsibilities of parents expected in treatment, were never fully discussed with Ruth. The conflict with her value stance and lack of connection with the treating clinician resulted in Ruth terminating treatment at CAMHS.

Values of clinicians were particularly visible to parents when specific issues were explored in sessions. For example Chakor, a non-Maudsley parent, described an experience of the clinician enquiring about the source of his daughter’s isolation at school:

_There have been questions about whether my religious belief is a factor. My daughter mostly wears a head scarf and I was asked whether she has the feeling of isolation because of that ... I thought it was unreasonable to put that question forward. So I tried to refuse to answer it and not offend anyone because I know that I need those people to help._ (Chakor)

Chakor’s experience of a value-laden style of enquiry from the treating clinician resulted in his ambivalence about his overall experience – he felt wedded to a disrespectful process. Parental guilt about causation of illness was easily triggered by questions that were asked as being critical of the familial or personal belief system. In Chakor’s experience, unreasonable questioning is something he was left to manage. It was his sense that if he challenged the value base of the team, he may lose them. As helpful as it may have been, treatment had come at great personal cost to him, resulting in an overall ambivalent stance about the treatment experience.
Ambivalence about the treatment experience was also expressed by parents when reflecting upon their child’s overt objection to attending. Parental success in managing to get their child to a session, under duress, came with an expectation that their child may experience benefit from attending. Although parents sought guidance, through ideas borne out of treatment sessions, meaningful participation became an increasingly difficult task when parents felt sessions offered little to their child’s circumstances. For example Sherry, a non-Maudsley parent, said:

*She said it was doing no good; so to me it was very crass. It was somewhere to go and weigh her and that’s all it was. They were great, but it was just to see that I was doing all right. Isabelle got nothing out of it and I didn’t know whether she was manipulating me or not, so I had to keep taking her in case she was.* (Sherry)

Sherry’s experience illustrates how difficult it is to remain engaged in a treatment that her daughter conveys is of little help. Sherry struggled with the truth, wanting to believe her daughter yet felt manipulated by the tricks of AN. This confusion, and Sherry’s need for reassurance determined by her daughter’s mechanistic weigh-ins, eventually wore at her belief in sessions. Sherry’s experience of attending treatment had become inane.

Making sense of their struggles and remaining engaged in treatment was also influenced by clinicians’ attitudes towards their child. Sherry made additional comments about difficulties in continuing to remain engaged with treatment because she felt her daughter was objectified by clinicians:

*Isabelle’s been a person, a normal, sane, human being up until twelve years old. She’s been a person a lot longer than she’s been an anorexic person. The whole way through she’s been spoken to as an anorexic, put in a box, there’s like a piece of paper that says anorexics do this, this, and this and she’s up there in that pigeon*
Sherry describes how she felt that clinicians did not see her child. She felt clinicians saw only a prescribed set of behaviours attached to an illness rather than a whole person. Clinicians had no sense of who her daughter was prior to the advent of the illness. In this way, she speculated children with AN in treatment at CAMHS are dishonoured.

It was important to each parent that their child be recognised as unique and engaged appropriately in treatment. Parents were naturally protective of their children in sessions and sensitive to clinician interaction. Ruth, a Maudsley parent, also comments upon a similar experience to Sherry in reflecting upon her child in treatment:

She was still a human and she didn’t feel like she was being treated as a human.

She felt like they were just totally ignoring her own personal side in life by talking about anorexia making her do things. (Ruth)

Externalising the problem, without a balanced focus on the child’s self, alienated both Ruth and Sherry from treatment. Neither felt their child was seen as a human person who at the time was living with AN. It is also interesting to note that both parents reported that their child resented the externalisation of the illness in sessions. Neither child accepted it as part of therapy, creating conflict over the conceptualisation of the illness and subsequent acceptability of treatment.

### 7.3.3. Positive experiences of treatment

While some parents experienced Maudsley as disrupting their relationship with their child, other parents held a different view, claiming that joint sessions in Maudsley were helpful in maintaining a relationship with their child. Trevor and Michelle described their experience of
joint sessions in Maudsley as an opportunity for trust to be built into their relationship, through a set of shared agreements that were negotiated in sessions:

Because Grace was with us, the task for the week would be something we all had to agree on each week. So it was something that feels like an agreement we were having together. (Trevor)

Even though she wouldn’t agree at the beginning she knew by the time we left our session she had agreed to how it had to be and the weigh-ins was how we checked how we went. (Michelle)

Trevor and Michelle were able to openly set tasks that required the agreement of their daughter each week in treatment. They were able to refer back to their agreement during the week to help them keep the “momentum” towards recovery. Sessions provided the means to contractually move forward each week, where all parties were subject to the same agreement. This gave Michelle and Trevor a strategy that helped them maintain a relationship with their daughter by keeping to an agreement made and measured in treatment. The success of such was measured in the weekly “weigh in’s”.

Sabar and Kabir had a similar experience, suggesting Maudsley helped them move forward in maintaining a relationship with their child while managing the impact of AN. For example, Sabar said:

They (clinicians) did a heck of work on us; they changed us ... in sessions, in front of them something starts. They won’t say things directly, they want us to think, to realise that we are dealing with two individuals. One is our daughter, who needs soft treatment with a lot of care and a lot of love. The other one is anorexia that
needs straight on answers like ‘you’re going to eat; you’re not going out and have that meal.’ (Sabar)

Kabir commented that during the treatment process they made discoveries about themselves as a couple. This occurred through reflection on sessions and through dialogue with each other and with the clinicians in treatment:

One day my husband said to me ‘I understand, you want your daughter back; this is my daughter too. I understand you are upset and emotional but we have to deal with anorexia now; you have to change yourself. You’ve got to learn and be with anorexia.’ So at that point, I thought that was my turning point, I shouldn’t cry, I have to do something to get my daughter back; Monica (clinician) is not going to change her. (Kabir)

In this extract Kabir refers to her emotions initially getting in the way of being clear about how to manage her daughter with AN. This resulted in her sense that responsibility for recovery rested solely with treating clinicians. As she and her husband learnt more about the nature of the illness and their responses to it, they realised that they needed to take charge of decision making. In moving forward, this couple reflected upon the logic and style of circular questioning used in sessions that promoted thinking before emotions. They discovered that when emotions were in charge, AN thrived. This helped Sabar and Kabir to unite in parenting by shifting emotional decision making to logical thinking about dealing with two separate entities, one being their daughter and the other AN. This was a major realisation for the couple in their experiences of parenting and treatment.

For Kabir and Sabar, their learnings were more important than clinicians dealing with their emotions. That was something they could do together in their own time. Sabar’s and Kabir’s emotional states were attended to within the context of their own relationship, unlike Diane and
Ruth who sought this support from clinicians due to their sole status in treatment. Michelle spoke of Maudsley family therapy uniting the family along a path of recovery as follows:

*With Maudsley every week there’d be … one more task we took together … and each step you think, oh good we got through that!* (Michelle)

The task-centred approach, combined with new learning, was something Michelle felt the family needed to help push them forward. She described needing the tasks associated with Maudsley treatment to help everyone remain united and focused. These tasks provided a point of reference to guide parental behaviour when challenged by the illness, particularly when they felt overwhelmed by their emotions.

Other parents who undertook non-Maudsley treatment spoke about how the relationship with the treating clinician helped parents stand up to challenges in parenting AN. Although Alison’s initial contact with CAMHS was distressing and negative, a change in clinicians, who also appreciated the quality of the therapeutic relationship in facilitating outcomes, saw a change in her experiences of treatment:

*…and then we had Margaret. I found her very easily approachable and helpful. She’s just an ordinary sort of person that you can talk to. A couple of times she got a bit snippy with me but most of the time I found her very helpful. She wasn’t overly direct. She was really like a support, she might make some suggestions, but it felt to me like she was a support.* (Alison)

Alison’s extract highlights that even though the parent-clinician relationship faces challenges, if the essence of the relationship is good, then this reduces dissonance over time. This is evidenced by Alison’s description of her overall experience of treatment in CAMHS as follows:
Like our family was like a plane that hadn’t crashed but it looked like it was going to crash, it was a bit wobbly. The psychologist and the dietitian were like two other planes that came alongside and propped up our wings until we could fly off. Not that anorexia’s gone, it’s still there, but they helped us to learn how to deal with it, to be stronger and fly on our own a bit, so yeah, coming to this service was a really huge help to us. (Alison)

Alison’s metaphor of a circumvented plane crash illustrates the stabilising effect that treatment can have with families. This needs to be provided in a supportive and respectful manner and help parents to tap into existing resources. Learning and problem solving is apparent in Alison’s extract, but key to this was that the clinicians “came alongside” the family in treatment. Clinicians began and remained where she was at in order to facilitate new learning until the family could fly off independent of treatment. Alison’s thoughts imply a mutual learning between clinician and parents, where treatment was adapted through turbulent times.

Alison’s final reflections on her experience of treatment illustrate an inextricable link between clinician relationship and recovery:

It was just like our family was really struggling and then I had people to come alongside and help me. I think the coming alongside is the issue rather than we’re the experts. It was more like, O.K. there’s this problem, we’re going to work on it together and we’re here to support you. I just don’t know how we could have got by without this. I’d hate to think of any family struggling with anorexia which doesn’t have this service. (Alison)

This extract again draws our attention to the importance of parents feeling as though clinicians are working with them in treatment. For parents to transpose ideas and concepts from treatment session to home, they needed to feel as though their experiences were validated and to have
worked through their particular issues if they were to manage these between appointments. As seen in Alison’s extract, the clinician’s personal approach and ability to recognise and incorporate the family’s lived experience had a substantial bearing on the experience of parents in treatment.

Finally the issue of separating the illness from the child, as mentioned previously in this chapter, is worth re-visiting because it has the potential to either alienate or unite families against the common foe; AN. Separating the illness from the child occurred in all treatment types and was continually referred to by parents as being one of the single most important breakthroughs in their management. For example Diane, a Maudsley parent, said:

> Once I understood about Tex (externalised name used to describe AN) it made the tasks at hand a lot easier to manage believe it or not. I could tell the team what did to get around Tex. I became the manipulator really in some aspects; the fog had cleared. (Diane)

Separating the child’s usual behaviour from the one driven by AN helped Diane target behaviours that she was finding most challenging, rather than thinking she had to go into battle with her son. This preserved her ability to parent and respond to circular questions in treatment.

Alison, a non-Maudsley parent, also related how the process of separating the illness from her child helped her daughter:

> Kerry (clinician) looked at what was important in Abby’s life and she showed her that anorexia was the enemy of that … the turning point was where Abby went from ‘I don’t really want to come here and do this’ to getting on board and taking control of that herself saying I want my life back from anorexia.” (Alison)
In Alison’s case, pitting the child against AN helped her daughter gain a sense of mastery over the illness, and subsequently she became more active in treatment. Alison added:

*Anorexia became the enemy; it was the enemy to work against.* (Alison)

Alison inferred that once AN was exposed as the enemy, it required management.

Michelle, a Maudsley parent, had a similar experience in learning how to separate the illness in sessions. Michelle found this helpful in understanding how to work against the illness:

*There was one session with the girls, talking about the ‘friend’ anorexia that comes to stay the night and it was that, that helped me. Just helping you to see anorexia is separate to your child. Anorexia was my enemy; I didn’t then think it was Grace doing it. It was anorexia I was battling with.* (Michelle)

Michelle referred to a particular session where the clinicians described AN as a ‘friend’ who arrives as an uninvited guest, to the house and how it might behave. This helped Michelle see that she was challenging a series of behaviours within her child that were outside of her child’s control. This understanding empowered Michelle. She was no longer in a battle with her daughter. Michelle pitted herself against a target, leaving room and opportunity to relate to her child outside of the moments dominated by AN.

Sabar, a Maudsley parent, also commented upon the importance of learning to separate the illness from his child. Seeing his daughter as someone influenced by behaviours associated with AN helped him reach out to his daughter:

*It’s not her we’re dealing with. Every time she becomes aggressive you know it is not your usual child. Once we identified that is not the person we know we are dealing with, you find a soft spot in her and work on it; it is hard. It is hard*
because sometimes you feel insulted, sometimes you get intimidated, sometimes you feel down. (Sabar)

Understanding AN as a separate entity helped Sabar learn how to be “with anorexia” while simultaneously reaching out to the child he knew. Chakor, a non-Maudsley parent, had similar comments:

You have to know there’s something in her; you have to know how to separate this, your daughter and the sickness. (Chakor)

While both parents’ extracts illustrate potential estrangement from treatment as a result of externalising AN, this aspect of treatment is nonetheless recognised as a powerful element of treatment. For example, although Ruth resented the objectification of her child, when clinicians externalised AN in sessions, she reflected:

I guess one thing was they helped us separate anorexia from her. I guess that was helpful to me. Just to know it wasn’t her. If she was bashing into me I could think this is not my daughter. It helped me cope knowing that she really didn’t hate me.

(Ruth)

In summary, irrespective of the type of treatment received, parents’ experience of clinician compassion for their circumstances and empathy for their child shaped their overall experience. Parents felt empowered when their lived experiences were validated and had this knowledge privileged in treatment. They felt disempowered when the only legitimate knowledge in treatment was determined by the clinicians’ reliance on scientific methods alone to guide practice. The responsiveness of clinicians to present treatment in accordance with parents’ needs or emotions was central to their experience of treatment. A parent attending sessions by
themselves, either representing a couple or as a sole parent, required greater levels of support in treatment, than couples who attended together.

The element of treatment identified by parents as most helpful in understanding their child’s experience was separating the illness from the child. This helped parents to understand the complexity of illness-driven behaviours and to see their child governed by something outside of their control. This insight empowered parents to act. Externalising the illness from the child was not perceived to be helpful, however, if the clinician failed to balance this in sessions with a focus on the child, separate from the illness.

7.4. Quest for meaning

The following section explores the sense that parents made of AN in their lives. While most parents experienced high levels of guilt and shame about being blindsided by a demanding illness, many have gained enormous insights discovering meaning from AN in their lives. These insights have altered the way they now think about themselves and relate to others. For most parents, parenting an adolescent with AN proved to be a painful journey of learning. While some found this learning enriching, others continue with their search. Meaning making for parents occurred by reflecting upon their vulnerabilities in parenting and reconstructing their sense of self, either through treatment and/or through facing challenges posed by the illness at home. All parents found themselves exposing their vulnerabilities to clinicians and to significant others in their social world, in order to help their child recover.

7.4.1. Making sense of AN

Trevor described what it was like for him to expose his vulnerabilities in sessions:
I suppose it was laying yourself open because they go through the family dynamics. So yeah, that was confronting I suppose. I mean we were comfortable with it but it was just like being naked. (Trevor)

The challenges and exposure in making sense of anorexia nervosa in Trevor’s family started to shape his behaviour in parenting:

Anorexia made me develop patience. I was very bombastic, volatile. I would react to more things, but as you grow up as a parent with a child who has anorexia I suppose you have to adjust the way you do things. I knew how I was, wasn’t working. So I’ve got more placid. (Trevor)

In parenting adolescent AN, parents were confronted by their child’s behaviour, the process of treatment, and ultimately their own beliefs and behaviour. Parents made new discoveries about themselves which would not have occurred without AN being in their lives. Like Trevor, other parents felt as though the experience of parenting their child through AN made them a different person. For example, Alison delineated the person she used to be from the person she found herself to have become:

In some ways it hit at the core of who I am. My husband was unemployed and we really struggled; I had this desperate need to provide for my family. That’s why I went to University and in that desperation I put aside other things. One really big thing that came out of it was that Abby really needed just to hang out with her parents and with me and just enjoy our relationship that’s really important ... anorexia did show me to just enjoy my children. Anorexia totally reorientated me; like it has served a purpose. (Alison)
Like many parents interviewed, Alison was trying to fulfil many roles: that of a student, employee, wife and mother. This left her no time to be as present and engaged in parenting as she felt she needed to be. AN challenged her inner core. She shifted her values and way of defining herself in the family from a provider to someone much more valuable in the lives of her children. Alison adds:

*It really helped me face up to really hard things that I probably wouldn’t have faced up to in my parenting. So going through the process and having counselling can make a big difference in your life and help you... I wonder if it means that a child uses anorexia to almost force you to deal with something.*” (Alison)

The impact of parenting adolescent AN had a profound effect upon parents in the study. They not only had to battle with their child but also with themselves about the value they placed on tasks associated with parenting. In doing so, they answered their own questions and began to create a meaning that helped them move forward in their lives. Moving forward was important to parents because AN forced them to take retrograde steps in parenting in order to deal with their child’s regressive behaviours during the time their child was most unwell.

Diane also spoke about her personal transition bought about by parenting her son through AN. She described that by becoming more introspective as she and her son moved forward:

*I was one of these people who didn’t show my emotions much, very tough orientated, very much the job at hand. This actually helped me get through early treatment with the eating disorder; that was obvious ... once I understood what anorexia was like for my son, it helped me change. Now I’ve let my guard down and let people in ... If I had to say one thing about the eating disorder then I think it’s made me a better person and a better parent believe it or not, as much as it nearly killed me.* (Diane)
In exploring the impact of her son’s illness, Diane described how she became more attuned to her emotional wellbeing that ultimately re-connected her with her child. She achieved this through understanding what AN meant to him and in doing so discovered a meaningful connection. During the treatment process she learnt more about her son; how the illness influenced his behaviour and her reactions to his behaviour. Her tendency to sideline emotions, acknowledged as useful in helping her stand up to AN initially, was something she had to challenge as an obstruction to her understanding of her child and herself. Ultimately, parenting AN helped Diane transcend her need for self-protection to self-discovery; allowing her and her son to move beyond their constructed sense of selves.

Although most parents were able to make some sense from the experience, one parent’s search for meaning is left bereft of an answer. For Chakor, confusion and desperation remain as present today as they were when suspicions were first realised:

*You know that your daughter is seriously sick and she needs help in a way that she doesn’t know she needs. If you want to help her she needs the capacity to accept that help. Both of these things are missing with anorexia. We’re trying to help but she’s not listening; she gets upset, this happens all the time. There is no meaning; how long you can tolerate this.* (Chakor)

Chakor made no sense of a situation that robbed his child of a willingness to receive help from the people responsible to provide it. He felt they were all trapped in an unrelenting and intolerable situation.

Although Chakor’s despair continues, most parents in this study felt the illness bought new meanings and depth to the parent child relationship. Sherry’s comments illustrate this point:
Isabelle and I are a lot closer. We were close before but obviously she had issues that she couldn’t talk to me about. So in a lot of ways anorexia brought us closer together because we have to sit there and discuss. We have to trust each other. Sometimes I really don’t want to trust her and I check up on her all the time but you’ve got to get trust to receive it. (Sherry)

Most parents found meaning associated with AN in their lives. Making sense of their grief and distress created opportunities for significant personal transitions in some and for others; it has served to consolidate familial relationships. One parent felt no sense could be made of an illness which deprived his child of insight and immobilised efforts to help.

7.5. Conclusion

This chapter described how parents conceptualised their experience of the tension and distress AN creates within their child, family and social context. As the illness took greater hold over the life of the child, it demanded more within the family. It became more forceful and drove a wedge between family members and those around them. Treatment was experienced by some as empowering, and for others, as alienating. Irrespective of treatment type or outcome, the relationships families had with clinicians were a significant factor in shaping treatment experience. An acceptance that knowledge for treating adolescent AN can be derived in multiple ways is central in reducing parents sense of isolation in treatment. Knowledge gained through scientific discourse, such as Maudsley, can provide a structure for working with parents, but processes of self-reflection throughout treatment can provide additional knowledge to enhance this treatment.

Many parents were able to identify some positive outcomes for their child and family, as a result of the battle with AN, which transcended the sacrifices associated with the illness. The
following chapter explores clinicians’ experiences of treating adolescent AN and the meanings for them associated with care and treatment.
Chapter 8. Findings from interviews with clinicians

This chapter provides an overview of findings from 20 in-depth interviews with CAMHS’s clinicians who provide family-based treatment for adolescent AN. Fourteen interviews were held with clinicians who are trained to provide Maudsley family therapy, in addition to other forms of family-based treatment, and six interviews were with clinicians who are not Maudsley trained and provide other family treatment interventions. Table 8.1 provides a list of clinician pseudonyms with type of treatment provided. Using interpretative phenomenological analysis (IPA), this chapter explores the way in which clinicians make sense of the parental experience, and the personal meanings clinicians made of: the treatment provided in CAMHS; how parents may perceive family therapy provided; and parenting an adolescent with AN.

Table 8.1: Pseudonyms of clinicians according to type of treatment provided

<table>
<thead>
<tr>
<th>Maudsley clinician</th>
<th>Non-Maudsley</th>
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<tbody>
<tr>
<td>Louise</td>
<td>Jane</td>
</tr>
<tr>
<td>Ann</td>
<td>Sean</td>
</tr>
<tr>
<td>Carla</td>
<td>Donna</td>
</tr>
<tr>
<td>Monica</td>
<td>Kerry</td>
</tr>
<tr>
<td>Jessica</td>
<td>John</td>
</tr>
<tr>
<td>Mandy</td>
<td>Mick</td>
</tr>
<tr>
<td>Margaret</td>
<td></td>
</tr>
<tr>
<td>Kristie</td>
<td></td>
</tr>
<tr>
<td>Emma</td>
<td></td>
</tr>
<tr>
<td>Katrina</td>
<td></td>
</tr>
<tr>
<td>Sandra</td>
<td></td>
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<tr>
<td>Nick</td>
<td></td>
</tr>
<tr>
<td>Andrew</td>
<td></td>
</tr>
<tr>
<td>Sue</td>
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</table>

Five primary metaphoric themes relating to parental involvement in AN treatment emerged from clinician interviews. These five broad themes have been titled as follows: professional judgement and choice; realising the challenges in treating AN; making sense of parental vulnerability in treatment; making sense of parents’ experiences outside of treatment; and insights into parents’ sense of self. Table 8.2 provides a summary of these themes.
Table 8.2: Themes and subthemes from clinician interviews

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Key quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Professional Judgement and Choice</td>
<td>1.1 Considering Maudsley</td>
<td>“… in the manual it says we don’t know who Maudsley is going to work for and who it’s not.”</td>
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<td></td>
<td>1.2 A structured approach to treatment</td>
<td>“… important if cognitively, someone has been severely struggling with anorexia.”</td>
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<td></td>
<td>1.3 Adapting Maudsley</td>
<td>“… it wasn’t the purist Maudsley at all, so we adapted it to suit them better.”</td>
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<td></td>
<td>1.4 Treatment driven practice</td>
<td>“… with eating disorders you start with the treatment first and then learn about the family.”</td>
</tr>
<tr>
<td></td>
<td>1.5 Power and oppression</td>
<td>“… the father was saying you must do as I say or else.”</td>
</tr>
<tr>
<td>2. Realising the Challenges in Treating AN</td>
<td>2.1 Shaping of initial experiences</td>
<td>“Parents may never have had experiences with mental health; parents need time to understand what that means.”</td>
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<td></td>
<td>2.2 Cohesive team</td>
<td>“… she’d got a handle on managing different scenarios through multidisciplinary input.”</td>
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<td></td>
<td>2.3 Challenges in treatment</td>
<td>“… it’s their responsibility in treatment that becomes challenging.”</td>
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<td></td>
<td>2.4 Searching for more</td>
<td>“Sometimes parents just feel terribly frustrated that we don’t just tell them what to do, like we’re holding a big secret or something.”</td>
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<td></td>
<td>2.5 Connecting with beliefs and values</td>
<td>“Part of the treatment that we offered with this family was to understand how values attached to their culture impacted upon re-nourishing.”</td>
</tr>
<tr>
<td>3. Making Sense of Parental Vulnerability in Treatment</td>
<td>3.1 Laying themselves bare</td>
<td>“I think it means a mixture of relief and a sense of just putting themselves on the line.”</td>
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<td></td>
<td>3.2 A lifeline</td>
<td>“… parents say can you figure out how to parent this child because I don’t think I know how to parent them anymore.”</td>
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<tr>
<td>4. Making Sense of Parents’ Experiences Outside of Treatment</td>
<td>4.1 Disempowerment</td>
<td>“Anorexia nervosa confronts parents with their own inadequacy or self-perceived inadequacies about their parenting; it takes something away from them.”</td>
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<tr>
<td></td>
<td>4.2 Shame</td>
<td>“There’s a shame in saying, well I need to monitor her because she has an eating disorder.”</td>
</tr>
<tr>
<td>5. Insights into Parents’ sense of Self</td>
<td>5.1 Questioning themselves</td>
<td>“Question how you feel about yourself as a parent”</td>
</tr>
<tr>
<td></td>
<td>5.2 Loss</td>
<td>“They’ve lost their child to something else”</td>
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<tr>
<td></td>
<td>5.3 Meaning in recovery</td>
<td>“Strengthening the parenting relationship”</td>
</tr>
</tbody>
</table>
8.1. Professional judgement and choice

Each clinician reflected on their decision-making process in describing how they determined the type of family-based treatment to be offered. Some of the clinicians in this study, who reported to be Maudsley-trained therapists, said that their perception of parental capacity shaped their decisions about the type of treatment offered. Some further commented that their assessment of power differentials in families or cultural factors influenced their decision about suitability of treatment type. In making a choice about the type of treatment offered, clinicians disclosed concern about how they might be perceived by other therapists if they did not offer Maudsley therapy, which is regarded within the service as having the strongest evidence base.

The interviews revealed that no clinician reported strict adherence to manualised Maudsley; rather they found ways to integrate clinical judgement and associated modifications into the treatment process. Maudsley therapy, with adaptations when appropriate was described by clinicians as the treatment model of choice for adolescent AN in CAMHS, with two main exceptions: Aboriginal families and families where violence or abuse occurs. Despite these findings, many clinicians reported a pressure from Maudsley-trained clinicians to justify their decisions, not to use the Maudsley approach. A Maudsley metanarrative appears to have developed in CAMHS, with the ever-present question: “so why aren’t you doing [manualised] Maudsley?” (Jane).

8.1.1. Considering Maudsley

In thinking about AN as a complex illness, most clinicians thought that treatment needed to match the multifaceted needs of the family, rather than offer, or continue to offer, a manualised approach to treatment. Maudsley clinicians reported assessing whether a family had the capacity to undertake manualised treatment.
The strength of a family to do the Maudsley model is considered. If there’s limited family supports, then our interpretation of how the family would work in a Maudsley way, we might think, ‘oh I just don’t think this family could do it’. I think we have a lot of expectations on what families can do with Maudsley. (Louise)

Louise, like many Maudsley identified clinicians, thought that Maudsley therapy was a demanding treatment for parents, particularly if they had limited support. This was due to the strict expectations placed on parents to comply with the framework of Maudsley. Consideration of parental capacity and ability to undertake Maudsley was important for clinicians to reflect upon because:

The demands on the parents are really extraordinary, really extraordinary in Maudsley. I’d be interested to see how many clinicians can keep up that level of vigilance on a day to day basis with a child, because I think I’d find it extremely challenging to do. (Sean)

Although clinicians were aware of the responsibilities placed on parents to comply with treatment protocols and had conflicting thoughts about placing further demands on parents, Maudsley was offered because:

In the manual it says we don’t know who Maudsley is going to work for and who it’s not. (Carla)

Clinicians additionally thought they had a sense of responsibility to initially offer evidence-based treatment, where the severity of the illness had compromised the health of the child and a sense of urgency prevailed about the wellbeing of the child. Research that supported scientific knowledge in treating AN offered a frame of reference for clinicians with that provided
legitimacy and an acceptable way forward. Despite the demands of Maudsley, considering it as a first option of treatment appealed to clinicians, as it represented a model that:

… ensures that parents kept the focus on the severity of the illness, highlighting that this isn’t going to go away easily, and that this is very severe, and that they really need to pay it a lot of attention for a long time. (Margaret)

8.1.2. A structured approach to treatment

Many Maudsley clinicians conceptualised treatment they offered in stages, similar to phases in Maudsley, and referred to it as ‘structured treatment’ rather than ‘manualised’. This gave clinicians permission to conceptualise and assess parental capacity against each stage of treatment they offered, rather than force all interventions, such as the family meal in manualised treatment, upon a family. Capacity to attain a stage of treatment provided a marker of ability to proceed with or further adapt “structured Maudsley treatment” (Monica). An approach to treatment that was structured and sequential in nature, like Maudsley, yet deviated from interventions in the manual, formed the basis of what appears to be a Maudsley-type approach to treatment.

There was general agreement amongst Maudsley identified clinicians, that structured treatment was the path to follow, because it provided a framework for dealing with the physical and cognitive complexities associated with starvation, as well as “working with probably the trickiest families that you are going to come across in CAMHS” (Ann).

… a structured model is really important if cognitively, someone has been severely struggling with anorexia for quite a long time and lost a lot of weight and is at a very low BMI; they simply cannot think through therapeutic intervention. So I totally think that in that situation, you really need to be working with families and maybe Maudsley or a form of it should be considered. (Margaret)
The structure within manualised treatment provided a point of reference for clinicians to conceive an overarching framework for working with adolescent AN. This allowed clinicians to conceptualise and describe to parents three stages of treatment, without a sense of needing to apply all of the interventions in the manual. It additionally permitted a greater sense of flexibility for clinical decision making in choosing the type of interventions in each stage, while also providing a sense of direction in treatment for parents:

*The structure associated with Maudsley could be seen to provide containment. If families really want that clarity, want to know what their next step is and really want a more rigid structure then I think that can be really helpful for some families.* (Katrina)

Conceptually, the overall structure of treatment agreed upon by many CAMHS clinicians mirrored the three phases reflected in the manual for Maudsley. The first stage of a structured approach to treatment had a focus on re-nourishment, as in Phase 1 of Maudsley. It was seen as particularly important when the physical wellbeing of the child was severely compromised by the illness. This approach to treatment provided a framework for clinical practice that was viewed as standard practice in CAMHS. No clinician, however, reported using manualised Maudsley therapy consistently for all clients or adhering strictly to the manual:

*I would never have used the manual, like the complete manualised version with any family.* (Carla)

Kristie held a similar view, stating:

*Lots of families aren’t suitable for complete manualised Maudsley. I haven’t had one yet suitable.* (Kristie)
Another clinician said:

*I don’t think anyone’s been a purist in their delivery of Maudsley, and maybe some people thought that team members have been.* (Monica)

Here, being purist means a clinician who has maintained strict adherence to the manual. As a Maudsley trained clinician, Monica pointed out that the adaptations of Maudsley made by individual clinicians may not be obvious to other clinicians.

Although some clinicians remarked upon the burden of responsibility placed on parents for refeeding their child in Maudsley, many Maudsley and non-Maudsley clinicians thought the importance of focusing on re-nourishment in the initial stages of treatment actually helped in dealing with the complexity of the illness. A focus on re-nourishment provided a concrete and focused task for parents who were managing an array of complex illness-driven behaviours aimed at distracting the refeeding process. Clinicians were less clear in describing other stages of the treatment in their structured approach. They tended to talk of principles they would apply to any form of structured treatment such as:

*… encouraging regular eating, not blaming anybody, not blaming parents, seeing the families as a resource, helping the families to externalise the problem, helping them to be firm with the eating disorder but caring and loving towards the young person.* (Monica)

Only a few clinicians mentioned either systemic family therapy, family of origin work or individual therapy for the adolescent, as the final stage of treatment after weight had been restored in the child.
Clinicians’ conceptualisations of Maudsley treatment involved strong references to the importance of structure in treatment. The use of the term ‘structure’ replaces conceptualisations of treatment as manualised. Clinicians reported delivering a structured approach to treatment, with stages of recovery, rather than consistently applying interventions described in phases of treatment detailed in the manual for Maudsley. They were more comfortable with a structured approach, where stages in recovery provided the framework within which clinical judgement and flexibility in treatment is permitted. Stages in recovery were similar to phases in Maudsley. The primary difference was the interventions clinicians used in their stages of recovery differed from those in phases of Maudsley. This legitimised practice which was outside strict adherence to the manual yet maintained a sense of a conceptual framework to treatment.

8.1.3. Adapting Maudsley

The following extract describes circumstances where a clinician adapted Maudsley:

Where it’s more of a straightforward family, where the eating disorder pops up; you do treatment and eating gets back on track. That’s where we would do more of structured Maudsley and not take little, um excursions to do some other interventions. Where it’s more complicated, that’s where we’ve noticed we’ve had to do some other stuff; as an adjunct to the Maudsley treatment. (Monica)

Here Monica assertively refers to “structured Maudsley” as the primary point of reference for family-based treatment in CAMHS and “other stuff” as adjuncts to Maudsley when needed. Structure has been paired with Maudsley’s re-framing of manualised treatment. Monica provides a clear example of the reconstruction of manualised Maudsley as “structured Maudsley” for “straightforward” families; meaning where treatment focused solely on re-nourishment. In this way, “structured Maudsley” was viewed as frontline, frank, intervention for treating AN requiring additions, not replacement of, for “more complicated” presentations.
It was additionally conceived as treatment separate to, but consistent with, manualised treatment.

A powerful message about how to treat AN in CAMHS is conveyed: structure is not manualised but structure is to be adhered to. An “adjunct to the Maudsley treatment” was viewed as an intervention or series of interventions aimed at orienting parents to tasks associated with re-nourishing their child in a manner similar to that espoused in Maudsley. The extract also reveals a covert message about any other family-based treatment outside of structured Maudsley as a less valid treatment option, by referring to them as “um excursions” and “other stuff.”

Another Maudsley clinician comments on her adaption of Maudsley:

> Initially we had the whole family coming in for a manualised Maudsley approach and that just wasn’t working. It was easier for them if some of the younger children weren’t there so it wasn’t the purist Maudsley at all; we adapted it to suit them better. (Kristie)

Unlike Monica and Kristie, other Maudsley clinicians thought they needed to justify deviations from manualised Maudsley, referring to a sense of criticism from other Maudsley clinicians for such adaptations. This was a dominant response from clinicians; despite the fact no clinician reported offering Maudsley treatment in its puristic form. The following examples illustrate clinicians’ acknowledgement of judgement from other Maudsley clinicians, when adapting treatment to suit family capacity or need:

> Well it felt to me when I really pushed it, they’d just pull out. So it seemed better to do some compromising rather than sticking with a really rigid framework. So I know that that’s been a criticism that’s been levelled at people who aren’t sticking with the manualised Maudsley treatment but I felt I needed to do it. (Margaret)
I know that flexibility in treatment goes against what Maudsley is about and what other clinicians say you should do under Maudsley but I think that’s what I do. I’ve moved away from what others say I should be doing. (Mandy)

Matching structured Maudsley with parental capacity proved a challenge for Maudsley clinicians, in circumstances where they thought parents did not have the capacity to assume responsibility for refeeding their child in stage one of Maudsley treatment. One Maudsley clinician reflects on her decision to alter treatment:

...with Maudsley, the whole emphasis is they’d take the responsibility for feeding their child and in the case I’m thinking of, the parents refused it. Mum just wasn’t coping and there was just too much for mum to do, so we had to change what we offered. (Ann)

When expectations within Maudsley treatment could not be achieved, such as shared parental responsibility to work in unison against the illness, Maudsley clinicians thought they were obliged to either change treatment modality or further adapt Maudsley. Maudsley clinicians tended to seek evidence of limitations in parental capacity to adapt treatment pathways, whereas some non-Maudsley clinicians felt quite angry about a seeming need to justify non-Maudsley treatment approaches in CAMHS:

I had been working with another clinician who had done quite a good job, but hadn’t done Maudsley model as such. The way they talked about what they had done, it was almost like they felt like they were a fraud because they were actually using a range of their clinical skills, including some components of Maudsley learnt through some vicarious exposure to Maudsley in many meetings, but not
actually having done the training and not working with the manual. I thought this is ridiculous, like where does it say that it has to be Maudsley! (Jane)

Some non-Maudsley clinicians were particularly incensed at what they perceived to be a culture of uncritical acceptance of a model assuming to hold the answer for treating AN in all families presenting to CAMHS. Despite this, perceived judgement from some Maudsley clinicians, coupled with a desire to provide evidence-based treatment, gave many clinicians a sense they needed to apply a form of structured Maudsley, or justify a need for alternate treatments. This was especially so in the early stages of treatment (either stage one of structured treatment or Phase 1 Maudsley) because:

... the importance of doing phase is about stabilizing weight and medical safety;
that’s a priority. I guess if there’s not a capacity to get that happening in phase one that might be where we might do some other work. It’s sort of almost doing preparation for Maudsley because the parents aren’t really able to do even Phase one. (Monica)

Attending to the life threatening potential of this disorder in treatment, meant clinicians thought they needed to justify any adjustments to the evidence-base for reversing the effects of starvation. For some clinicians, adaptations to Maudsley or Maudsley-type treatment, were simply deviations from the model until they could re-direct the family back to the model. In other instances, Maudsley-type treatment was characterised by: an additional stage of family assessment at commencement of treatment; altered interventions to those located in Maudsley, where it was assessed the expectations in Maudsley exceeded family capacity; and family-based treatment without all members of the household attending. The underlying principles of working with families with adolescent AN located in Maudsley were retained in Maudsley-type treatment. These principles were: an agnostic approach to causation; removal of blame from parents; externalising the problem; eating together; helping parents reclaim parental authority
early in treatment; and viewing the family as resourceful in the recovery process. If parents rejected Maudsley or a Maudsley-type approach, other treatment was offered such as separated family therapy or individual therapy for older adolescents.

8.1.4. Treatment driven practice

All non-Maudsley clinicians were aware of principles and stages of treatment in manualised Maudsley family therapy and thought they should offer it as treatment. A non-Maudsley clinician said:

*I wouldn’t say that I’m very comfortable in running a pure Maudsley model but I would certainly introduce that as a way of treatment and if the family really wanted that, then I’d be looking at getting another therapist who’s very experienced in that to work alongside me.* (Donna)

The above extract provides some insight into a perception that, unlike other forms of treatment, Maudsley is offered and families need to make a choice between Maudsley and other forms of therapy. Although there was a prevailing view that Maudsley should be offered to parents, some non-Maudsley clinicians such as Sean and Jane viewed Maudsley as treatment-driven rather than a client-centred practice.

*Maudsley kind of model, again my impression, is generally favoured at the moment here in our health service. In most other presentations to CAMHS, clinicians assess the family then work out what therapy to use but with eating disorders you start with the treatment first and then learn about the family.* (Sean)

*It’s a very should thing, you’ve always got to argue why you wouldn’t do Maudsley. I think if I just said I was going to do some work with a family with an eating disorder, the Maudsley clinicians would say ‘so why aren’t you doing Maudsley?’ and I would say ‘yes well, that’s because I haven’t met the family yet!’*
There’s almost the assumption now that you go in ready to do Maudsley, that’s the start point. (Jane)

Some non-Maudsley clinicians were able to challenge what they perceived to be treatment-driven practice. They often referred to the appeal of Maudsley in its puristic or manualised version as something for clinicians who sought comfort in the direction provided by a manual. This point is well illustrated by the following clinician:

There’s one case that comes to mind recently where clinicians were strongly pushing a Maudsley model of treatment and the parents were just refusing. This clinician was really saying ‘well if you don’t do it this way, you are not going to get it done at all!’ I think as therapists we need to be skilled up in a variety of treatment models so that we can like tailor it to the clients’ needs rather than saying, well this is the model we feel comfortable with, so this is what you get, no negotiation. I actually think it’s about some clinicians’ level of experience too. I think clinicians with less clinical experience seem to be drawn to manuals. (Donna)

However, contrary to the beliefs of some non-Maudsley clinician’s, some Maudsley-identified clinicians said they would, in fact, gain an understanding of family dynamics and capacity before applying Maudsley. Carla, as a Maudsley clinician, would take a similar approach to non-Maudsley clinicians:

It’s more about what the family brings, and what will fit for them. So I wouldn’t go in thinking, do they fit with Maudsley? I would definitely give that as an option and describe that to them but I guess I’d be going in just looking at what the family [and] its needs. I guess having a few different approaches in my head of what to offer them but the final choice being theirs. (Carla)
8.1.5.   Power and oppression

The following subtheme, ‘power and oppression’, explores how clinicians’ conceptualisations of behaviourally based family therapy, such as Maudsley, may be experienced by vulnerable groups in society. Here clinicians conceive of Maudsley as a non-Indigenous, Western treatment that may reinforce power differentials within the family, if they exist, or be experienced by parents as oppressive. Disparities in power were well recognised by clinicians who offered family-based treatment to Aboriginal families. An Aboriginal CAMHS clinician reflected upon the likely effect of the use of Maudsley family treatment with Aboriginal families:

I just think Maudsley is too rigid, if you think about an Aboriginal family, you’ve got to think more differently. You’ve got to go with a step to your left or to your right quite comfortably, and if you don’t, well if you’re stepping left and they’re stepping right, well you’re not going to meet are you. So you’ve got to step together as one. So for an Indigenous family that’s what we do, we step; we dance, at the end the song finishes. Then we’ve got a result. So it means that we’ve done a nice waltz, the person is now eating O.K. You have to be together, be on that journey, or it doesn’t work. (Mick)

Here, Mick refers to meaningful treatment for Aboriginal families. He describes the approach of Maudsley as “rigid”; not allowing for flexibility with Aboriginal families to establish the elements of treatment that resonate and makes a difference. Being seen to be on the same journey and matching each other’s momentum in treatment is at the core of treatment for Aboriginal families. In referring to stages of treatment in Maudsley treatment, Mick adds:

If you come in with the Maudsley approach for an Indigenous family you probably wouldn’t get many more than two sessions. It wouldn’t work because it’s again
pushing the family and telling the family what they’ve got to do instead of giving them ideas or helping them through that process, so they can do it themselves.

(Mick)

Mick suggests Maudsley is a proscriptive treatment that disempowers Aboriginal parents. He suggests that the phases of treatment in Maudsley would be experienced as linear; resting outside the ‘dance’, required for recovery. Another clinician, who works with Aboriginal families and is Maudsley trained, thought Maudsley would be experienced by Aboriginal families as being:

_Uptight and white._ (Margaret)

For Margaret, Maudsley therapy is culturally incongruent with the way problems are resolved in Aboriginal communities. As a non-Aboriginal clinician, she reflected on the discourse of Maudsley treatment as:

_White people talk that gets in the way of maintaining engagement with Aboriginal families._ (Margaret)

Structured therapy or Maudsley-type therapy was not considered the choice of treatment by clinicians working with Aboriginal families because it did not engage with a journey of recovery in a meaningful way. Further concern was raised about the notion of family participation in Maudsley and, in particular, the family being defined through dominant discourse as the immediate family. When treating adolescent AN in Aboriginal families, other family members such as Aunts or Uncles were described as potentially influential in recovery:

_I’d start off with the kinship person in the family. It mightn’t be mum or dad; it might be uncle or aunty. So mum and dad might appear to be in charge of this_
child but the kinship scenario is active, so that might be uncle or aunty that I need
to talk to. (Mick)

Clinicians working with Aboriginal families also pointed to the socio-economic difficulties of getting family members to attend treatment:

Like there’s economic and other issues that get in the way of trying to get a family-based program from the beginning to the end. If there are the other kids in the family, you know, what else needs to happen around their needs? There are fathers who are absent from treatment or virtually absent. It isn’t neat; it doesn’t seem to work neatly. I’m sure it doesn’t work neatly anywhere, but in the Indigenous community there’s a lot less neatness than anywhere else, is my experience. If I’m not prepared to make compromises around that they won’t come. (Margaret)

Flexibility in treatment and attunement to culturally respectful practices were central to working with Aboriginal families. The above extract shows the clinician reflecting upon multi-layered needs within Aboriginal families who seek treatment, and how these needs cannot be separated in treatment for AN. Offering a model that attends to one need is inadequate. Clinicians working with Aboriginal families therefore conceptualised the type of treatment they offer as kinship-centred and responsive to multiple needs. In this way, treatment aims to reduce alienation and encourage culturally respectful connectivity in recovery.

Clinicians also referred to the need to deviate from Maudsley treatment when considering the needs of other disempowered groups in society. This was particularly so in situations where the clinician had noticed power imbalances within parental and/or gendered relationships within the family. One clinician reflected on commencing Maudsley treatment with a family, and later discovering domestic violence:
The father was already controlling, I think we were almost giving him permission to be more controlling because, with Maudsley, it was almost like saying, it’s O.K. to get control. But the way the father was supervising and managing meals; I was fearful we were saying it’s O.K. to be super tough if we continued. This was after finding out about the violence. We thought the father was saying you must do as I say or else. So we changed the way we worked with the family. (Louise)

Louise’s extract highlights the risks in commencing a treatment regime that emphasises and encourages parental authority early in treatment, before having a clear understanding of family dynamics. This concern was acknowledged by a number of clinicians.

I think since Maudsley has become more popular, it’s like this is the way it’s going to be done but I think you really need to get a sense of what’s going on in that family and what the dynamics are … then you need to make a decision about what treatment might suit best. (Louise)

On recognising the potential for Maudsley treatment to reinforce abusive relationships, Louise revealed how her approach to treatment would be shaped in the future, irrespective of the pressure for using Maudsley in CAMHS. Another Maudsley clinician thought similarly:

... if you have a known perpetrator for example, of say verbal or physical abuse, then I wouldn’t use the strict Maudsley therapy as it is written in the manual. I’d perhaps look at doing more separate work with that family and with the parents separate to the child, so that you’re not reinforcing that pattern of abuse through the therapy itself. Because I think Maudsley can be taken in different ways by different parents and some parents are very authoritarian in the way that they would enforce their child to eat rather than assist their child to eat. (Carla)
For many Maudsley-trained clinicians, the need to assess family dynamics before applying Maudsley to families, came after a realisation of parental misuse of power in treatment.

*It’s something that I do more of now than when I started using Maudsley family therapy with parents. There’s nothing in the manual that I have read recently that talks about the assessment of the family but I think I now spend longer with the family in the initial stages and try and get a sense of what the dynamics are after some of the experiences I have had.* (Carla)

Although clinicians generally perceived that parents benefitted from structure within treatment, most suggested adherence to one form of therapy for all families in a generalist CAMHS was neither suitable nor in the best interests of families. All clinicians adjusted treatment according to either perceived need or ability of the family to engage in the treatment offered. All clinicians who treated non-Aboriginal families stated that they used principles of manualised Maudsley family-based treatment to either direct or guide interventions, irrespective of whether they identified themselves as either Maudsley or non-Maudsley therapists. The ways in which clinicians utilised self–reflective processes to build upon knowledge obtained empirically are aligned with processes advocated by a critical social work perspective. By engaging in such reflective processes, clinicians unearthed multiple meanings of experiences for parents and reconstructed their approaches to treating AN. The deconstruction of empirically based knowledge through critical reflection created new and inclusive means of treatment within a family based framework.

Some clinicians thought they were duty-bound to adopt a treatment before assessing dynamics in the family. This was largely due to a lack of acknowledgement in manualised Maudsley that it may not be suitable for some families. From their own practice and experience some clinicians recognised that the model was not suited to families with evident power imbalances, and consequently reviewed their approach to assessing suitability to Maudsley. Clinicians who
work with Aboriginal families regarded the undeviating approach of Maudsley treatment as ineffective in engaging Aboriginal families and inadequate in meeting the diverse needs of the Aboriginal families presenting for treatment.

8.2. Realising the challenges in treating AN

The following section explores clinicians’ perception of parents’ experiences of undertaking treatment in CAMHS. It will commence with clinicians’ perception of predisposing factors which shape parents’ initial experiences with CAMHS, and then explore treatment experiences through the following subthemes: shaping of initial experiences; cohesive team; challenges in treatment; searching for more; and connecting with beliefs and values in treatment.

8.2.1. Shaping of initial experiences

Three clinicians noted being attuned to issues which may impact upon parents at commencement of therapy was important in understanding how they engaged with mental health services. These clinicians thought that appreciating those experiences was important because the quality of this relationship could impede a shared level of understanding about the nature of AN and what needed to be accomplished in treatment. For example, Katrina thought parents needed time to come to terms with their child having a mental illness:

... because anorexia nervosa is a mental illness, parents may never have had experiences with mental health services. They need time to understand what that means. They need to be able to make sense of why they are being treated in a mental health service so they understand the approach we might take. (Katrina)

Katrina normalised parents’ need for time to comprehend AN as a mental illness and to understand the ensuing context of treatment, recognising that this may influence a parent’s ability to absorb components of therapy.
Jane comments on the emotional stance of parents at the commencement of treatment which could impact upon their capacity to comprehend treatment objectives:

*I think that parents come to us in a great deal of distress and as clinicians we often fall into the trap of assuming that parents will understand what we’re about to work on with their children ... I don’t know that we actually spend enough time acknowledging that these are people in crisis and distress and they’re not actually listening very well; so they don’t pick up on what’s happening.* (Jane)

Jane’s extract highlights how distress obstructs a parent’s capacity to interpret concepts discussed in treatment. She suggests failure to appreciate this phenomenon can cause divergence between clinicians and parents in understanding concepts in therapy.

Another clinician points out how parental disempowerment in initial presentation may affect engagement:

*One of the classic presentations of parents, and different to other parents, were that they felt disempowered by this powerful or pervasive thing in their family. The way they reacted to it might have been very different from an older child that they manage quite well through their adolescence; after all, if your kid starves what does that say about us as parents, that we’re not doing the right thing. So there’s very strong guilt component ... parents of kids with anorexia are going to be hypersensitive initially, even more so than your regular sort of presentations.* (John)

John suggests that parents of children with AN present differently than other parents to CAMHS. He thought that a parent’s sense of self could be eroded by an inability to help their child overcome an illness. It attacks a core component of parenthood; feeding. This brings
intense feelings of guilt into the treatment setting, which manifests as hypersensitivity and adds to parental vulnerability in treatment.

While many clinicians acknowledged parental disempowerment and vulnerability upon initial presentation to CAMHS, their level of appreciation varied for parental distress prior to attending CAMHS. Clinician empathy for the emotional stance of parents at the commencement of treatment was often overlooked in favour of a focus on helping parents reclaim their authority and confidence within the family so they:

... reconnect with their parenting abilities that had been targeted by the illness.

(Monica)

8.2.2. Cohesive teamwork

In helping parents reclaim authority and confidence, most clinicians promoted treatment aimed at active parenting against the illness. This involved parents and clinicians working together to determine the behavioural challenges parents would face against illness-driven behaviour at home. This approach was adopted by both Maudsley and non-Maudsley clinicians. In adopting this stance in treatment, some clinicians thought parents would, in time, recognise their potency as active agents in recovery and “feel like part of a team we are all committed; that sense of we’re in this with you” (Mandy).

Clinicians believed that the unity between them and parents against the illness, helped parents sense they were receiving comprehensive and cohesive treatment. For example Kristie said:

I would hope that they would view the treatment as quite thorough. They could see it’s thorough because of the multi-disciplinary nature of the team that joins with the parents. They get to see a paediatrician, psychologist or social worker and dietitian usually working in joint therapy to help them parent.” (Kristie)
Kristie thought a network of multidisciplinary input supported parents through the recovery process.

Donna also provides an example of how the multidisciplinary team helped a parent:

> Because it was quite a multi-disciplinary approach the mum was able to use that kind of, we’re working on this together approach, rather than just going to one service and going to another service. She was relieved that there were other people who could chat to her about what was going on for her daughter because her own daughter wouldn’t talk to her. (Donna)

Many clinicians believed parents would report that they received guidance, support and strategies to recovery, through multidisciplinary input at CAMHS.

Other clinicians thought parents would describe experiencing respectful interactions from clinicians because; recovery from this life-threatening illness requires parents to work as part of a team with clinicians:

> I think parents would describe that they’d received a lot of important attention to their concerns around anorexia. I think they’d feel listened to and well respected as people who are battling with a very serious condition. Hopefully they’d get the idea that anorexia is something that could be approached together and that treatment would interrupt their blaming of themselves. (Margaret)

Other clinicians did not share Margaret’s views of treatment demonstrating respect. For example, Mandy suggests clinicians’ judgement within Maudsley can result in a frustrating and blameful process for parents:
With Maudsley, we set parents up with these really hard tasks to take on to get their child to eat. Then when something happens that they don’t do right we can be a bit critical of that. We give the control to the parents and say you’re the expert of your child and you’re going to be the one who’s helping the child yet we still have these thoughts about what’s right and wrong for them to do. It’s almost like we wait and see if they get it right or they get it wrong for the week and I think sometimes the parents get that. (Mandy)

Mandy illustrates the ease with which clinicians bring the potency of expertise into Maudsley treatment and equally how disempowering this experience may be for parents. Her extract highlights a contradiction in treatment values and the subconscious process of the clinician. She believes that parents see a divide between themselves and clinicians, particularly when they were unsuccessful with the tasks set in treatment to target the illness.

A Maudsley-trained clinician commented on the way clinicians’ behaviour in Maudsley treatment has potential to adversely affect the way in which parents experience the treating team:

_I remember once when Carla and I had to hand over to other Maudsley clinicians. We were more reflective in our Maudsley sessions; sharing our thoughts and feelings with parents, it wasn’t, ‘this is what we are going to do with the family’. I remember just when the next crew came in to continue Maudsley, just the way the conversation was so different and potentially off putting for the parents._ (Margaret)

Margaret’s extract suggests that parents’ experience of cohesiveness with the treating team is not dependent on the treatment model but upon the manner and style of the treating clinicians. Clinicians may be applying the same model of treatment but whilst one clinician may work
with parents and share thoughts and feelings, another clinician may approach treatment as doing something to a family.

Other clinicians reflected upon themselves in therapy where they and the parents became the team against AN. In these instances, clinicians saw themselves as providers of education to parents, particularly in helping the parent to separate the illness from their child through the use of externalisation in therapy. The sharing of clinical knowledge, over time, helped parents to join with the treatment objectives and unite with the clinician against the illness:

*The feedback of what’s most helpful for parents is some psycho-education around what is the illness and what is the child. I find though that it takes quite a while to help parents see that this is actually something that’s out of their young persons’ control; they’re not just being naughty ... how to not engage in the battles with their child is also very useful, when to step back and when to step in. I suppose it’s about balancing that tightrope of keeping their child alive but also empowering them by joining with them in the battle through mutual understandings.* (Donna)

Here Donna describes the importance of working with parents to educate and help them to understand their child’s behaviour as something happening to them, rather than a wilful or deliberate act designed to agitate the parent. Donna’s comment illustrates how time and space is required for clinicians to join with parents as they develop additional skills to manage a complex illness. This allows for working together to reduce dissonance in understanding illness driven behaviours.

While working in a unified manner with parents was an overtly desired pursuit reported by most clinicians, some acknowledged parents can be exposed to covert clinicians’ judgement that undermines a team approach. The importance of a cohesive approach was as much about
8.2.3. Challenges in treatment

I think some families may potentially describe treatments provided as unrealistic for them; very difficult for them and probably feel that they don’t have an understanding of why treatments would be the way that they are and why we would require the level of family commitment and involvement that we do. (Katrina)

While supporting parents to battle with the illness rather than their child, was viewed as an element of helpful treatment, many clinicians thought parents would experience the treatment as “difficult and challenging.” (Sean)

Some clinicians perceived that the challenges for parents commenced with parents preparing themselves to undertake treatment.

I think it’s a big step. I think they have to acknowledge that there’s a major problem in order to come to treatment. They have to then be able to expose themselves to that process which could be quite confronting and challenging. (Sandra)

Another clinician thought that the most confronting and challenging aspect of treatment is having parents accept and manage the level of responsibility required to help their child recover.

It’s their responsibility in treatment that becomes challenging: having to manage the eating disorder twenty-four hours a day and then having to come back into therapy and go through what’s happened each day; the times where things have
worked. Facing it head on and realistically that’s what therapy does. It gets you to really look at what’s happened in much greater detail than what you ever would if you were not going through that process.” (Carla)

Carla points out that the fundamental challenge in treatment is the constant reflection upon minute details of success and failures after an exhausting and demanding week of managing the illness between sessions.

Other clinicians commented specifically on the type of responsibilities parents assume as part of Maudsley treatment:

*I think that they describe Maudsley as very difficult and challenging because of the kinds of limits and restrictions they have to place around the child’s range of activities and the degree of control they have to exert over things like, food consumption and activity … they find it exhausting and they quite often tell us that they find it extremely difficult to engage in our treatment because of this.* (Sean)

In Maudsley, expectations are placed upon parents to assume the primary role in the recovery of their child which other clinicians identified as a major challenge for parents in treatment.

*A family that did the Maudsley model did find it very difficult with those really firm limits and boundaries. I’m thinking of the family meal we did as part of treatment. How hard that must be for those parents each meal time with this young person, banging the table and pulling their hair because each bite of that sandwich was so difficult to take and to gently keep encouraging the parents in that session to say, ‘you’re doing great, look you just need to finish that last half.’ To go through that every meal time must be really difficult.* (Kristie)
Challenges for parents in treatment were viewed as the core component of treatment for AN. Challenging parents to remain committed to firmness against behaviours associated with AN, was viewed as a vital component of treatment:

*Parents challenging anorexia at meal times is essential. Parents might say that the only way they’ve been able to manage the meals is to just let their daughter or son eat whatever they want because otherwise it’s just too hard and they won’t eat anything. We’re asking them to challenge that idea to help them to give their child more or different kinds of foods. I think that’s really confronting and important to do.* (Jessica)

Other clinicians, who did not provide Maudsley therapy but applied principles of Maudsley to treatment, agreed that challenges are an expected part of treatment because:

*If there is no challenge, the anorexia remains alive in the family.* (Donna)

Just as Monica claims “food is medicine for anorexia nervosa”, many clinicians thought challenges for parents in treatment, is the treatment. The following extract shows Mandy reflecting upon the enduring nature of challenges in treatment with parents she had worked with:

*Every time they turned up it wasn’t really, getting any easier, because there were more challenges that we had to talk through and more reflection of how the week went and what to do next week. There were no periods of times where it felt for them like this is getting a lot easier. So it was hard work for a long, long time.* (Mandy)
Some non-Maudsley clinicians commented on the difficulties associated with the clinicians’ stance in Maudsley or Maudsley type treatment as being a challenge for parents. Sean reflected upon his mechanistic style, in applying a Maudsley-type approach, and related his perception of one parent’s experience:

*This one family we would say ‘what is it you think you need to do to stand up to anorexia?’ Then they come up with something. The next week and in inverted commas - they didn’t comply - so you run them through the education again and they make another set of challenges for during the week ... they quite frankly started getting pissed off with us repeating this stuff in this Maudsley way. We really did start grinding away with circular questions and challenges and it became palpably difficult for them to keep coming back when they couldn’t meet the challenges during the week.* (Sean)

Here, Sean refers to the clinicians’ stance in Maudsley, persistently urging parents to challenge AN utilising circular questioning which served to anger and alienate parents. In this extract, both Sean and parents “*grind away*” with education and challenges that seem outside the capacity of parents and, as he speculates, they also grow weary of the tedium of treatment. This ultimately resulted in a change of treatment because:

*... it was more difficult than it seemed like it needed to be and re-visiting things, the second time, the third time, the fourth time. There was obviously something not going right and so rather than just keep building that friction we needed to start looking at something else to try and relieve that pressure.* (Sean)

Some clinicians expressed that parents could feel criticised or judged if they were unable to address the challenges set in treatment, to confront the illness-driven behaviours at home.
While some clinicians adjust treatment on the basis of parental fatigue or frustration, other clinicians continued with the same treatment in spite of parental lethargy, saying:

I’ve had parents say ‘I felt like giving up and felt judged for not getting it right but I just had to keep going, I had to keep pushing, and I had to persevere with this because I’m not giving up.’ I guess that’s the stand out part of Maudsley; it’s really about persistence and reassuring the young person and the parent that we’ll all continue until their child has gotten better … It’s about the commitment to the process and that’s a principle that we, kind of borrowed from Maudsley with the families that we haven’t done Maudsley with. (Monica)

For Monica, strong parental emotions are something to work with and through. While treatment may be harder for some parents than others, Monica felt that perseverance was fundamental to any treatment for AN, as it is the key to recovery. This was promoted to parents irrespective of expressed emotional fatigue.

Other clinicians pointed out that it was difficult for parents to really understand what they were committing to when undertaking Maudsley treatment. Treatment expectations were difficult to attain because Maudsley treatment asks parents to make:

… sacrifices … we say to them at the very beginning, ‘this is going to be hard, it’s going to be difficult. It will get in the way of your social life, your work life,’ whatever so they commit to this but perhaps sometimes they don’t understand what they are getting themselves into and aren’t able to sustain it. (Kristie)

Kristie’s extract highlights clinicians’ awareness of parental vulnerability in committing to a treatment model involving a series of unforeseeable changes to lifestyle. This made treatment difficult to endure. At a pragmatic level, Andrew said:
All of the parents that I recall have made comments about the frequency in which they have to attend appointments and the difficulty in finding the time and juggling, say work commitments and the kids with school. (Andrew)

Some clinicians mentioned the particular difficulties that parents faced, in remaining committed to challenging the illness-driven behaviours when their child self-harmed, in response to the challenges they posed to the illness:

“There was this one girl who would make serious attempts at self-harm when the parents stood up to anorexia. One day they tried to get her to Emergency because she was so unwell; she just kicked the back window out of the car … the suggestion that parents challenge things even more, when they’re faced with the real risk of their daughter running away from home or running out into traffic, is just incredibly confronting. (Jessica)

Clinicians mentioned other challenges for parents were associated with dealing with disappointment and maintaining motivation to continue to challenge AN, when there was no evident improvement. For example:

Sustaining encouragement in the face of all anorexia throws at parents is really tough. I think that’s always a hard moment when you do a weigh and it hadn’t changed or it dropped slightly when parents have given it all they can and keep their motivation going. (Margaret)

Sean spoke of the difficulties for parents, when clinicians continue to ask them to focus on their child’s intake of food as the frontline intervention when parents suspect underlying issues affecting their child’s presentation need addressing. For example Sean said:
Some parents say to us something else is going on for their child that we’re not paying attention to. The longer treatment goes on and the longer you focus solely only on the refeeding aspects, the more problematic that’s going to become for parents like these because you’re just grinding away at something that’s really just an outcome of what parents perceive to be some other processes. (Sean)

Here Sean refers to the parents’ concern with the focus on re-nourishment if the treatment fails to address underlying mental health concerns which they believe to be a core part of the problem. He claims the unyielding pursuit of re-nourishment, at the expense of addressing other concerns parents may have about their child, could result in disengagement from treatment.

Other clinicians referred to the processes of reflection and exploration in treatment as causing internal conflict for parents. This was predominantly cited when clinicians recounted how AN challenged parents’ perceptions of illness-driven behaviours at home:

The dad said it’s been a difficult week. In questioning more about that week we finally got to the core issue; he had noticed tricks that anorexia was playing .... it actually felt like he was exposing a part of himself too much and a part of his family too much, I think he felt like he was telling stories. He was reluctant to tell us exactly what happened. It was like he felt he was betraying his daughter in telling us this in detail. (Jessica)

Jessica shows us how this father struggled with telling others (treating clinicians) about his family, and how AN was trying to manipulate behaviours in the family. This father struggled with potential disloyalty to himself as a father, his child and family. Although Jessica adds:
… but I think perhaps in continuing to externalise the problem, as we tend to do right from the beginning, perhaps that helps in distancing parents from being disloyal to their child. (Jessica)

Exploring parental responses to AN in treatment, using strategies such as externalisation, was regarded by clinicians as a challenge to parents’ emotional stability in many ways because:

… if you’re in the moment, you know you’re living with it every single day twenty-four hours a week, you can either not really see what’s going on because it’s there all the time or maybe you don’t want to see what’s going on because it’s just too hard. (Emma)

Many clinicians felt treatment took parents to those hard places. Treatment is somewhat frightening and anxiety provokes anxiety because it challenges parents to actively engage in and reflect upon conflict with their child in order for them to recover:

Treatment is confronting because we’re asking them to do things and think about what’s happening and, while that’s necessary, they probably don’t want to really do in a way because they might be afraid of what it means and what it’s going to create in the household. (Ann)

For many clinicians, challenging parents to work with their fear and anxiety was a means of helping them to stay on track and remain vigilant against the illness. Nick says:

Treatments like Maudsley are about creating anxiety in mobilising parents into taking action, so while this makes them frightened and it’s a big challenge for them, we’ve got to help them push through that. (Nick)
Whilst remaining vigilant against AN was a core component of all treatments offered; clinicians thought the duration of the illness was perhaps the most perplexing element of treatment for parents. For example:

... it’s difficult thing to treat and because it takes a long period of time to treat, you see confusion and frustration in parents. (Lois)

In treating AN, all aspects of parenthood were perceived by clinicians to be challenged by an illness that interrupted most aspects of family lifestyle over long periods of time.

8.2.4. Searching for more

... how do parents see us? I can think of some parents that felt we were really woefully inadequate, and said ‘you didn’t fix the problem’. (Margaret)

Clinicians reflected upon some parents’ desire for more from treatment than was offered. This is understandable when the illness has high levels of psychiatric and physical complexity that wear at parental resilience. Some clinicians thought that parents wanted the clinicians to tell them what do because they either felt powerless against the illness, or they did not feel able to meet the expectations placed upon them in family-based treatment. For example, Nick commented on the delivery of Maudsley treatment and how the intent to support parenting can in fact do the opposite. This is particularly so for parents who are searching for more than a framework to enhance or reconnect with their own skill set when coping with AN therapy.

... because we tend to veer towards Maudsley, some parents want more of an answer with somebody stepping in and saying, ‘here’s what you do’ rather than, ‘what do you think you should try next?’ ... to use a model that doesn’t give you specific clear answers can be frustrating and parents can get angry. Some can do
really well with it and others we had to back off and go for a different approach.

(Nick)

Here we see Nick reflect on the process of Maudsley treatment and parents’ experiences of circular questioning. He describes how adopting a questioning stance with parents, in order to help find solutions, works for some and yet frustrates others. Nick speculates that parental frustration in treatment is linked to an expectation that they will receive more direction from clinicians about how to help their child rather than as another clinician speculates “well you tell us and we’ll support you.” (Ann)

Kristie suggests a need to balance circular questions in therapy with guidance for some parents to help manage frustration:

If we kept asking a parent what they thought, when they didn’t know, I imagine that would be unhelpful ... but if parents felt like we were telling them what to do - that could have the converse effect of what we want. So there’s the risk I guess, that too many circular questions, would be like, ‘what am I bloody coming here for, I’m not the counsellor’, so I guess it’s a balancing act; giving that guidance and metering that out. (Kristie)

Another clinician, however, thought that parents want and seek more direction to manage an illness which takes them into uncharted waters, similar to parenting for the first time:

Anorexia is a minefield for parents. They live with this person who won’t eat. Eating is extremely primitive, like taking your first baby home from the hospital and you can’t feed it! Parents want to know, they want basic information. They want they want instructions from us to help. (Sue)
Sue likened parents’ experience of help seeking through CAMHS as being similar to that of a parent seeking help to feed their newborn when instruction is sought for dealing with uncertainty and distress.

The following extract from Jane’s interview suggests that ongoing parental distress in treatment was a sign that parents sought or needed more than what was being provided. For example:

_Distress comes with parents in treatment for anorexia and if it’s maintained, that impacts on their ability to actually engage with the therapist. I think this means they’re often desperately searching for perhaps a bit more than the clinician is providing in each session. So if the clinicians are feeling parents are asking for more, when they think they’ve already given them what they need to know, this is a real problem and can really maintain the problem of the illness._ (Jane)

Jane contextualised parents’ search for more information from clinicians as a consequence of desperation and distress. She further speculated that the frustration and confusion that came with searching for more in therapy has a functional relationship to the preservation of illness-driven behaviour.

Other clinicians, however, regarded the parent’s search for more direction in treatment as an indication of an unwillingness to disclose:

_Sometimes I feel that often parents just want us to tell them what to do instead of being a bit more reflective about what’s going on in the home or at meal times … I get the feeling that sometimes parents just feel terribly frustrated that we don’t just tell them what to do, like we’re holding a big secret or something._ (Jessica)
Yet Jessica highlights the ease with which dissonance can occur between parent and clinician, where both feel the other is suppressing important information and both are searching for more from each other.

Other clinicians thought that parents sought more than family-based treatment to help their child recover:

... we’ve seen evidence when anorexia’s got a very firm grip on the young person and on the family and sometimes parents say ‘it’s all way too hard, I don’t want to know about this, I want it to be fixed, I want you guys to fix it, I don’t want to be really part of this at all’. (Margaret)

Margaret refers to parents being overwhelmed by the level of vigilance required to help their adolescent recover from AN. In some instances, when the illness has worn down the internal resources of the family, some parents sought individually-based treatment for their child. However, treatment with little input from parents was at odds with the therapeutic approach of clinicians in this study.

There was variability of clinicians’ attunement to parental frustration or desperation, in wanting more from treatment. Some clinicians saw this as a sign that parents needed more information to help them sustain the energy required to undertake their role as an active parent in recovery. Other clinicians regarded asking for more from treatment demonstrated an unwillingness or inability to continue in the therapeutic process offered. The perception that a failure to connect with parental requests may serve to maintain the illness, poses a serious challenge for clinicians in pursuing treatment that does not resonate with parental desire or need.
8.2.5. Connecting with beliefs and values

Some clinicians attempt to achieve unison with parents by connecting with parental values and beliefs. These clinicians believed that gaining an understanding of parental values linked to cultural background or beliefs, was extremely important in shaping treatment experience. For example, Donna reflects on an experience of a Bosnian mother angered by her sense that her daughter’s failure to eat, was a deliberate act aimed at rejecting her:

*The Bosnian mother’s role was to very much feed and fatten their children ... she asked me why her child was throwing this back in her face. The father in the family was also Bosnian. He was the one who finally brought the mother and daughter together and helped them see each other’s sides; through like a mediating role in the family. He really stepped back from his cultural beliefs and part of the treatment that we offered with this family was to understand how values attached to their culture impacted upon re-nourishing; how it is different for this young girl growing up in Australia. In the end she got better. (Donna)*

For Donna, engaging with and understanding parental beliefs and values were central to helping parents through treatment. Her understanding of the roles and responsibilities attached to gender, from the parent’s country of origin, helped the parents extend the boundaries of their culturally defined responsibilities to help their daughter recover. In acknowledging cultural norms, Donna capitalised upon the parent’s belief system and shaped treatment accordingly. Although the father was not central to the actual tasks associated with re-nourishing his daughter, he was pivotal in mediating the conflict. This was an essential ingredient in his daughter’s recovery.

Engaging fathers in the recovery process, where cultural beliefs would otherwise restrict their level of participation in treatment, was mentioned by other clinicians:
...with an Indian family I worked with there was a huge emphasis on food that was mum’s role it, wasn’t a male role at all but mum was burning out. So working around why it was important for dad to be involved in an activity, which his culture would say males aren’t involved in, was a really important process to go through. In the end mum was able to let the dad know what she needed him to do at meal times, it might have been the distracting of the young person or sitting with the young person. He was comfortable with those roles which then freed mum up. (Carla)

Carla found that creating an acceptable space for the father to become involved in what appeared to be a culturally-bound female activity was pivotal in activating the recovery process. Her extract shows how refeeding became a shared process between parents, where the father engaged in activities that could be reasonably ascribed to a male, while his wife did not compromise beliefs about her role in the family. In the following extract, Carla describes the unfolding of cultural beliefs in this family that resulted in activating the father:

*In the therapy sessions the father watched her struggling, saying she couldn’t do her role that she was failing as a mother. I then explored that and she was then able to say ‘well I’m having trouble doing everything that I need to do and I feel like I need a bit of support?’ The dad was fine when he heard that. It would have been extremely difficult for her to ask for help outside of therapy sessions because that was just not what you did and he didn’t want to intrude on his wife’s area either, because he didn’t want her to lose a sense of who she was. (Carla)*

Respectfully exploring culturally defined gender roles and responsibilities allowed the father, in Carla’s extract, to understand his wife’s perspective and, in doing so, gave him permission to enter aspects of her domain within the family without encroaching on her role.
Working with culture is integral to treatment for Aboriginal families. Mick, an Aboriginal clinician working with Aboriginal families, views AN in Aboriginal males as:

An identity thing, because before colonization happened we were very tall and slim built … a lot of us still think we need to be our images; have to be a tall, lean aboriginal man in the city, quite strong, so it’s a real belief. So we did the simple things with the family like suggesting getting some kangaroo from the butchers or from out west. He and his family did this and his family had a real a sense of pride because he was where he wanted to be and they helped him. It was the pride about being Indigenous and wanting to connect and wanting to have the traditional food stuff and that’s how I got them to come down to appointments. (Mick)

Encouraging traditional foods had greater significance for this boy and his family than refeeding. Mick’s extract shows how the process of weight restoration through eating traditional food reconnected this family with a sense of identity, in addition to addressing re-nourishment. In this way, the treatment process helped this family reclaim how they wanted to be, rather than a reminder of the pride they had lost through the effects of colonisation in Australia.

Respecting cultural and religious beliefs was viewed as important in helping parents engage in treatment. This was also cited by clinicians who had worked with Muslim families:

It is essential in understanding how Ramadan for Muslim families can be integrated into treatment. (Sue)

Three clinicians reflected upon a need to understand Ramadan in working with parents because:
Sometimes 6 meals per day are required to re-nourish children in Stage one and although it was problematic, we just had to work out with our Muslim parents if they could get an exemption from Ramadan or work with it somehow. (Ann)

Ann, like other clinicians, had to work with conflict between the need to refeed through early stages of treatment and demonstrating respect for parents’ religion. In most instances, clinicians reported finding a way to help parents integrate Ramadan into treatment or find ways to manage expectations of Ramadan. For example:

… she was still in hospital but she could’ve been discharged except the parents said, ‘no please keep her in’. They wanted her to stay because she could get an exemption from Ramadan. This girl thought it was really important, something she needed to do, so staying in hospital was very important to her parents or she’d be very torn. (Sue)

However there were other instances, as in the following extract, where there was clear tension between parents and clinicians over participating in Ramadan.

The parents said that Ramadan is coming up and ‘we would like our daughter to participate’. I didn’t agree and there were concerns from the Paediatrician that it was not appropriate for her at this time. The father though insisted on her still participating in Ramadan. So we had to work with that. (Jessica)

In Jessica’s example, the father’s conviction to follow religious beliefs outweighed the opinion of the treating team. In this instance, clinicians felt obliged to work with the father’s firm belief rather than pursue what may have appeared to be ideological differences.
In summary, while some clinicians see the importance of understanding cultural domains of families who present for treatment, most did not routinely ask parents about cultural influences prior to the commencement of treatment. With the exception of Aboriginal families, it was not until cultural issues revealed themselves as maintaining factors in the life of the illness that clinicians attempted to understand the broader belief and value system within the family. When cultural issues became apparent, clinicians attempted to integrate religious and cultural beliefs into the treatment process to assist the recovery.

Although most clinicians agreed with a focus on enhancing parental abilities to work against the illness, variation along the treatment trajectory was evident in the degree of awareness of parents’ cultural needs and emotional wellbeing. These differences influenced clinicians’ conceptualisation of treatment experiences for parents.

8.3. Making sense of parental vulnerability in treatment

The following section will explore clinicians’ sense of what it means for parents to attend treatment at CAMHS for adolescent AN. Meanings are explored through two sub-themes:

*laying themselves bare* and *a lifeline*.

8.3.1. Laying themselves bare

Some clinicians in this study conceptualised treatment meanings for parents as exposing their internal world of vulnerability to help their child recover. For example Kerry said:

*I think there would be a mixture of facing your fear, exposure and relief. It’s so public. There would be some part of me that would feel extremely vulnerable that would be mixed with a sense of relief and hope that someone can provide the magic pill. It means a mixture of emotions and a sense of just putting themselves on the line.* (Kerry)
Kerry presents a blend of meanings such as fear which is associated with judgement from exposure of the problem and relief which is linked to hope for recovery. This fusion of meanings helps parents to take emotional risks in the hope that clinicians will help.

Other clinicians felt similarly to Kerry:

_I can think of many parents who blame themselves that their child is in this predicament, these parents are usually very worried that the therapist will blame them. Then there is another group of parents who are just so relieved to be able to hand this problem over to somebody else and get some support. So you know it’s almost those two opposites._ (Donna)

Donna suggests that there are two types of parents in treatment, those who use treatment to reinforce negative self-schema through blame, and others who are comforted by treatment and draw clinicians into their internal world to help.

However, other clinicians thought that the meanings parents’ attributed to their experiences of attending treatment were more a reflection of their readiness to receive help:

_I think for some parents they would initially feel failure and like something is really quite wrong within the family unit. Whereas I think others, who are open to mental health experience, if they really want help for the child, quite often they can’t wait to get that initial appointment. So I think the meaning of treatment is really different depending on where they are on the spectrum of help._ (Katrina)

For Katrina, meaning is perceived on a continuum of readiness and subsequent exposure to receiving help, particularly from mental health services, rather than opposing internal experiences related to emotional risk taking. Her reference to “where they are on the spectrum
for help” relates to her sense about parents’ inclination to internalise and interpret treatment in terms of help-seeking behaviour. She implies that, in the early stages of seeking treatment for AN, some parents may perceive there is something wrong with the family unit, reinforcing a sense of the problem as a private issue. Under these circumstances, treatment may not be embraced in the same manner as by those parents who are open to help from a mental health service.

Another clinician also spoke of meanings associated with parents’ perception of where help should originate, but additionally suggest parents’ construction of the problem also shapes their sense of treatment:

I wonder if parents might see it as just a feeding issue it’s their primary role. So I wonder if it means they feel a little bit ashamed by that or worry what we might think about the fact that they haven’t been able to manage this. For other parents, they’re very grateful that there’s somebody there to finally help them with something that they feel completely helpless with. (Jessica)

Jessica’s extract suggests that if parents view AN as a problem with eating and something to be attended to as a private issue, then treatment could be shameful. However, if it is perceived as a problem requiring external help as something unable to be attended to in the private domain, then it may mean a welcomed addition to parenting.

Irrespective of a desire for help, many clinicians felt the meaning of receiving help through CAMHS meant parents were:

... laying themselves bare to what they perceive as people judging their parenting skills, because having their child not eating or vomiting and not getting sufficient
nutrition is one of the key components or perceived components of bad parenting.

(John)

Parents’ subjecting their skills and emotions to the potential judgement of clinicians, alongside their perceived failure to provide for their child, was a common theme in clinicians’ reflections on the meaning of treatment for parents:

A lot of parents see themselves as a failure as a parent. So it’s sort of a risky thing for them to go into a clinical world and to put themselves out there because they do risk or fear perhaps being criticised. (Louise)

Despite risking a self-fuelled sense of failure and judgement, some clinicians felt parental desperation for help eclipsed the pain associated with such exposure in attending treatment:

It means having to open up and they have their family explored and a lot of people are very uncomfortable with that but I think the desperation for something to change makes them step over that line and reach out. (Louise)

Accessing treatment as a result of parental desperation was mentioned by other clinicians:

I think it means they’re getting quite desperate usually because, by the time they land at CAMHS doors, it’s pretty much your child has a problem or at least other people are sure your child’s got a problem ... and they’re scared that coming is going to get in the way of their relationship with their child. (Jane)

Jane’s extract highlights the dilemma that treatment presents for parents. At one level it attends to their desperation, after trying and failing to help their child at home. At another level it means
placing themselves in the hands of a third party to help, which may impinge upon their relationship with their child.

Meanings of treatment attached to the parent-child dyad were referred to by a few clinicians:

*Most parents would have a mixture of feeling guilty that their child has got to this stage versus angry at the child for putting them here, exposing them to judgement.*

*While there’s guilt associated with having a child with anorexia, sometimes they can be made to feel guilty by the child for bringing them along because they don’t want to be there.* (Sandra)

Sandra refers to meanings resulting from a combination of parental guilt, perceived failure at being unable to cease the progression of AN and anger toward the child for forcing the exposure of feelings in the clinical setting. She additionally points out that just attending treatment can cause conflict between the child and parents because the illness prevents the child from wanting to recover. Attending treatment to recover from AN therefore places the parents in an arena for conflict. Sandra presents treatment as a battleground of loyalty where parents battle being perceived by their child as disloyal while they work at loyalty to attending to a process of recovery. Parents being loyal to recovery, places them in a position of vulnerability in relation to both their child and the clinicians.

Carla suggests meanings associated with attending treatment alter over time for parents, due to the enduring exposure of parents to challenges in treatment in working against illness-driven behaviours:

*Parents are initially engaged, and they’re quite motivated to want to be involved.*

*Then parents get overwhelmed; it’s hard, they start to feel tired, exhausted, and perhaps want to withdraw a little bit from the therapy itself. They want their child*
Carla conceptualises meanings in treatment as a continuum of energy. Her extract shows an initial energy in the recovery process reflected in parents’ motivation and activation early in treatment. However, sustaining parental responsibilities sees meanings alter to burden, reflected in lethargy and desire to transfer responsibility to their child. Carla’s extract suggests the meaning of treatment can transfer from ones that are initially stimulating and active, to ones that over time are linked to the parent’s fatigue.

Other clinicians referred to treatment as a representation of future fears and eventualities:

*Parents come to a mental health service for their adolescent with anorexia and think if they’re this bad now, what that means for their future and what that means for us as parents, for our responsibilities to them. It can mean that they might worry about children in the family and what’s going to happen to them.* (Andrew)

Andrew’s extract signifies meanings attached to a series of losses, disruptions and burdens in the present and future. These relate to the child, the parents themselves and other children in the family. The trajectory of future relationships within and beyond the family has been unhinged by the realisation of a need for mental health services.

Mick also commented on meanings treatment poses for parents that are associated with their fears for their child’s future. He refers to the mother of a young man he was working with when she said to him:

*... ‘is this something that’s going to be with him forever?’ She was looking, you know, ten or fifteen years down the track.* (Mick)
Clinicians generally thought the act of attending treatment meant parents were placed in a position of having to acknowledge current and projected meanings associated with desperation, fear and at times anger for both themselves and their child.

8.3.2. A lifeline

While many clinicians connected meanings of treatment with emotional tension and loss, other clinicians referred to treatment as a means of providing a sense of salvation to parents because:

... really they’re not just saying, help my child with a mental illness they’re saying, here, can you figure out how to parent this child because I don’t think I know how to parent them anymore. (Kristie)

Seeing parents who no longer know how to parent a child they once parented soundly, prompted clinicians to conceptualise treatment as a lifeline for parents:

For most of the parents it’s their absolute lifeline. For some of them they’ve come post-hospital, they feel really super worried that they’re going to lose their young person. So for some people they’ve really seen the severity of it and they’re desperate to think about what they should do. (Margaret)

Here Margaret refers to the meaning of treatment as a pathway for parents to save their child’s life. She suggests this is particularly so in circumstances where the severity of the illness has resulted in hospitalisation, where mortality associated with the illness is realised by the parents. Margaret thought parents knowing that treatment could literally save their child’s life and thereby, metaphorically, their own, drove parents ‘desperation.
Other clinicians conceptualised the meaning of treatment as “the last stop” where children were not hospitalised but parental resources had all but been exhausted and they did not know how to help their child recover:

... she was trying to manage on her own but it just got too big for her to manage. I think it meant she comes to CAMHS knowing that this is the last stop for him. If she didn’t get some support or therapy, she didn’t know where it would end up for her or him. (Mick)

Mick conceptualises treatment as providing deliverance from circumstances beyond the control and capacity of some parents, particularly sole parents. His extract highlights how sole parents struggle to parent an illness which challenges multiple domains of parenting. This makes it difficult for a parent to continue to manage the problem in isolation. Treatment is conceived as an adjunct to sole parenting and without it, in Mick’s example, it is difficult to predict the eventuality of future circumstances for either son or mother.

Nick however, conceptualises treatment as a form of submission to a process of support and learning as follows:

Some parents come when they are at the end of their tether and it’s kind of humbling for them that they seek help. They feel they can’t do it anymore and need someone else to help out ... sometimes it’s a relief for them to have some support and back-up and somebody who can teach them about what’s going on. (Nick)

Nick perceives that treatment could mean a reduction in parental isolation because it invites clinicians into the world of the parents, particularly when they feel that they have surpassed their level of endurance with self-managing the illness. Treatment provides an opportunity for the clinician to educate parents about AN.
However, Jane warned of the dangers of potential ‘expertness’ in clinicians, by conceptualising treatment as lifesaving:

_Sometimes people come in helpless, needy and urgently seeking assistance. It’s very easy for clinicians to drop in to, ‘yes I’ll save you, I’m the expert’ without actually realising now hang on these people are just like this at the moment because they’re feeling so devastated and actually they’re still the experts. If you just jump in and you’re the expert and you remain in that position, you’re sort of talking down to them and coming from that stance._ (Jane)

While some conceived treatment as an exposure of emotional and physical vulnerability, and others as lifesaving, only a few clinicians associated it with optimism and hope. Treatment meanings were generally linked to parents sustaining energy to maintain a level of responsibility to help their child recover. While treatment helped parents reflect upon how they may offer support to their child and then to act upon this, treatment meant taking risks outside the range of previously held parenting experiences.

### 8.4. Making sense of parents’ experiences outside of treatment

This section explores how clinicians made sense of the phenomena of parenting an adolescent with AN outside of treatment. Conceptualising the reality of parents’ day-to-day experiences challenged clinicians to think beyond the safety net of the therapeutic context. In reflecting upon parental experiences, outside of those either heard about or observed in sessions, clinicians painfully reflected upon themselves under similar circumstances, or projected themselves into the perceived struggles and battles of the parents they treated. Clinicians tended to either view parenting an adolescent with AN as a disempowering experience or one of self-reproach.
8.4.1. Disempowerment

Anorexia nervosa confronts parents with their own inadequacy or self-perceived inadequacies about their parenting; it takes something away from them. (John)

As a way of gaining greater empathy and understanding for a parent’s perspective, some clinicians drew parallels between their own personal circumstances and those of the parents they treat. For example, Mandy reflected on the challenges parents face in dealing with a combination of adolescent developmental issues and AN, by juxtaposing her own struggles with her two year old child’s refusal to eat:

I had a two year old who refused to eat their dinner. I would have this Maudsley thing in the back of my head, ‘one more mouthful than what they really wanted’... I think it would be very difficult for our CAMHS parents to have those battles around food because adolescents are a lot more cluey than a two year old. There’s a lot more secrecy with anorexia and there’s a lot more ability to manipulate as well.” (Mandy)

Ann also reflected upon her personal circumstances to help her make sense of what it must be like for parents of adolescents with AN:

I’m going to put myself in the context of this happening to my daughter. If she had an eating disorder, there is the potential to feel incredibly isolated and helpless. Even though I’ve worked in this field for so long, as a parent, I still would think, “have I done anything to contribute to this?” You’d be scared and anxious and as a result not sure how to help. (Amy)
Another clinician commented on her experience of parenting her child, born with a disability, and how this helped her empathise with the fear and negative self-schema in parents of children compromised by illness or a weakened developmental trajectory:

_I have a child with a disability and as a parent; you want to build resilience in your kid. There are things that you’d like to develop in your child so they have buffers in life. When that doesn’t happen, like with anorexia then parents are terrified and do question, “have I not done my job?”_ (Kerry)

Another clinician, however, found it too challenging to conceptualise parents’ lived experiences outside of the treatment setting because they could not imagine themselves coping with the complexities and challenges of parenting adolescent AN:

_Part of me wants to imagine what parenting is like and then the empathic part of me is like I don’t want to go there. You question, that’s really hard just to sit here and try and put myself into that position, what that must be like for them, my immediate response is I won’t go there._ (Nick)

Clinicians reported the phenomena that parents of an adolescent with AN most commonly experienced, was disempowerment, fuelled by the fear and frustration of not knowing how to help their starving child. Not knowing how to help, meant their child was more at risk of death, through starvation. For example Louise said:

_When you think that your child’s going to starve themselves to death and you don’t know how to actually stop it, I think you just go through a whole range of overwhelming feelings and fears._ (Louise)
Another clinician spoke of parents’ prolonged apprehension and fear resulting in their overall sense of subjugation to the illness. For example:

*Parents have chronic anxiety, chronic worry, chronic fear which then erupts at times into anger because they feel guilty about being angry. All of that anger coming back from the child and worries about what other people think as well, all creates a sense of powerlessness that they often must have in the face of this illness.* (Sandra)

Many clinicians regarded parental powerlessness as having evolved from the gradual and secretive nature of an emerging illness that once established, “*rejects parents doing their job to parent*” (Donna). For example:

*Parents quite often don’t see this coming. There are a lot of behaviours along the way that can be justified that seem to make sense to parents, so when they get this end result they blame themselves for not noticing it was anorexia sooner. Then they get caught by it.* (Mandy)

Parents’ unwitting alignment to behaviours linked to an illness that relies on “*secrecy and manipulation*” (Donna), was viewed as a contributing factor in undermining parental ability to parent their child. Some clinicians thought that a parent’s sense of self is so severely compromised by the realisation of being deceived by AN over long periods of time that they become immobilised and overwhelmed:

*I think that a lot of parents feel completely helpless and hopeless about what to do. After a while they know that anorexia is getting them to do things but sometimes their child sounds so believable that they don’t know what to believe and then what to do; it almost incapacitates them to take action.* (Kristie)
Alternatively, three clinicians believed that parents did not continue to be disempowered by AN. These clinicians described parents living through a range of experiences, which over time and with therapy shifted from disempowered to empowered parenting. For example, Carla describes differing experiences inform the stage of first being diagnosed through to recovery:

"At the very beginning of the therapy journey there’s lots of questions ... then parents go through another phase and feel quite helpless and hopeless thinking, it’s not changing’ and they can get very angry at their child ... when they can start to see some changes, parents go through a phase of relief and hope comes back." (Carla)

Another clinician also comments on experiences shaped by treatment:

"At the outset of treatment it must be incredibly heart breaking to see your child diminish in front of your very eyes and feel unable to assist them. That changes throughout the course of treatment where more hope is generated, more of a sense of agency, a sense of being able to play a role in recovery and being seen as being resourceful towards the solution." (Monica)

Katrina also comments on empowered responses within the family in dealing with illness-driven behaviours around meal times which resulted from therapy:

"Prior to treatment there can be a lot of changes to accommodate the illness and then throughout treatment, there can be a lot of positive changes within the family unit regarding who takes responsibility around eating and nutrition." (Katrina)
Although these clinicians commented on the impact of treatment upon a parent’s sense of self and agency, there was general agreement among clinicians that ongoing fear and unmanaged worry undermined parental potency against AN.

In realising the challenges of parenting an adolescent with AN, some clinicians commented on parents becoming ‘a different kind of parent’ (Kristie) than otherwise intended, in order to help their child recover. These clinicians referred to existential questions parents may raise as they adjust to disruptions to most aspects of family life:

... anorexia creates stress in the relationships ... on a deeper more profound level it would totally make you question who you were as a parent, how you think as a parent and who you are as a parent. It causes profound disruption to self and relationships in that family. (Nick)

Another clinician commented on the range and impact of choices parents are forced to make to keep their child alive. These come at a great cost to aspects of family life:

... every day making choices ... to stay home and not go to work, so there’s less money for the family ... to sit at the table for three hours with my child with anorexia means I don’t spend time reading with my younger children. If I choose to spend time reading a book with my younger child rather than the child with the illness ... someone always misses out. (Mandy)

Here Mandy perceives family life as a series of trade-offs in an unwinnable battle to find the time and energy to meet the needs of all family members.

John also commented on disruptions to sibling relationships caused by a need to focus on maintaining vigilance around AN at home:
Anorexia can be very powerful within family dynamics ... what gets cooked, what doesn’t get cooked, what’s eaten, and when they all eat. This causes a lot of tension in sibling relationships because they get resentful about everything being organised around anorexia. (John)

Katrina comments on how everyone living in the family unit is affected, in some way, by maintaining a commitment to recovery:

There can also be a lot of changes within the family because of the time commitment and the energy required to help their young person recover ... the way the whole family manages the distress of the young person who’s trying to recover, can pose a lot of difficulties and a lot of changes within the family unit as well. (Katrina)

8.4.2. Shame

Some clinicians perceived the pressure on parents to help their child recover could manifest in a sense of shame. This is often realised in the social interactions of parents:

How does a parent say, ‘oh I’ve just got to start late and finish early because I need to monitor my teenage daughter’s eating,’ people would go ‘huh’ because the public perception is that adolescent’s don’t need that support. So there’s a shame in saying, ‘well I need to monitor her because she has an eating disorder’. (Kristie)

Kristie also reflected upon the impact of parents’ sense of shame about their seeking help:

... I wonder if parents keep it a secret as well because they feel shame and then that makes it difficult for them to access support. (Kristie)
Jane commented on the level of public exposure for parents on an outing with a child who is severely underweight:

Well it is, isn’t it, shame on display. You walk around with a skeletal child and it’s like, it’s out there. There are lots of things that go on in households that families may well choose to cover up. You can’t cover this one up, it’s out there. (Jane)

Nick reflects that shame in parents he treated was strongly associated with a religious community:

There were some incidences where members of their religious community actually intentionally shamed them saying ‘you shouldn’t be putting her in the hospital, you should be able to do this at home, now you’re letting outsiders treat her, this is something you should be able to handle.’ It was really full on. (Nick)

Mick comments on the effect of shame in Aboriginal communities:

When the person has gone wonba, they’ve got a mental illness. The family will then come around and support them, smother and try and hide that. The family would come and all live in the one house or two houses and try and look after that person in the house, because of the shame factor. (Mick)

Feelings of shame and the judgements of others in the social context of parents, were thought by clinicians to be the primary factors contributing to parental isolation. However, a few clinicians did not perceive parental isolation as being related to shame. They perceived parental isolation as an experience of everyday life associated with the demands of managing the illness, or
associated with the difficulties parents face with others understanding the complexity of the illness:

*I think there are a lot of misconceptions about eating disorders making it hard to talk with your friends and your family because it’s so complex; how do you explain this? Then if you haven’t let them know, it maintains what becomes a secret.*

(Mandy)

Mandy describes a loop of isolation produced by the judgements of others and experienced as silencing, by parents. Parents were perceived to experience a sense of isolation and awkwardness with those who would ordinarily provide support and reassurance, thus preserving the misunderstandings about AN.

Jessica comments on parental isolation as a consequence of the demands on parents to help their child recover:

*I think anorexia just takes over the young person’s entire life but also it kind of takes over the whole family. Some parents give up work perhaps, some don’t go out like they used to ... there’s a whole period of their life, hopefully it’s a defined period in their life, where they’re kind of lost to everything but anorexia.*

(Jessica)

In summary, while many clinicians viewed parenting experiences outside of treatment as largely disempowering, a few clinicians remarked on how the treatment process shifts parental experiences along a continuum to a more empowered sense of self. Although many clinicians commented upon the impact AN has upon most aspects of family functioning, a few clinicians further speculated that a sense of shame compounded parental isolation.
8.5. **Insights into a parent’s sense of self**

The following section explores clinicians’ perception of what parenting a child with AN means to a parent’s sense of self. It will commence with clinicians’ perception of how they think parents see themselves through the subtheme *questioning themselves*. It then explores clinicians’ conceptualisation of meanings associated with parents’ future expectations that have been destabilized by an illness, through the theme, *loss*. It concludes with a few clinicians’ perception of positive meanings arising from parenting adolescent AN through the theme *meaning in recovery*.

Many clinicians struggled to translate their perception of day to day experiences for parents into broader conceptualisations related to the meaning of parenting an adolescent with AN. As a result, their responses were less descriptive than other parts of the interview.

**8.5.1. Questioning themselves**

Several clinicians thought that meanings were connected to the way parents question themselves and measure themselves against their ideals of what being a parent involves. Some clinicians thought this occurred when parents assessed their preconceived notions of parenting against their ability to parent through the harshness of AN:

*As a parent there’s a picture of how we’re going to be able to handle things .... these preconceived notions that you have of how I’m going to do things or what’s going to work don’t apply with anorexia ... it leads you to just really question how you feel about yourself as a parent and how you look at your abilities as a parent because it’s a tough disorder to treat.* (Nick)

Other clinicians believed meanings were linked to parents questioning their role in causing the illness:
I think that it really attacks a sense of their self and certainly their sense of their role as a parent. They really question themselves like what they’ve done and what they haven’t done, how they might have played a role in the development of this eating disorder by not noticing it earlier and doing something about it then.

(Monica)

Louise thought similarly and stated:

I think they probably question themselves, their own values, beliefs and there’s probably guilt around, you know, could I have done things differently, why didn’t I notice it? (Louise)

Another perspective provided by many clinicians was that meanings were associated with parents’ self-interrogative processes about how successful, or not, they had been in protecting their child from adversity in life:

The biggest thing it may mean is that they have failed the tasks of a parent to bring their child up safe, no pain. When the child has anorexia nervosa they are doing this thing to themselves ... that just simmers away at parents and I imagine is a great cause of sensitivity, that cause parents to jump to the conclusion, ‘it’s me isn’t it? I knew it was all my fault.’ (Kristie)

Kristie’s description of a pervasive sense of failure, which “simmers” within parents, occurs with parental realisation that their child hasn’t internalised the sense of safety they’d hoped to have instilled through their actions in parenting. They had failed to provide an optimal environment for their child.
Another clinician commented on how meanings connected to self-perceived failure are powerfully endorsed by unsuccessful attempts to help. The outcomes are counter to those required of parent-child interactions when children are in need of help:

*It might mean for parents they’ve failed at their job to parent because, in the past, they couldn’t stop anorexia progressing and currently nothing they do is working and their child is refusing their help; it’s so difficult to do the job of parenting.*

(Margaret)

Only one clinician referred to a difference between genders when considering what AN means to parents:

*“Dads look more at how do I solve this problem? and how do I do it quickly? Mum’s get really caught emotionally for a while and find it hard sometimes to be as firm as they need to be against the illness.*

(Monica)

For heterosexual parents, Monica suggests the sense each make of AN has a direct influence on how they respond during treatment.

8.5.2. Loss

A few clinicians referred to the meaning of parenting an adolescent with AN as an experience of loss. Parents lose their relationship with their child, or with the child they once had, to an illness:

*It means they just don’t know what to do; they’re confronted with something that they feel incapacitated by. So for some parents it means that they’ve almost lost their child to something else and that their child isn’t there anymore. They’re a completely different person in that they’ve kind of lost them.*

(Jessica)
Jessica suggests parents’ sense of self is weakened by the provocation of AN in the life of an unfamiliar child. The child that the parents once knew has been reshaped and redefined by the illness, rather than through their parenting.

Another clinician commented on the perplexing nature of parenting a child who is unfamiliar to their parents:

*I think it means losses and for some families, it’s about the hugest loss of all, they actually do lose their child to the illness and don’t know how to parent their child anymore.* (Carla)

Louise connected meanings for parents to the way AN re-shapes the manner in which parents behave in relation to interference caused by the illness:

*I think its meaning has to do with the whole way it changes parents’ lifestyle. It can interrupt people’s work and their family life, their relationship with their other children. So its meaning is about the complete disruption to their life, loss of their dreams, their ambitions, and their whole way of living.* (Louise)

Another clinician also spoke of the meaning of projected losses for parents as follows:

*“There’s an enormous amount of grief that parents come in with about the possibility of damage to organs... death... they’ll never have children of their own because they can’t get their child to eat. So it’s not just the loss of what’s happening now, it is with the loss of the future quality of that child’s life. It’s like you suddenly had an able-bodied child who’s now disabled and disabled into the future.* (Margaret)
Margaret views the parents of adolescents with AN as losing their own sense of being able to protect their child against a life-threatening and life-altering illness as they struggle to provide the medicine (food) required to keep their child well.

Another clinician spoke of parents having to make sense of the risk of potential mortality when adolescent AN is given little credit for its conceivably fatal consequences:

For a parent it’s invalidating because ... they’re just stuck on the horns of this horrendous dilemma because it’s not taken seriously in the community because people think it is related to something seemingly so obvious to fix but it’s a psychiatric problem that directly impacts on physical health. (Jane)

Jane speculated that parents have to make sense of the loss of the child they once knew in a society that has little understanding of just how serious the threats of AN pose to their child’s mortality.

8.5.3. Meaning in recovery

Although most clinicians thought the sense parents made of their experiences of parenting were generally adverse, some did not think this way. Some clinicians thoughts were similar to Donna’s who said “for some families it’s about gains and other families it’s about losses.”

Carla provided an example of the gains in family relationships with parents she had treated:

I think a lot of parents have found a way to come together as a family. They’ve found meaning in supporting each other, meaning in connecting again, and for them, it’s been about them being able to find a sense of being a parent again
because that changed for various reasons over time and they’ve found strength within it. (Carla)

Positive meaningful experiences that bought families or relationships together were commented on by clinicians when they reflected upon families which had moved into recovery. Katrina also provided an example of strengthening in parental relationships:

... one very positive example is where the parents weren’t entirely working together, which they needed to be to assist in the recovery ... what it ended up doing is strengthening the parenting relationship and allowed them to communicate a lot more openly together about their parenting style and about the consistency in that. (Katrina)

While the intent of family-based treatment is to bring parents together to help their child recover, only a few were able to provide examples of strengthened parental relationships in parenting an adolescent with AN.

8.6. Conclusion

In relation to the theme of, professional judgement and choice, clinicians reflected upon their decision-making processes in choosing the nature and type of treatment offered to parents. Clinicians attempted to balance perceived needs, responsiveness and capacities of families with a desire to provide evidence-based treatment. While 14 participants reported using Maudsley in treatment, none of them said they had ever provided Maudsley by strict adherence to the manual. Clinicians who identified as non-Maudsley also add principles of manualised Maudsley to their existing treatment modalities. All participants adapted manualised Maudsley to either meet the needs of the families they treated or to address power imbalances in therapy. Clinicians who worked with Aboriginal families regarded Maudsley or Maudsley-type
treatment as an inappropriate choice of treatment. These clinicians viewed treatment that focused on kinship networks, values and beliefs were culturally respectful and appropriate for this population.

In this study clinicians critically reflected upon their decision making process and deconstructed empirically based knowledge regarding the type of family-based treatment. This occurred in five noteworthy ways:

1. Considering Maudsley - Here decisions were influenced by perceived needs and capabilities of parents. The nature of therapy offered was largely determined by clinicians, with varying degrees of input from parents, by determining the capacity and willingness of parents to undertake treatment.

2. Structured approach to treatment - Decisions about the type and format of family-based treatment offered were made by balancing family capacity with risk factors associated with illness. Empirically based knowledge informed a structured approach to treatment that offered clinicians a framework for assessment. Self-reflective processes additionally helped clinicians link parental capacity to perceived and expressed ability to manage risks. Stages of treatment in this approach were not well conceived by clinicians beyond an initial focus on re-nourishment early in treatment. Only three therapeutic interventions were mentioned as final stages of treatment, post-weight restoration in the child. Structured and sequential treatment that deviated from interventions in manualised Maudsley formed the basis of what appears to be a Maudsley-type approach to treatment.

3. Adapting Maudsley - To allow for clinical judgement in treatment, clinicians reflected upon their practice and adapted evidenced based (manualised) treatment for adolescent AN. Adaptations to Maudsley tended to occur in circumstances where parents were unable to re-nourish their child in the manner proposed by manualised Maudsley therapy or where
principles that guide practice using Maudsley reinforced abusive patterns within the family. Stages of manualised treatment were deconstructed and enhanced to meet family need or capacity.

4. Treatment driven practice – Despite no clinician saying they strictly adhered to manualised Maudsley, clinicians spoke of their sense that treatment models drive clinical practice for eating disorders in CAMHS, rather than clinical judgement. Clinicians regarded knowledge derived from scientific research as privileged knowledge, whilst the knowledge derived from their critical reflection on practice experiences was minimised.

5. Power and oppression - Clinicians noted power differentials when reflecting upon the application of manualised family-based treatment to vulnerable groups in the community. Particular reference was made to treating families where power differentials existed within the family unit. In these instances, clinicians thought either the authority given to parents, or the authority of the clinician in manualised Maudsley or Maudsley-type treatment, mirrored societal inequality through either race or gender. As a subtheme, power and oppression included clinicians’ perceptions of family-based treatment as having the potential to further oppress families who already experience marginalisation, by reinforcing systemic oppression in the treatment setting.

The theme: realising the challenges in treating AN, explored clinicians’ perceptions of parents’ experiences with aspects of treatment including the elements of treatment that parents may find helpful. Clinicians’ conceptualisations of parental experiences in CAMHS occurred in five significant ways:

1. Shaping of initial experiences – Clinicians explored the factors that influence parents’ engagement in family-based treatment. Empathy for the emotional state of parents at commencement of treatment was viewed by some as the first step and the most important
consideration in engagement in service delivery. Others viewed this as less important than early activation of parents in treatment.

2. Cohesive team - Clinicians thought that parents’ experiences of a multidisciplinary team approach to treatment created opportunities for differing perspectives on most aspects of care.

3. Challenges in treatment - Here clinicians empathised with the energy and commitment parents experience in attending and meeting the demand of expectations in treatment. Clinicians’ perceptions of treatment as challenging raised their consciousness to the effect of treatment burden on parents. The momentum in treatment was also seen to challenge parents’ sense of agency.

4. Searching for more - Clinicians’ perceived parents often asked for more direction or information from clinicians in treatment. While some clinicians think parents sense they know more than they actually convey, others thought parents sought something beyond either their clinical skill base or capacity. In searching for more, clinicians’ accounts of parental desperation for assistance were often paired with their lack of omnipotence in circumstances presented in treatment.

5. Connecting with beliefs and values - For some clinicians, integrating parental cultural beliefs and values in treatment enhanced components of family-based treatment and provided opportunities for new knowledge creation in treating adolescent AN. Reconnecting or connecting with parental cultural beliefs and values provided more respectful and helpful interventions for parents. Clinicians’ accounts of attunement to and integration of parents’ beliefs and values in treatment were associated with greater achievements in treatment.
The theme: *making sense of parental vulnerability in treatment*, explored clinicians’ perceptions of what it meant for parents to undertake treatment at CAMHS. How clinicians perceived the sense parents made of attending treatment was explored through two subthemes:

1. *Laying themselves bare* - In understanding the meaning of attending treatment, ‘laying themselves bare’ concept captured clinicians’ reflections on parents’ battles with AN in the treatment setting. Here clinicians referred to treatment for adolescent AN as exposing the private domain of parenting, and discussed how the treatment process raised powerful emotions of fear, guilt and shame in parents.

2. *A lifeline* - Many clinicians identified that parents experienced a sense of relief and renewed hope in sharing the management of a complex illness with a team of clinicians. Here clinicians saw themselves as active agents in the minds of parents, working in unison on new understandings to assist in the recovery process.

The theme *making sense of parent’s experiences outside of treatment* explored clinicians’ perceptions of the lived experiences of parenting a child with AN. Two subthemes emerged:

1. *Disempowerment* - Clinicians attempted to place themselves in the shoes of parents as a way of connecting with the day to day power struggles involved in engaging in a battle with an illness that attacks the core of parenting. The ‘disempowerment’ theme saw clinicians reflect on their perception that parents lose a sense of themselves in all facets of personal and social interactions when parenting their child with AN.

2. *Shame* – This theme explored clinicians’ sense that judgement by others or perceived judgement by others reinforced a sense of shame in parents. The exposure of self-perceived failure in parents was viewed as paving a path for parental isolation.
The concluding theme of the chapter, *insights into parents’ sense of self*, explored clinicians’ conceptualisations of the meaning of parenting a child with AN and how those meanings shaped the treatment process. Three subthemes emerged:

1. *Questioning themselves* - In searching for meaning, most clinicians identified that parents questioned their intrinsic beliefs about themselves as parents and their potency to help their child.

2. *Loss* – Here clinicians reflected on parents’ perceived failures to re-claim their child’s life and identity when it had succumbed to a life threatening illness.

3. *Meaning of recovery* – A few clinicians provided an alternate picture of adolescent AN as raising strengths and unity within relationships through the process of helping the child recover.
Chapter 9. Discussion

This research examined the treatment of adolescent AN from the points of view of parents and clinicians. Fook’s (2012) exposition of postmodern critical social work provided the lens through which the findings of this study were interpreted. These findings make a unique contribution to the literature in the following ways:

1) It is the first Australian study to adopt a mixed-methodological approach to create new ways of thinking about, and approaching family-based treatment for, adolescent AN.

2) It examines experiences of treatment for adolescent AN from the parents’ and clinicians’ perspectives in a community-based mental health team.

3) It identifies the ways in which Maudsley based treatment is adapted by practitioners.

4) It explores service provision to families which is inclusive of different treatment approaches.

This chapter discusses and merges the major study findings presented in Chapters 6, 7 and 8. It presents new ideas about practices that could enhance care and assist in the recovery from adolescent AN, by drawing upon parent and clinician conceptualisations of actions and behaviours that optimise treatment. It commences with an explication of core issues regarding utilising a mixed-methodological approach in research. Comment is then made on how interpretative phenomenological analysis of qualitative data enriched the quantitative findings obtained from the surveys. Interpretations of participants’ views have been made in order to make sense of treatment experiences. In this chapter findings have been synthesised and integrated in the presentation and discussion of three key findings:
• Parents value being in tune with clinicians, and an effective therapeutic relationship enhances their parenting;
• Clinicians integrate evidence-based treatments into clinical decision-making processes to invent a ‘Maudsley-type’ treatment;
• Treatment is enhanced when parents’ cultural and spiritual value systems are considered.

9.1. Use of a mixed-methodological design in the research

The uncovering of new ideas to inform practice occurred through the research process, by integrating descriptive quantitative data with qualitative data, and analysed using IPA. Before commencing further explication of the findings, it is important to revisit some of the salient issues in utilising a mixed-methodological approach in research.

The fundamental issue for mixed-methods researchers is the degree to which they “genuinely integrate” their findings where both components of the study are “mutually illuminating” (Bryman, 2007, p.8). Although the integration of data in the writing-up phase of any mixed-method study is important, the primary issue is whether the end product of a mixed-methods study is more than the sum of the individual parts (Bryman, 2007). A lack of such integration suggests that mixed-methods researchers may not always be making the most of the data they collect. An integrative stance is adopted in this study to help illuminate the findings and contextualise the experiences of participants, adding new dimensions that would not have been possible had only the findings using either paradigm been presented.

In this study, findings were enhanced by integrating data from the survey questionnaire that encapsulated both quantitative and qualitative data, with further in-depth qualitative data gathered from semi-structured interviews. Rather than treating each component of the study as a separate domain, each section provided opportunities to illuminate data from the other, and to
help amplify the responses of participants in a small study. It was particularly useful to use data from semi-structured interviews to clarify the essence of any incongruity between parents and clinicians in the data produced from the survey. Similarly, data in the survey was used to provide answers about perception of importance and effectiveness in treatment that could be juxtaposed with parents’ and clinicians’ reflections in interviews about what both found helpful. This was important because the survey used in this research was based on an outcome effectiveness survey used for manualised Maudsley (Krautter & Lock, 2004). In order to make sense of overall treatment experiences, semi-structured interviews provided a means by which data about aspects of Maudsley could be illuminated, and characteristics of helpful non-Maudsley family-based treatment, not accounted for in the quantitative component of the survey, could be identified. By accounting for experiences of participants that sat outside the dominant form of family-based treatment, new knowledge in working with adolescent AN was created.

9.2. **Interpretative phenomenological dialogue with mixed methods**

Just as a mixed-methods approach sought to amplify data in research findings, the use of interpretative phenomenological analysis of qualitative data in this study helped illuminate meanings, cued by a close engagement with the concerns of participants (Smith et al., 2009). In referring to the relationship between mixed-methods research and IPA, Smith and colleagues state:

*The power of mixed methods designs lies in the combination of insights and leverage which can be offered by IPA when it is used alongside quantitative approaches* (Smith et al., 2009, p.192).

In this study, as in other IPA studies, the phenomenological investigation was used to explain and expand upon the quantitative data in a way that helped understand the meaning of
experiences beyond those listed in the survey. An interpretative phenomenological analysis assisted in the comprehension of parents’ and clinicians’ lived experiences, and their relatedness to aspects or characteristics of treatment. By paying attention to the significance of small elements of experiences, and offering an interpretation of personal meaning of various ‘outcomes’, IPA offered insights into experiences given little credibility in experimental designs. If integrated into family-based treatments, these insights may help clinicians seeking practice guidance with families where multifaceted social and cultural issues impact upon parenting during treatment.

9.3. **How a mixed methods approach enhanced the interpretations and findings**

Insights and new knowledge were generated in this study using IPA, which provided an approach to the analysis and interpretation of quantitative findings in the survey in combination with qualitative findings from interviews. In this thesis, the quantitative part of the research was concerned with determining in a general way whether Maudsley or non-Maudsley treatments had, for the most part, been helpful and or effective. It was useful in identifying broad trends that could be examined more closely through the qualitative interviews. By undertaking a phenomenological analysis, the qualitative component of the research helped to understand how Maudsley and non-Maudsley interventions worked from the perspectives of those who received and provided it.

IPA illuminated how experiences of participants, such as their use of culture and beliefs, impacted upon parenting and treatment. From a critical social work perspective this creates a new and novel knowledge base, which may be used to inform parenting and treatment of adolescent AN. Understanding the meaning of these experiences provides opportunities for further interpretation of the findings that can be illustrated to a broader audience of researchers and clinicians interested in cultural domains of recovery in adolescent AN.
9.4. Three key findings

9.4.1. Parents value being in tune with clinicians, and an effective therapeutic relationship enhances their parenting

In considering processes that optimise parents’ experiences of treatment, parents consistently commented on the quality of their relationship with the clinician as foundational to enhancing interventions in treatment and reducing their sense of isolation in parenting. Parents’ connection with clinicians was dependent on their sense of the clinicians’ appreciation for their actual lived experiences. Irrespective of the type of family-based treatment received, or the actual outcome of treatment, parents wanted clinicians to have a greater connection to the lived experiences of parents, such as an overt and sincere appreciation for the context in which they parent, and an understanding of any marginalisation that may occur as a result of seeking help. Clinicians’ sensitivity to parents’ lived experiences signified to parents that clinicians understood the emotional costs of undertaking specific “challenges” in treatment and reassured them that the expectations placed upon them did not exceed their ability. As a result, parents who felt more attuned to their clinician reported a greater degree of uptake of responsibilities negotiated in sessions, as well as confidence to transfer concepts discussed in therapy to the home environment. This is important to understand in light of the studies discussed in the literature review that reveal high levels of distress in carers of those with AN (Haigh & Treasure, 2003; Zabala et al., 2009; Ma 2010). Moderating the distress of parents is therefore of critical importance if the family is to be engaged in treatment for adolescent AN. Perceived clinicians’ appreciation of the emotional burden of mounting challenges to AN at home, and a sense clinicians were matching specific challenges to ability, gave parents hope and confidence in their capacity to reclaim areas of parenting, such as re-nourishing their child or dealing with emotional outbursts.
To make sense of experiences within the therapeutic relationship, it is important to appreciate the subjective contexts of parents and clinicians that may influence actions and behaviour in the treatment setting. Fook (2012, p.33) refers to this as the concept of contextuality, “understanding how experiences, ideas and practices are very much an artefact of the context in which they are developed”. The experiences which parents brought to treatment, combined with how clinicians are trained as mental health practitioners to treat, created either convergent or divergent relational experiences. Firstly, parents brought their family to a mental health treatment setting. Parents had to contend with the voice of their inner critic which held them responsible for failing to feed their child, as well as the voice of others, who misunderstood experiences of parenting a child with AN. The stigma, shame and guilt of parents for having a child with AN was the background noise that they attempted to conceal, as they sought help. The private domain of their world became exposed to the public sphere where they felt open to potential judgement and criticism, in seeking help for an illness they could not address by themselves. Clinicians came to sessions with knowledge sourced from: treatment manuals for adolescent AN; previous family-based work treating adolescent AN; clinical supervision; experiences shared by colleagues; professional practice codes and standards; and an understanding of how to deliver treatment in a mental health service. These contextual factors create a strong power dynamic between the parent and clinician.

The degree to which clinicians addressed this dynamic and connected with the lived experiences of parents, at the outset of the therapeutic relationship, was a determinant in overall treatment experiences for parents. Parents experienced divergent relational experiences with clinicians’, describing them as “cold” and “remote”, when clinicians did not attend to power differentials in the therapeutic relationship. Examples provided were parents’ perception of a superior tone of the voice of the clinician in treatment, and instances where clinicians seemed disinterested in acknowledging parents’ previous encounters with health professionals and how such experiences translated into the current experience of seeking help. Alternatively, convergent relational treatment experiences, described by parents as being “supportive” and “helpful”
occurred when the clinician acknowledged the lived experience of parents, reflected upon those experiences with parents, and integrated the parent into treatment processes. An example of this was provided by one parent who spoke of their clinician being approachable and willing to “come alongside” her to work together on problems rather than adopt an expert stance to the issues at hand. In fact, the amount of time and space clinicians spent on blending the experiences of themselves and parents, by listening, not just assessing, throughout the relationship, helped treatment to have meaning for parents because it was “situated in the lived experience” (Bland et al., 2009, p.22).

The overall narrative about parental experiences of treatment was based largely on their interactions with the clinician. Their sense of how they were perceived, and related to, as either another family with AN, or a family in their own right seeking help with a challenging illness, was a key factor in the way they described their experiences of treatment. The parents’ and CAMHS’s clinicians’ interface rested outside of all parents’ previous experiences of interactions with health professionals. Parents had to create a new narrative for an unrecognisable and foreign parenting experience. Most parents had taken their child to see a dietitian or a general practitioner but no parent had previously experienced the formal mental health setting; a place that signified they were dealing with an illness affecting both the body and the mind. Furthermore, parents were realising they were dealing with a life-threatening mental illness that had dangerously re-authored their interactions with their child. In this unfamiliar and confusing context, parents first had to make sense of seeking help in the highly stigmatised context of mental health, through narratives they developed with the clinician, before they could embrace concepts of care. Parents’ concerns and orientation to mental health services were pooled with clinicians’ dialogue regarding mental health risk assessment; focus on immediate physical symptom reduction, and ongoing notions of management. Opportunities for an attuned narrative with parents depended on clinicians’ ability to empathically listen, with the intention of understanding the parents’ perspective, and integrating these experiences into current clinical formulations. Clinicians’ assuming more responsibility for being in tune with
parents was an approach aimed at taking the pressure off parents so they could cope with their
tasks of helping with their child’s recovery.

Parents’ narratives about treatment experiences were also influenced by clinicians’ professional
discourse in the treatment setting. Bland and colleagues (2009) suggest that professionals in
mental health services often assess and treat consumers against diagnostic criteria, and that this
can form the basis of dialogue in treatment settings between consumers and clinicians,
particularly where a sense of powerlessness prevails in the person(s) seeking help. In seeking
treatment, most parents came to CAMHS in a disempowered state and most clinicians were
versed in an approach to treatment that commenced with a focus on empowering parents to
refeed their child. The propensity for dialogue to focus solely on symptom reduction
(refeeding), to swiftly reverse the course of a life threatening disorder, is understandable and
initially appreciated by parents. However, the findings of the present study suggest continued
patterns of dialogue that solely focused on parents’ ability to refeed, were particularly unhelpful
and disempowering for parents who struggled with this task. This discourse was more evident
with treatment closely aligned to Maudsley.

Understanding how easy it is for interactions to sideline parental engagement needs further
examination. Bland et al. (2009) suggests that how we talk about our experiences as either
consumers or practitioners in mental health, has the potential to value discourses above
experiences, in circumstances where interactions between consumers and clinicians ensue over
symptomatology. This thesis suggests that parental engagement was compromised by continued
discussions about tasks associated with weight restoration at the expense of additionally
exploring parents’ other challenges and experiences. This tended to increase the sense of
isolation for parents and reduce their sense of agency. Evidence of this was found in parents’
reflections on what it was like for them ‘reporting’ back each week to clinicians about their
success or ‘failure’ in meeting tasks and challenges set in treatment, against illness driven
behaviour. Interactions in treatment were experienced as a ‘test’, that was perceived to be awarded a pass or fail by the clinician.

Parents’ sense of agency in parenting and treatment was more obvious in the group of parents who undertook Maudsley treatment. This is consistent with the findings of Krautter and Lock (2004) presented in the literature review. While Maudsley parents felt more potent than non-Maudsley parents in relation to re-nourishing their child, they tended to experience more power imbalances in the therapeutic relationship with clinicians about treatment. A possible explanation for this is that in Maudsley sessions, continued discussion about symptom reduction may have privileged dialogue and practices associated with manualised treatment, over transformative processes associated with self-reflection and interaction about other familial experiences that impact upon parenting. Treatment experiences may have been constructed and transacted in a way where parent’s and clinician’s dialogue occurred through the lens of the clinician’s understanding of the parent’s circumstances. This may have come at the expense of talking about a parent’s lived experiences. Notwithstanding the imperative to manage the life threatening aspects of care for AN sufferers, a purely scientific discourse and approach to symptom reduction and treatment has the potential to “strip away” the identity of the family, and their agency, in the recovery process, where “the person is lost” (Bland et al., 2009, p.25). Continued dialogue based on scientific discourse also provides a possible explanation for some parents’ sense of their child not being visible in treatment. They felt their child was viewed as a set of symptoms, rather than who they were as an individual with AN in their lives. Dialogue in treatment shaped by scientific discourse may additionally have influenced the clinician’s manner, which explains parents’ accounts of clinicians behaving in a mechanistic way. The style of Maudsley clinicians was often perceived to be sourced from a “textbook”, rather than situated in the context of the family’s particular experience.

Within the field of mental health, Bland et al. (2009, p.41) suggest that research evidence from qualitative studies “are less highly valued” than RCTs, that are classified as constituting the
strongest evidence for efficacy. Interventions therefore with qualitative indicators, such as the experience of caring for someone with AN, may be considered less useful to mental health clinicians than interventions clearly defined through RCTs. CAMHS practise knowledge for adolescent AN was predominantly sourced from research using experimental designs which thus predominantly support dialogue and practices associated with manualised Maudsley. A focus on empirical knowledge may have resulted in clinical practice gaps, where clinicians see little value in connecting with parent’s lived experiences to assist in recovery from adolescent AN. Fook (2012, p.17) contends that knowledge for use in practice should be more than “a reflection of empirical knowledge”, as it is “actively constructed by those studying it”.

Therefore, CAMHS clinicians driven by predominantly pragmatic designs, with little reflection, may miss uniqueness and contextual factors in favour of processes that primarily support ‘scientific’ discourse. It is also possible that as research to understand the lived experiences of caring for someone with AN is relatively new, qualitative findings are in the early stages of contributing to knowledge in this clinical area (McMaster et al., 2004; Tierney, 2005; Highe et al., 2005; Hillege et al., 2006; Honey et al., 2008; Zabala, MacDonald, & Treasure, 2009; Ma, 2011). CAMHS clinicians are perhaps yet to formulate how best to integrate this newer knowledge into their practice, and consider the skills and values needed to engage with the human condition behind emotional or psychological symptoms.

In this study there were clear associations between parents’ desires for their circumstances to be understood, the quality of the therapeutic alliance, and parents’ views on processes contributing to treatment outcomes. However, there is little in the literature to support these findings, with only one empirical study of adolescents with AN receiving family-based treatment which examined whether the therapeutic alliance with parents had any effect in treatment outcomes (Pereira et al., 2006). Although Pereira and colleagues’ research indicated that behavioural change in the child, rather than any alliance, predicted outcome in treatment, greater parental alliance early in treatment was found to improve treatment retention. The finding is important for this study because many parents experienced health professionals as dismissive or unhelpful
prior to attending CAMHS, creating an anxiety about attending treatment. Helping parents overcome such concerns can therefore be central to processes that support continued exposure to treatment for adolescents with AN, especially when the child is resistant to treatment and attendance is dependent on parents’ willingness to engage (Hoste et al. 2007).

The association between the therapeutic relationship and perceived treatment outcomes was complex. In the survey, regardless of the type of family-based therapy received, most parents rated the therapeutic relationship between the parent and clinician as a component of effective treatment for their child (Table 6.7). However in the semi-structured interviews, parents stated that the therapeutic relationship was only effective if it was based on empathy and compassion. Whilst most parent respondents in the survey rated a good relationship with the clinician as crucial in achieving effective outcomes, the interviews revealed that some parents did not actually experience such a positive relationship.

While parents were generally satisfied with treatment outcomes, they were less satisfied with their relationship with clinicians. Clinicians, however, generally thought parents both valued them and felt supported by them. In considering the desire of parents to be understood by clinicians, a possible explanation for the difference between parents’ and clinicians’ perception of their alliance may be associated with how each conceived the meaning of parenting the adolescent with AN. Divergent views between parents and clinicians about what parenting adolescent AN meant was revealed in the survey data which showed this was generally perceived by parents and clinicians as a journey characterised by fear, despair and frustration. In the open ended responses, parents tended to describe their experiences as a test of emotional and physical endurance, whereas clinicians conceptualised parenting as a series of challenges posed by AN. The differences in conceptualised meanings could have influenced interactions between parents and clinicians in sessions. For instance, as clinicians’ conceptualisations of helpful interactions with parents were based on targeting challenges in parenting, interactions with parents were likely to focus on skills acquisition or attempts to restimulate good judgment in
parenting. Parents wanted acknowledgement of their pain and circumstances through empathic interactions in addition to knowledge acquisition, so that knowledge in treatment could be linked and contextualised to actual experiences. So, although both parents and clinicians rated the relationship between parent and clinician as an either ‘very’ or ‘reasonably important’ aspect of treatment (Table 6.6), the way they viewed the meanings attached to the parent-child dyad potentially impacted upon interactions in treatment. Evidence of what is valued in interactions is seen in responses to the open questions in the survey; only parents valued support and reassurance provided by clinicians (Tables 6.10 and 6.11), whereas clinicians tended to focus on attainment of skill to build resilience in parents. As discussed in the literature review, given that the role of the clinician in empirically based treatment for AN is to implement behavioural approaches to recovery (Selvini-Palazzoli, Boscolo, Cecchin, & Prata, 1980; Dare, 1985; Lock et al., 2001; Eisler, 2005), it is easy to see how clinicians tend to adopt the roles of teacher or coach. This approach may however overlook the meaningful subjective context of parenting a child with AN if there is inadequate clinical supervision to encourage reflective processes or training for clinicians in the use of Maudsley.

The different perspectives on the nature of the therapeutic relationship were further delineated in the semi-structured interviews. Many parents’ described the clinician’s stance as remote or detached, when using Maudsley therapy, in which parents were expected to undertake tasks and challenges to help their child recover. Some parents experienced a lack of connection with the clinician in Maudsley, which invoked a lack of trust in the clinician’s assessment of the translation of treatment into the context of their lives. It is possible, however, that the clinician’s approach may be more a reflection of a lack of skill in providing family therapy, than the fault of the Maudsley model. It is also possible that some clinicians have over identified with one of the guiding practices in early stages of Maudsley treatment, where parents are placed in charge of refeeding to reversing the course of a life-threatening illness, at the expense of acknowledging the emotional struggles involved in ‘taking on’ AN. While consistent with the clinicians’ stance in Phase 1 of manualised Maudsley, a failure to offset the notion of
authoritative parenting with genuine concerns for parental context could result in a lack of empathy with the parents about how they will be perceived by their child when refeeding. Finding the balance in sessions between clinicians urging parents to demonstrate their claim on authority over AN whilst simultaneously signifying to parents compassion for their pain in undertaking this role, is referred to in manualised Maudsley as the “therapeutic paradox” (Lock et al., 2001, p.47). A failure to recognise and convey the importance of this complex balance in treatment seemed to create a distance between clinicians’ perceptions of a helpful alliance with parents, and the realities of parents’ experiences. Furthermore, too much focus on one aspect of treatment, such as reclaiming parental authority, together with the parents’ sense they no longer knew the child they were attempting to parent, made the quest of skills attainment or reconnection with prior parenting skills, an incongruous task.

Attunement in the therapeutic relationship was also affected by how parents perceived the style of questioning used in the family-based treatment. For some parents, the use of circular questions ‘helped them think outside the square’, where for others it was experienced as critical and demeaning. Clinicians reported the use of circular questions in all forms of family treatment provided. As discussed in the literature review, this is consistent with techniques employed to help parents challenge processes in the family that may maintain AN (Selvini-Palazzoli, Boscolo, Cecchin, & Prata, 1980; Eisler, 2005). The interviews revealed that parents who had a partner with whom they could problem-solve, or those who were accustomed to independent problem solving, were more likely to experience circular questions in a helpful and supportive manner. In situations where parents and clinicians established a good relationship, parents were more open to reflection through circular questions and to tackling the challenges posed by the treating clinician. Parents who experienced circular questions as demeaning or critical were more likely to have had experience with Maudsley family therapy, and felt clinicians were relating to them in a manner prescribed by transcript. In these instances, parents did not feel connected with the therapists because they felt their own unique circumstances had been
overlooked in favour of a ‘one size fits all’ approach to treatment, applied to all families that presented with AN.

The quality of the therapeutic relationship was more important for single parents, or parents who attended treatment by themselves, than where both parents attended. Parents attending treatment by themselves sought more from the therapist in terms of empathy, direction and guidance. Although most of the parents who participated in the study were from two parent households, (Table 6.1), most attended treatment with their child, but without a partner. Many of these parents expressed a desire for more time and connection with the clinicians, to help think about ways of managing and coping because they were socially isolated and unsupported in providing care in the home. It is interesting to note that the need for additional support by clinicians to single parent families is referred to in manualised Maudsley. Maudsley researchers suggest single parent families may require longer in treatment, because they lack the resources available to two parent families to share responsibility and burden of care (Lock et al., 2005).

The findings from the current study suggests that families where only one parent attends treatment also need extra support from health services, because either the attending parent acts as the primary source of support for the child or the other parent is less active in the recovery process.

Many clinicians were somewhat wary of providing more support to parents, as they were concerned that they may be ‘over involved’ with parents. This perception is largely influenced by their interpretation of the Maudsley ideal of parents as experts in their child’s life. Providing additional support was perceived by clinicians as undermining the skill base and integrity of the parent’s knowledge of their child. This appeared to be an overvaluing, or perhaps incorrect interpretation, of a Maudsley principal at the expense of a thorough assessment of the needs of the attending parent. The addition of a comprehensive assessment of family functioning and need, prior to the commencement of family based treatment, is an enhancement of Maudsley suggested by Eisler (2005). It is also possible that those clinicians were unaware of the
additional comments in manualised Maudsley, suggesting single parents potentially require more support. For those parents attending treatment singly, greater empathy for their circumstances in management facilitated greater tolerance for challenges in treatment and broader thinking around managing AN at home.

Although divergence in presumptions of the therapeutic relationship between parents and clinician were more evident in Maudsley than non-Maudsley treatment, divergence was present across both forms of family-based treatment. Applying Fook’s (2012) critical postmodern perspective, it could be argued that the clinicians applying treatment constructed their sense of what being a clinician means by reference to the dominant perspective of manualised Maudsley, particularly in Phase 1 where the therapist “reinvigorates parental roles in the family system” by adopting a serious and concerned approach (Lock et al., 2001, p.2). Given the serious nature of the illness and the high levels of anxiety and desperation exhibited by parents in their search for assistance, the pressure for clinicians to search for certainty themselves through the lens of scientific objectivity is evident. This however, seems to create a level of dissonance for clinicians, in working with parents who have no team at home with whom to unite against a persistent foe.

While some parents attending on their own found the knowledge gained through the clinician acting as a teacher or objective observer extremely useful, upon reflection in interview, the experience of the clinicians continuing to act in this role, particularly when their child was self-harming, was perceived to be alienating. It could be argued that CAMHS’s clinicians tend to adopt a top-down, expert approach to treatment where they attempt to turn their sense of ‘objective’ knowledge into practice, rather than adopt a stance based on their reflection of the current circumstances and context of the parent (Fook 2012). Apart from simply identifying with a scientific paradigm for practice, another possible explanation for why some clinicians operate in this manner is that it is a source of self-protection in treatment. This factor arose in the clinician interviews. Clinicians found it extremely difficult to place themselves in the shoes
of parents in the daily experiences of parenting an adolescent with AN. As one clinician said, they just “couldn’t go there”, (meaning fully empathise), because it was too painful. The ultimate need for self-protection arises from the objective potential for death of a child. Despite the ability to understand barriers to the therapeutic alliance from the perspective of both parents and clinicians, there is clearly a great deal of reflection and processing required to reconcile these issues.

Attunement was observed when parents perceived clinicians sharing their thoughts and feelings more openly with them in sessions. In these circumstances, clinicians demonstrated to parents a rejection of dichotomous thinking (‘us’ therapists treating ‘them’ parents). This type of practice is consistent with concepts associated with a critical, reflective approach to knowledge attainment in social work practice (Fook, 2012). Only a few clinicians espoused practising in this manner.

9.4.2. Clinicians integrate evidence-based treatments with clinical decision making processes

The CAMHS clinicians in this study made adaptations or additions to Maudsley, as has been observed in Australia (Rhodes et al., 2008), the USA (Le Grange & Lock, 2007; Lock et al., 2010) and in the UK (Eisler, 2005). While some important concepts of manualised Maudsley are retained, phases of treatment or interventions within phases are adjusted to better suit the needs or capacity of the parents attending treatment. Manualised Maudsley was viewed by these participants as a framework for therapy that gave clinicians and parents a sense of direction in treatment and a degree of predictability regarding the nature and style of work to be undertaken, rather than adhering to a strict protocol. Reconstructing and conceiving manualised Maudsley as a structure or framework, rather than a manualised approach to treating adolescent AN, seemed to give clinicians ‘permission’ to integrate their own clinical judgement into treatment and to adapt interventions or phases of manualised Maudsley. Adaptions to treatment still utilised the underlying principles and ideals of manualised Maudsley, in particular, the use of parents to
help re-nourish their child, maintaining the basis of a ‘Maudsley-type’ approach to treatment. Regardless of Maudsley training received (Table 6.3), most CAMHS’s clinicians championed a ‘Maudsley-type’ approach as the treatment of choice for working with families who have adolescents with AN. However, there were two notable exceptions: Aboriginal families and families where abuse occurs between parental, and parent-child, relationships.

Conceiving manualised Maudsley as a guide rather than a protocol is aligned with views on knowledge creation from a postmodern critical social work practice perspective, in contrast with positivistic practice that supports observance of standardised interventions. Postmodern critical social work thinking does not automatically value knowledge created through ‘scientific’ research at the expense of learning from reflective processes and experiences in practice. Rather, it acknowledges the need for empirical knowledge to help us understand the way dominant discourses shape practices, alongside learning arising from self-reflection of practical experiences, that challenge the manner in which dominant discourses shape lives (Fook, 2012). If CAMHS’s clinicians operated solely from a modernist stance, legitimate knowledge to be utilised in practice would be based on scientific research. This would support adherence to manualised Maudsley in the absence of a scientific evidence base for other approaches, with little, if any, adjustment.

Although most of the clinicians in this study were not social workers, in viewing manualised Maudsley instead as a guide for practice, CAMHS’s clinicians seem to be embracing an approach that rests beyond a puristic perspective, in the manner in which evidence-based social work practice models have evolved. Gray et al. (2009, p.51) suggest that while a positivist puristic perspective to evidence-based practice “retains strong position in social work”, evidence-based social work has advanced to meet the demands of work with complex human experiences. Adherence to practices supported by experimental designs in controlled environments may not always be applicable to the context in which they are to be translated.
... while the internal validity of the experiment under controlled conditions may be strong, the external validity needed to apply the findings to other contexts can be weak (Gray et al., 2009 p.55)

By integrating professional judgement into practice, CAMHS’s clinicians seemingly acknowledge the limitations in applying all interventions or phases in manualised Maudsley, and allow their clinical judgement to take treatment in different directions in response to contextual factors. This suggests a pragmatic approach to evidence-based practice proposed by Plath (2006), which recognises that while the findings of RCTs can contribute relevant information, they are context dependent and may not provide the most relevant information for a particular practice context. Plath’s approach acknowledges a need to critically reflect upon and evaluate knowledge gained from a combination of quantitative and qualitative methods, to ensure that professional judgement is contextualised by the best available evidence. While CAMHS’s clinicians reported valuing qualitative contributions to knowledge attainment in working with adolescent AN, integrating clinical judgement with manualised treatment suggests a questioning of the transferability of knowledge purely sourced from experimental designs for this illness, and an appreciation of the need for contextually driven practice.

Although all clinicians interviewed expressed an appreciation for multiple discourses in treatment options, their opinions varied about the level of clinical judgement that could be integrated into manualised Maudsley. Maudsley clinicians tended to start with manualised Maudsley, integrating clinical decision-making processes into manualised treatment. These clinicians adapted Maudsley by undertaking other interventions in preparation for Phase 1 of Maudsley or undertaking other forms of family therapy with a focus on principles and interventions used in manualised Maudsley; much the same as Le Grange and Lock (2007). Non-Maudsley clinicians’ decision-making hinged on the degree to which manualised Maudsley was integrated into their treatment. These clinicians commenced with clinical judgement integrating concepts from manualised Maudsley, to support that process. While non-
Maudsley clinicians adopted most of the principles of manualised Maudsley, foundational principles in Maudsley such as parental control over refeeding, were rejected if the clinician felt it interfered with engagement in treatment. No CAMHS’s clinician had a singular approach to treating adolescent AN.

Adapting treatment caused some confusion among clinicians in regard to what constituted Maudsley-type treatment. It also raises questions about how much of Maudsley was provided or used in treatment, in order to be regarded as Maudsley-type treatment. Yet parents who underwent Maudsley treatment had a much clearer sense that the components of treatment had been effective than parents who had other family treatment (Table 6.7). In interviews, these parents were also more definite about the type of treatment received than non-Maudsley parents. Non-Maudsley parents were able to identify important aspects of treatment, but were not sure about how to name their treatment. Perhaps one way to describe the type of treatment most parents received is contextually oriented family-based treatment, where clinicians draw on a range of skills and knowledge obtained from research and reflection.

One aspect of treatment that clinicians consistently upheld was an initial focus on re-nourishment. Strategies to help parents re-nourish their child varied and were dependent on assessed parental need or capacity. Given the physical risks associated with starvation, there was a commitment amongst most clinicians working with non-Aboriginal families to commence treatment following the ideals and sometimes the interventions in Phase 1 of Maudsley treatment. This involved inviting immediate family members to attend weekly sessions aimed at empowering parents to take control of re-nourishing their child, with focus of treatment on a return to healthy weight. Clinicians described different approaches to family participation during this phase, with some seeing families all together, (the child, siblings and parents) whereas other clinicians only saw the child and parents, and siblings did not attend. All clinicians expressed commitment to a focus on empowering parents, or people responsible for the child, to take some control over the weight restoration process to minimise the risk of death.
This constituted an initial focus on “food as medicine” occurring in all instances of treatment. All of the adaptations to Maudsley and other forms of family therapy occurred outside of the “food as medicine” principle.

In the survey, each of the Maudsley principles was found to be positively regarded by parents as important and effective components of treatment (Tables 6.4 & 6.7). This is consistent with Krautter and Lock’s (2004) findings on parental satisfaction with manualised Maudsley. Generally, the current study has found congruence between the views of parents and those of clinicians regarding the important elements of treatment, reinforcing the need for aspects of manualised Maudsley. The survey data in Table 6.7 suggests parents who received Maudsley family therapy reported higher levels of perceived effectiveness with all aspects of treatment listed, than did those who received non-Maudsley family therapy. Interestingly, interviews with one parent who identified as non-Maudsley in the survey had in fact experienced Maudsley, rejected it and sought treatment elsewhere. This parent was dissatisfied both with Maudsley treatment and their relationship with the clinician.

Despite clinicians adopting a broader approach to treatment than that prescribed by manualised Maudsley, those who identified themselves as a Maudsley clinician expressed a need to rationalise any clinical decision making in treatment that caused a deviation from interventions prescribed in the manual. A possible explanation for this could be that Maudsley clinicians believe that the only legitimate knowledge for practice is that generated through scientific research. Therefore, they experience more internal conflict over a movement away from evidence-based practice, where RCTs support adherence to Maudsley. Bland et al. (2009, p. 41) suggests that, while principles of evidence-based practice (EBP), based on positivist paradigms, are more evident in psychology and psychiatry, “all mental health disciplines have adopted the language of EBP in describing their practice”. This makes it difficult for all CAMHS’s clinicians to talk about reflective or reflexive practices in a way that values evidence related to
psycho-social complexity, particularly in treating a life threatening illness such as adolescent AN, where ‘effective’ treatment has been determined through RCTs.

Alternatively, the disquiet expressed by clinicians making shifts from Maudsley may also be a reflection of clinicians practising within the current socio-political context, where there is a close connection between EBP and the development of neo-liberalism and new managerialism (Pease, 2009). Pease (2009) argues that this context for practice promotes interventions that meet the new managerialist agenda, where clinicians are encouraged to specify treatment goals, within an objective evidence-based paradigm, in order to provide ‘effective’ treatment. With the growing ‘scientific’ evidence for manualised Maudsley as standard treatment for adolescent AN, supported by Maudsley researchers such as Krautter and Lock (2004), Lock et al. (2005) and Lock (2010), Maudsley clinicians feel uncertainty in deviating from this paradigm. Consequently, most Maudsley clinicians tended to seek evidence of diminished capacity in parents prior to adapting the treatment model, whereas all non-Maudsley clinicians and some other Maudsley clinicians altered treatment paths upon observing the family struggle with challenges or the style of questioning in treatment. Interestingly, many non-Maudsley clinicians commented that the approach taken with adolescent AN differed from all other forms of interventions in CAMHS, being regarded as ‘treatment-driven’ practice, as opposed to ‘client-centred’ practice. Many of these clinicians questioned why treatment for adolescent AN is necessarily based on Maudsley and were sceptical of the evidence base. This critique is certainly borne out in a recent Cochrane Review of family therapy for AN, that suggests despite the growing evidence for Maudsley, the evidence is still weak (Fisher et al., 2010).

Perhaps the clearest example of clinical judgement overriding adherence to manualised Maudsley occurred in families where domestic violence or child abuse was identified. In Phase 1 of treatment, a commitment is made by clinicians to address weight restoration using principles of Maudsley, where parents are viewed as “competent agents for refeeding their starved offspring” (Lock & Le Grange, 2001, p.27). Realisations of abusive patterns of relating
in the family require a review of the treatment plan. Maudsley clinicians gave examples in interviews of how the application of manualised Maudsley principles reinforced parental misuse of power where an abusive parent used intimidating tactics to force their child to eat, and dominated relationships within the household. As all immediate family members attend treatment, children and spouses are subjected to covert domination in the treatment setting, without the knowledge of the clinician, if violence is not identified.

The failure to identify abuse in the family preceding commencement of treatment occurred because some Maudsley clinicians commenced treatment prior to completion of a full assessment of family dynamics. This could have occurred because Maudsley protocol states obtaining only “preliminary information about how the family functions” in Session 1 (Lock et al., 2001, P.46; Lock & Le Grange, 2013, p.44). Once clinicians identified violence in the home, they ceased Maudsley, and undertook either individual or separated family therapy. Experiences such as these resulted in clinicians incorporating more clinical decision making into family-based treatment, in particular, delaying commencement of AN treatment pending a full assessment of family dynamics. This approach is more consistent with Eisler’s (2005) adaptions to family based treatment for adolescent AN, where Phase 1 is characterised by a thorough assessment of family dynamics and establishment of a therapeutic contract, prior to undertaking family-based therapy.

Clinicians who work with Aboriginal families thought manualised Maudsley was counter-productive for effective engagement with those clients, and that the sequencing of treatment procedures was inadequate in meeting the diverse needs of Aboriginal families. Maudsley therapy was viewed as a white Western paradigm that lacked cultural integrity for use with Aboriginal families. The Maudsley structure in weekly sessions and dominant ideology, particularly related to family configuration, was at odds with respectful practice with Aboriginal families. Family work with Aboriginal families required a momentum, symbiotic in nature, rather than the linear structure of manualised Maudsley. No modification or adaption to the
Maudsley model was viewed as sufficient, given the empirical base of Maudsley in white scientific paradigms. Alternative approaches to treatment were necessary in order to keep Aboriginal families engaged with the service.

9.4.3. **Treatment is enhanced when parents’ cultural and spiritual value systems are activated.**

Although adolescent AN has been constructed as a middle to upper class female Caucasian phenomenon treated through Western paradigms, attention to the influence of socio-cultural factors that impact upon care and treatment are gaining momentum in non-Western research (Ma, 2002, 2009; Hadin, 2003; Chan & Ma, 2004; Hoek, et al. 2005). Evident in findings from research conducted in non-Western cultures, is a questioning of some of the tenets of Western oriented family-based treatment because they either fail to capitalise on the strengths of a family’s cultural or spiritual value system to assist in the recovery process, or do not account for the influence of the socio-cultural environment in the development and trajectory of AN. Much of this evidence is sourced through qualitative enquiry, across cultural contexts, whilst much of the evidence that has guided practice in family-based treatment of adolescent AN has largely been determined though experimental designs with predominantly Caucasian participants (Russell et al., 1987; Le Grange et al., 1992; Eisler et al., 1997; Eisler et al., 2000; Geist et al., 2000; Lock et al., 2005; Lock et al., 2006; Lock et al., 2010; Robin et al., 1994; Robin et al., 1995; Robin et al., 1999; Eisler et al., 2007; Gowers et al., 2007; Gowers et al., 2010).

The current study suggests that when familial culture and spiritual value systems were activated, recovery from AN was enhanced. These systems helped parents manage the strong emotional responses associated with parenting their adolescent with AN, and provided an alternate point of reference for ideas in managing challenging behaviours. In the semi-structured interviews, all parents stated their familial cultural and spiritual beliefs helped them to parent their child with AN. Clinicians, in contrast, only addressed cultural or spiritual values in treatment if families were Aboriginal, or had an identified cultural point of reference beyond Anglo-Australian
culture. In those cases, values and beliefs of Western origin were thus overlooked by clinicians as useful in treatment and were treated as a subjugated form of knowledge utilised by Anglo-Australian parents.

Irrespective of country of birth, parents drew on their spiritual values to help manage their emotions through challenging times, and to contest behaviours in their child that were clearly associated with AN. This was particularly useful for parents when their child was aggressive or oppositional towards them, or in situations where they felt intense emotions such as guilt, anger or shame. One couple, for example, spoke of challenging their child’s food-throwing by reminding their child of the family’s religious teachings about aggressive behaviour. This re-connected their child with her former sense of self, while aligning the family with a powerful point of reference that all family members respected. The alliance with and faith in spiritual values, provided a greater consensus for the parents’ opinion and behaviour, that not only anchored and reinforced the parents’ sense of what needed to happen to help their child, it additionally gave them a sense that had a point of reference beyond the illness and its treatment. For some parents, galvanizing their spiritual value system additionally gave them internal fortitude and guidance to respond in an empathic way to their child, and helped maintain a relationship frequently challenged by disruption caused by the illness.

Anglo-Australian parents also spoke of the strength they sourced through a belief in a Christian God being a forgiving entity. In these instances, parents sought forgiveness within themselves in order to manage their sense of guilt in having a child with AN. With the help of the clinician parents realised that guilt was a self-focused emotion that drove unhelpful behaviours that could potentially maintain the life of the illness. Appreciating and transferring forgiveness from a Christian God, to themselves, freed parents from feelings of guilt and helped them to focus on their child. There is a gap in the literature related to parent’s use of spirituality in helping their child recover. This presents new possibilities for knowledge creation in treating AN.
Other Anglo-Australian parents referred to values from their family of origin that helped them to undertake tasks such as re-nourishing their child. A long held family of origin expectation that all food provided on a plate was to be eaten helped parents in some families to maintain a position of no negotiation at meal times when the child with AN sought to do so. Although it’s difficult to be definitive about the influences of these cultural factors, with most of the participants in the 40-49 age bracket (Table 6.1), they are likely to have been brought up by a generation of parents which valued the tenant that parent’s know best and was less effected by current trends which sees parents negotiate more with children at meal times (Coveney, 2008).

It seems that some of the parents interviewed may have been subject to parenting values in their childhood, where decisions about food were determined by the parent and followed by the child. For some parents, maintaining this value in current parenting helped normalise the requirement of eating what was provided, because it had always been a part of their family of origin, and as such, less disputed by their child. Other parents in this study, however, struggled with the notion of assuming all decision making and control over their child’s food intake as a part of treatment. This may well be a sign of how parents’ relationships with their children have been influenced by the construction of a ‘good’ parent as a negotiator Coveney (2008).

Coveney (2008) suggests that over the past 60 years, the way in which parents feed their children is intertwined with the emergence of a view of children as citizens who have rights and autonomy. Alongside this is the view that knowledge on how best to feed a child is reliant on expert opinion. In this regard, children have emerged as citizens who have the right to be heard and parents are not considered to be the guardians of all knowledge related to their child’s wellbeing. These views have resulted in a current discourse of ‘good’ parenting that’s determined on the basis of the parents’ abilities to integrate expert opinion about what should be eaten, into negotiations with their child about what they will consume. It is possible that the parents who rejected the idea of assuming total control of refeeding may have been accustomed to negotiating with their child up until treatment, or had experienced ‘pre-War’ discourse on parenting and made a decision to discard it in favour of prevailing values associated with
parenting. It is interesting to note that while parental control over decision making fits more closely with ‘pre-War’ discourse on parenting; it is closely aligned with new Millennium treatment, Phase 1 of Maudsley. A clash between the values in treatment with the current discourse on parenting could account for some parents’ criticism of Maudsley treatment, in particular the family meal or the process of the clinician placing parents in a position of authority in sessions in front of their child. Maudsley treatment and current parenting discourse are more aligned to Phase 2 of manualised Maudsley titled “Negotiations for a new pattern of relationships” (Lock et al., 2001, p.29) and in the latest edition as “Transitioning control of eating back to the adolescent”(Lock & Le Grange, 2013, p.32). It is therefore important to reflect upon current discourse of parenting and treatment expectations because it is possible that it impacts on the degree of congruence between parent and clinician regarding each other’s responsibilities.

With the exception of clinicians working with Aboriginal families, it was not until cultural issues were identified by clinicians as factors which prolong adolescent AN, in families of non-Western origin, that clinicians integrated family culture and/or spirituality into the treatment process. This was particularly evident in families where food preparation and serving were reported by parents as the cultural responsibility of the mother, within the family unit. Clinicians cited instances where some mothers from non-Western cultures experienced rejection from their child, because their child refused to eat, and it was this sense of rejection that stood in the way of their ability to re-nourish their child. In these instances clinicians commented on a need to respectfully engage fathers to help their partner re-nourish their child. This entailed finding acceptable ways in which fathers could transcend cultural norms without compromising cultural integrity. To do this, clinicians spent time trying to understand the cultural parameters and responsibilities within the household, and obtained mutual agreement from both parents to experiment with tasks that sought not to compromise either parent’s sense of cultural role responsibility. Domains of cultural responsibility were preserved, for example, by mothers continuing to prepare and serve meals while fathers distracted their child during meal
preparation and eating and/or acted as mediator between mother and daughter in times of conflict. This facilitated re-nourishment and allowed parents to unite against illness-driven behaviours while observing cultural norms.

The only Aboriginal clinician in this study, and non-Aboriginal clinicians who worked with Aboriginal families, commenced treatment with an acknowledgement that a family’s social and cultural context was an integral component of treatment. The approach of these clinicians is an example of what Fook (2012) describes as practice from a critical postmodern perspective. Perhaps the only aspect of Maudsley that was met with approval by clinicians working with Aboriginal families was utilising the resources within the family to facilitate re-nourishment. The configuration of family members called upon in Aboriginal families to assist in re-nourishment was somewhat different to that espoused in manualised Maudsley. For example, clinicians advised that while the adolescent with AN may live with their parents, in Aboriginal communities it may in fact be the child’s Aunt or Uncle who has responsibility for mental health care. Therefore, clinicians working with Aboriginal families reported in interviews they initially engaged Elders in the community to identify extended members of the family.

The immediate family is the dominant construction of the family constellation presented in Maudsley. This construct was viewed as a one-dimensional conceptualisation of family that did not account for multilayered obligations given to extended family members for mental health care in Aboriginal communities. Maudsley, being a treatment model derived in a white Western context, did not account for parental responsibilities beyond dominant notions of family configuration. Given the range of family relationships that may be involved in the young person’s care, the weekly appointments with all family members in a clinical setting recommended in Maudsley may not be possible or even valued by community members.

Clinicians working with Aboriginal families felt there was a socio-political context associated with causation that needed to be understood, in order to engage Aboriginal families in respectful
and meaningful treatment. These clinicians rejected Maudsley’s agnostic view of causation, and felt an understanding of the reasons behind a desire for thinness was crucial, in order to re-nourish the child within the cultural context. The Aboriginal clinician interviewed said that promoting the intake of traditional foods assisted in the re-nourishment and cultural identity of a young Aboriginal male.

While knowledge and theoretical understandings that appreciate the influence of the socio-political context and causation in treating AN are lacking in Western research paradigms, they do feature in knowledge for practice sourced from non-Western qualitative research. As discussed in the literature review, non-Western qualitative research in the treatment of AN in Hong Kong contends that recovery is linked to an understanding of the meaning of food refusal that is inextricably linked to causes located in the socio-political context (Chan & Ma, 2004). Chan and Ma (2004, p.185) suggest it is important for practitioners to understand the socio-political issues situated behind the cause of AN in a young person’s life. This understanding will help facilitate a path to meaningful recovery by “subtle and powerful societal norms, values and beliefs” that contextualise the meaning of self-starvation for some young people and their families. A reliance on dominant Western paradigms does not account for experiences of marginalised groups shaped by the socio-political context, nor does it provide the flexibility in accounting for experiences situated outside dominant ideals of beauty.

Working with Aboriginal families was seen by clinicians as requiring treatment approaches that blended critically reflective and reflexive methods (Fook 2002, 2004, 2012) with practice consistent with contextual research evidence (Chan & Ma, 2004; Ma & Lai, 2006). This requires a much broader approach to treatment in terms of: treatment setting; responsibilities given to family members; appreciating the potential influence of aetiology as opposed to an agnostic view suggested in Maudsley; and adjusting expectations regarding the frequency of attendance. From a critical social work perspective, it is important to note how different types of knowledge were generated by parents of Western and non-Western origin and by Aboriginal
and non-Aboriginal CAMHS’s clinicians, in relation to different cultural scenarios. Values and beliefs that helped families move forward were not seen as arising from a dominant paradigm; rather they emerged as a result of parents simply applying what felt right for them, based on their intrinsic value base, or by clinician enquiry about cultural and spiritual circumstances with no ‘scientific’ proof to direct practice. Adopting what seems to be an experimental approach to recovery, where knowledge is contextually based and mediated through subjective experiences, are characteristics of Fook’s (2012) critical postmodern perspective for social work practice.

### 9.5. Potential for and limitations of Maudsley

AN is associated with significant psychological comorbidities, physical complexities and psychosocial consequences that pose challenges in treatment (Hatch, et al., 2010). It is therefore important to select therapeutic interventions that have empirical support, such as Maudsley. Despite advances in treatment outcome research for Maudsley, CAMHS clinicians look for ways to improve its application in the clinical setting, through adaptations and enhancements. The reason clinicians gave for adapting the manualised treatment was that it is too rigid or inadequate for the complexities and variety amongst the families they treat. None of the parents in this research realised that they were receiving an enhancement of an empirically supported treatment. Parents receiving Maudsley-type treatment thought they received Maudsley family therapy. Both clinicians and parents expressed there was a benefit in a structured approach to treatment that commenced with an initial focus on refeeding where progress to recovery was realised through advancement of stages of therapy. These are clear benefits of Maudsley for both parents and clinicians.

Maudsley was found to be limited in relation to assessment at commencement of treatment. This was found to be inadequate in relation to screening for family violence and other forms of
oppressive behaviours in the family and in the lack of recognition of cultural and belief systems in which may impact on treatment and recovery. New knowledge in these areas was created through both parents reflecting on subjugated knowledge related to their use of values and beliefs in parenting and clinicians self-reflection on the body of knowledge created through scientific methods and its applicability to all CAMHS families that require treatment. These reflections recognised different ways of knowing how to move forward in parenting and treatment in addition to those used in Maudsley. The findings indicate that there is a need to refine and expand Maudsley to better suit the families treated in a general CAMHS team. It is also important that training and clinical supervision of clinicians are strengthened to ensure the benefits from essential components of Maudsley are not lost in any enhancement of the model.

9.6. Limitations of the study

Although care was taken to optimise the study’s design, a number of limitations are acknowledged. Firstly, there was no way of comprehensively identifying adolescents diagnosed with AN for the period of the study 2006-2009, because there was no database that reliably recorded this diagnosis for clients within CAMHS. Therefore as a recruitment strategy, there was a reliance on clinician identification of potential study participants, resulting in potential selection bias due to a lack of recall or deliberate omission on the part of clinicians. Clinicians may have been concerned about feedback that might be given to the researcher and may have failed to identify potential participants who they felt could be negative about the treatment they received. To alleviate potential clinician concern about the possibility of negative feedback, the researcher discussed the nature of the research being about overall experience rather than evaluating the clinicians, and discussed the objective measures parents may provide regarding elements of effectiveness and importance in treatment. Clinicians may have been reluctant to share their experiences in interviews with the researcher, who is a professional colleague, if concerned about judgement or exposure, resulting in social desirability bias.
The study was also limited by there being only a small number of participating clinicians treating Aboriginal families in CAMHS. Only one Aboriginal clinician participated and two non-Aboriginal clinicians working with Aboriginal families participated in this study. No Aboriginal parents participated in the study. Additionally the voice of the child with AN was not included in this study. It is recognised that the documentation of experiences of adolescents in treatment would provide valuable insights for clinicians and that this is an important area for future research that may build upon the research reported here. What this research has, however, offered is an understanding of key issues that engage and maintain parents in treatment. This is important as adolescents with AN often resist attending treatment and need encouragement and support from parents to do so.

The consent and interview requirements may have prevented some parents from participating, particularly those who felt overwhelmed by their experiences of parenting their child to weight restoration, at the time of recruitment. However several current clients participated in the study. The sample was not biased to past clients of the service. The results of this study are limited by the small number of participants in one district health service, which challenges the generalisation of findings to other contexts where different approaches and professional cultures surrounding treatment implementation may be evident. The validity of the research evidence in this study was, however, strengthened through the process of integrating qualitative and quantitative data in a way that complemented the findings from, and offset the limitations of, both paradigms.

**9.7. Conclusion**

In this study, parents wanted to be connected with their treating clinicians by being understood and having their concerns and struggles contextualised. CAMHS clinicians attempted to meet the needs of the families they treated by integrating clinical judgement and decision making into treatment processes, but largely overlooked the cultural and spiritual values of the family. Both
parents and clinicians benefited in cases where the cultural and environmental milieu of the parent was recognised in treatment. The subjective experiences of parents and clinicians in this study have highlighted readily available resources for recovery which has been given little attention in the literature to date. What this means for practice in working with adolescent AN is explored in the concluding chapter.
Chapter 10. Conclusions and recommendations for practice

Conclusions drawn from this study need to be considered in light of the following:

_Note: Although the primary concern of IPA is the lived experience of the participant and the meaning which the participant makes of that lived experience, the end result is always an account of how the analyst thinks that participant is thinking...thus the truth claims of IPA analysis are always tentative and analysis is subjective_ (Smith et al., 2009, p.80).

The analysis of data in this research has demonstrated that treating adolescent AN in CAMHS is anything but the straightforward application of a manualised approach to family-based therapy. This chapter presents two models, one relating to factors influencing clinical reasoning for adapting Maudsley, and the other relating to processes which reduce dissonance with parents in treatment.

### 10.1. Clinical reasons for adapting Maudsley

Evidence from RCTs supporting Maudsley has helped social workers, and other mental health practitioners, form a conceptual framework for guiding and treating a complex and often perplexing presentation. This study found that all clinicians who treated non-Aboriginal families use the basic principles of Maudsley to either direct or guide interventions, irrespective of whether they were Maudsley-trained therapists or not. Some clinicians integrated greater degrees of critical reflection into practice than others and questioned whether the findings of experimental designs that support Maudsley can always be transferred to the context of a generalist mental health setting. Their practice of adapting Maudsley in CAMHS was contextually driven, and relied more upon reciprocal relationships between parents and
clinicians than clinicians who adapted treatment with the intent to prepare families for manualised interventions in Maudsley.

Adaptations of Maudsley occurred when practitioners critically reflected on knowledge from RCTs and how this translated to the context of their practice. Being responsive to the multifaceted needs and beliefs of parents also influenced clinical decision making in applying Maudsley. Figure 10.1 depicts four factors that influenced clinicians’ decisions to adapt Maudsley to retain families in treatment. These factors are: familial need or capacity to engage in the treatment proposed, identification of cultural and spiritual value systems that may impact upon care and treatment, parental requests, and the need to undertake additional interventions outside of the regime described in Maudsley. Although each factor has equal weight in the model, this research produced more findings about adaptations made in response to assessment of familial need or capacity, and cultural and spiritual value systems than adaptations to Maudsley due to parental requests and additional interventions being required.

Figure 10.1: Clinical rationale for adapting Maudsley
To engage the family in treatment, many clinicians adjusted treatment protocols in Maudsley to meet familial need or capacity. This occurred in circumstances where clinicians assessed that families would disengage from treatment if they observed the convention in Maudsley for the ‘entire family…who live in the same household as the identified patient’ to be involved in treatment (Lock et al., 2001, p.20). Clinicians advised they generally modified their expectations in relation to this treatment protocol after discussions with parents about challenges they would face in having all family members attend weekly treatment (Phase 1 Maudsley). Complying with a treatment protocol was less important for clinicians than engaging the family in a workable treatment paradigm.

Although parents may not have been aware of clinicians adapting manualised treatment to suit their needs, parents found treatment that incorporated their needs most helpful. Single parents and parents who attended treatment by themselves; however, felt that more support was required from treating clinicians, yet clinicians were concerned that if they provided more support they would compromise the role of parents. While clinical reasoning was influenced by multilayered needs in families, clinical approaches were at all times metered by principles in Maudsley such as: ensuring the reinvigoration of parental roles; parents knowing best how to refeed their starving child; and avoiding “the risk of unconsciously fitting into the family patterns that may render the family ineffective” (Lock et al., 2001, p.87). Despite adoptions to Maudsley, clinicians’ adherence to these principles is a possible explanation for some parents perceiving this as a lack of support.

Another key treatment adaptation identified by clinicians was the integration of cultural and spiritual value systems into treatment. This realisation often occurred after commencement of treatment with non-Aboriginal families when clinicians reflected upon barriers to recovery and discovered that culture and value systems in a family were having an impact on the treatment process. For example, in families where spiritual or cultural values reinforce gender specific responsibilities in relation to food or child wellbeing, the tenet of Maudsley that sees parental
figures unite and assume leadership in re-nourishment, did not always match with existing family patterns and behaviours. Adherence to protocols in Maudsley was ineffective for clinicians working with parents when spiritual or cultural values reinforced gender specific responsibilities. Clinicians reported they adapted Maudsley’s approach by setting time aside in treatment to identify and work with a parent’s value system, in order to understand the dilemmas treatment presented for fulfilling roles in the family, and how they might all work together towards recovery, utilising those values. By recognising and acknowledging the influence of culture and values in family functioning, clinicians found ways to integrate a family’s values and beliefs into specific ways of working with parents that respected their roles and responsibilities within the family. When perceived this way, clinicians viewed a family’s cultural influences and spirituality as a resource within the family that could be called upon to assist in recovery.

Although one of the primary principles in Maudsley is “mobilizing parents and family members as a resource” in the recovery of adolescents with AN, it is the authority of parents, and supportive function of siblings, that are viewed as resources in the family, rather than principles or standards that may also be active in the family (Lock et al., 2001, p.2). It is possible that a focus on mobilising family members in Maudsley obstructs clinicians’ perception of the inherent characteristics within a family that may be also helpful in recovery. Clinicians’ reflections, in the semi-structured interview, revealed a realisation of their role in the subjugation of cultural and spiritual value systems within the family, by not standardly recognising and realising them as potentially beneficial in recovery for all families presenting for treatment. As the treatment manual for Maudsley makes no reference to the recognition and use of culture, spirituality and values in treatment, the interpretation of what ‘the family as a resource’ means, is highly subjective and influenced by the social and political context of the treatment setting.
Clinicians also adapted Maudsley on the basis of parental requests. Clinicians made the decision to either adjust the sequence of treatment or withhold interventions within phases of treatment in Maudsley, based on parents’ requests. The clearest example of this, given by both parents and clinicians, was the objection to the ‘family meal’ in Maudsley. While many clinicians viewed the family meal, in Session 2 of Maudsley, as important in understanding transactional patterns within the family and an opportunity to reinforce parental control over refeeding, clinicians also felt the need for clinical discretion in complying with this manualised intervention. Although non-Maudsley clinicians tended to be more responsive to parents’ objections to them participating in the family meal, many Maudsley clinicians did not routinely follow treatment protocols for similar reasons to non-Maudsley clinicians. With the exception of a few parents who found this intervention useful, clinical reasoning for omitting the family meal from treatment was congruent with many parents’ description of this intervention as an artificial experience that might be more useful for clinicians, than for themselves.

Finally clinical decision making in adapting Maudsley was also influenced by clinicians perceived need to add further interventions as either an adjunct to treatment or to enhance Maudsley. Decisions made about adjuncts to treatment were generally made by Maudsley clinicians to prepare families for commencement of Phase 1. Adjuncts to Maudsley included a specific focus on parental education about the nature of AN or other forms of family therapy. Other forms of family therapy were described as systemic or strategic therapies, where clinicians focused on enhancing relationships within the family prior to calling upon “the entire family [as] an important resource in recovery” to commence Maudsley (Lock et al., 2001, P.27). Clinical reasoning for enhancing interventions was made predominantly by non-Maudsley, and a few Maudsley, clinicians. These clinicians questioned Maudsley’s protocol which attends to symptoms of starvation before obtaining a thorough understanding of how treatment may impact upon family’s functioning and wellbeing. For these clinicians, interventions failed to account for other dynamics in a family, such as the misuse of power in relationships, where the empowerment of the parent in Maudsley may result in the disempowerment or abuse of the
child. Enhancements to Maudsley that acknowledged the potential for abusive power imbalances in families included: in-depth assessment of family dynamics prior to commencement of any family-based treatment; separated family therapy; individual therapy for the child; and less emphasis on the notion of parental authority as an integral component of recovery.

In understanding the implementation of EBP, this study found that all clinicians adjusted Maudsley family-based treatment. No clinician reported a strict adherence to all sequences of treatment procedures outlined in manualised Maudsley as useful for all families. Maudsley remains a powerfully constructed source of knowledge for practice in this area, yet when uncritically applied, clinicians believed it could reinforce patterns of abuse in families if a standardised treatment regime was valued over clinicians’ judgment to assess the family milieu.

### 10.2. Social work responsibility to address the needs of marginalised groups

Identifying who would miss out when dominant, standardised approaches were promoted in service delivery is an ethical principal of practice for mental health social workers (AASW, 2008). Ethical principles for social work practice in Australia are based on the values and responsibilities integral to those defined in the ASSW Code of Ethics (2001, 2010). To achieve the aims and commitment of the profession to “maximise the potential and the fulfilment of human needs” the AASW Code of Ethics encourages the pursuit of:

- *the development of knowledge and application of knowledge, theory and skills regarding human behaviour, social structures, systems or processes*

- *the development and distribution of resources to meet the needs of individuals and communities.*

(AASW, 2010, pp.7-8)
More specifically, in meeting the needs of marginalised groups, the AASW Practice Standards for Mental Health Social Workers states a social worker “engages with marginalised individuals and groups in the community to identify community resources and gaps between resources and needs” (AASW, 2008, p.18).

Knowledge for social work practice is therefore concerned with contextualised relationships that are responsive to emerging needs and presenting issues where “varying needs and interpersonal dynamics often make it inappropriate to provide the standardised type of intervention” (Gray et al., 2009, p.54). While there is an ethical responsibility for practitioners to pursue knowledge to justify intervening in people’s lives, applying knowledge sourced from experimental studies, without a critical lens, has the potential to silence and oppress the voice of marginalised groups who may consequently disengage entirely from interventions. This can occur in applying interventions supported through RCTs without reflecting upon the internal validity of RCTs that control variables such as socio-cultural contexts, which may impact upon the outcome of an intervention under investigation (Gray et al., 2009). Social work researchers, Gray and colleagues (2009, p.55), suggest that while scientific experiments demonstrate a relationship between interventions and outcome by controlling variables of interest to social work practice “much of social work is reliant on context and interpersonal relationships”. An interest exists in social work practice about the extent to which, and under what circumstances, scientific findings apply to practice with marginalised and oppressed groups.

This study found examples of clinicians being concerned for marginalised groups being further disadvantaged when the dominant standardised approach of Maudsley was used. This was particularly evident in clinicians’ decision making about the applicability of Maudsley where complex family dynamics, such as domestic violence, are evident or where social and political processes influence the individuals to feel powerless and hopeless. In working with adolescents who are exposed to abuse in the home, clinicians stated that interventions in Maudsley can further oppress the child through the refeeding phase. Similarly, clinicians expressed concern
that if Maudsley was applied to Aboriginal families, the socio-political context of causation relevant in their recovery process would remain unaccounted and suppressed.

10.3. Processes that reduce dissonance with parents

The relationship between parents and clinicians is at the center of effective and helpful outcomes for parents and reducing any dissonance should be an aim of all clinicians working in this area. Findings from this study identified the key processes CAMHS clinicians regarded as ways to enhance collaborative practices with parents in order to unite against a life threatening disorder. Figure 10.2 depicts the processes to enhance collaboration and reduce dissonance. These are: attunement with parents; adapting treatment to keep parents engaged; and integrating parental cultural and spiritual value systems into treatment. An analysis of how a family’s unique circumstances and context impacts upon their ability to care for themselves and their child during the recovery process is integral to optimising outcomes for parents in treatment.

![Figure 10.2: Processes that reduce dissonance with parents](image-url)
When clinicians created an alliance with parents, based on empathy for their day to day lived experiences, this generated a sense of attunement in the therapeutic relationship. Irrespective of the outcomes of treatment, parents reported that a sense of being attuned with their clinician in treatment impacted upon both their experiences of family-based treatment and their sense of self as a parent. Clinicians reported that being attuned to parental experiences facilitated a mutual understanding of each other’s views that then assisted in supporting parental agency in the recovery of their child, integral to family-based treatment for adolescent AN. While the need for an attuned relationship in the therapeutic milieu should come as no surprise, the tendency for clinicians to objectify the experiences of parents for either self-protection or in an attempt to observe standardised treatment principles, has the potential to undermine relationship building in the provision of care.

Adapting manualised family-based treatment to provide what appears to be a Maudsley-type treatment approach was the approach of choice for clinicians in this study. Clinicians conveyed that their use of a Maudsley framework in treatment helped parents, because it gave them a sense of direction and purpose in treatment. Sequences or structure in treatment were perceived by clinicians to help parents understand and engage in specific interventions, with the knowledge that their responsibilities as a parent would ease as they progressed through phases. Although no clinician provided standardised family-based treatment, most reported that adapted Maudsley also provided them with a structure and focus in treatment they could amend in accordance with the presentation of the family. Parents in this study who had undertaken Maudsley treatment reported more effective outcomes and greater levels of satisfaction in treatment than non-Maudsley parents. Despite both non-Maudsley and Maudsley clinicians adapting treatment, it is possible that training in Maudsley provides a good framework from which flexibility in treatment can be created and offered to parents.

Perhaps the most enlightening finding emerging from the data was the varied use of parents’ cultural beliefs and spiritual values in facilitating recovery. Work with Aboriginal families
revealed a synergetic process aimed at enhancing family wellbeing. This treatment is not sequential and relies on both reciprocal acknowledgements between family members and clinicians about the effects of Western culture upon Aboriginal wellbeing and clinician flexibility about levels of participation in treatment. Treatment aims to build on cultural strengths, such as drawing links between the use of traditional foods and recovery. Most clinicians working with non-Aboriginal families did not routinely ask about family culture or spiritual beliefs, but upon reflection in interview, felt it would be useful in order to understand all of the resources at hand within a family. Clinicians reported that when they integrated parental cultural beliefs and values in treatment, they enhanced components of family-based treatment. Parents, however, made no mention of clinicians facilitating their belief systems in treatment. They tended to draw upon their belief systems in the private domain, and with the exception of two parents, did not realise how influential their belief systems were in helping them to parent an adolescent with AN prior to participating in this study.

10.4. Implications for professional development

The practitioners’ commitment to applying knowledge sourced from ‘credible’ sources and associated evidence-based intervention models is heightened when faced with the reality of the potential death of a child from AN. Under these circumstances, the attraction to adopt RCT-supported standardised approaches to AN before engagement, assessment and critical reflection, is understandable in managing this risk. This may have accounted for a lack of attention to the importance of skills in relationship-building as a conduit for effective practice by some clinicians in this study. It may also account for their propensity to overlook additional resources within the family such as values and beliefs, which are not addressed in the model. Although the treatment manual for Maudsley states the importance of the relationship between the parent and clinician, the focus on helping parents re-gain control swiftly, perhaps unintentionally sidelines the relational synergy between parents and clinicians, which this thesis suggests results in effective and helpful outcomes. While there is no disputing the need to help parents re-nourish
their child in order to reverse the effects of malnutrition as soon as possible, intervening to help parents undertake this challenging and confronting task requires an effective transactional relationship.

Working with complex conditions like adolescent AN relies on the ability of clinicians and parents to absorb information from a variety of sources and amass this information in a way that provides options and leverage for change. Maudsley’s linear approach to the complex problem of AN may give the impression of a quick cure, but it may not present a practical model for families facing additional adversity, or for those who need additional resources to facilitate coping over long periods of time. This study found that family resilience over time is sustained by drawing on cultural and or spiritual beliefs, and a sense of being understood by their clinician. This is especially important for practitioners to consider in their work with families, given not all families presenting for treatment for adolescent AN ‘fit’ the most researched model of care, Maudsley. Furthermore, on the basis of clinicians’ uptake of all components of Maudsley, this model does not provide an exact treatment protocol for real practice experiences of clinicians in generalist teams.

From a critical social work perspective, homogeneous categories ascribed by Maudsley such as ‘appropriate candidates’ for three distinct phases of treatment, suggest families with diversity or adversity need to be managed, not engaged. Families are deemed by clinicians as being ‘appropriate’ for Maudsley on the basis of who lives in the household irrespective of cultural, situational or relational context (Lock et al., 2001:20; Lock & Le Grange, 2013, p.24). The responsibility for thinking through who may or may not benefit from Maudsley is predetermined in the manual in a manner that is independent of clinical judgment. Pre-determined categorisations in Maudsley have the potential to set up dichotomous thinking and behaviour in the treatment setting. For instance, parents can be viewed as either passing or failing each week to re-nourish their child in the manner outlined in the manual, in the same manner they can be viewed as either appropriate or inappropriate for manualised treatment. Thinking and behaving
in oppositional categories may additionally pre-empt dialogue in treatment with parents about how they did or did not re-nourish their child, at the expense of more complex dialogue about other dynamics or influences on their parenting.

Clinicians’ dialogues with parents in treatment have the potential to serve the interest of maintaining treatment protocols and structural disadvantages rather than incorporating into treatment the challenges and dilemmas that treatment presents for parents. Helping parents to reflect upon the challenges and dilemmas treatment raises for parenting is important. For example, current societal discourse on parenting views a ‘good’ parent of an adolescent as a negotiator, yet treatment places parents in a position of authority and control. Clinicians engaging in dialogue with parents about these dilemmas may help validate parents’ actions at times in re-nourishing their child. Engaging in this way may allow clinicians to present a non-judgmental attitude to parents during this stressful period.

Interventions directed at working with socio-cultural factors that impact upon family functioning, such as a parent’s use of spirituality, values and personal/cultural history in recovery, acknowledges the subjugated experiences of parents through stressful times. Thinking about all resources available to parents and clinicians, not just the ones most obvious to white Western interventions, allows clinicians to explore how spiritual beliefs and culture systems of families shape interventions.

10.5. Areas identified for further research

This is the first Australian study that examines clinical practice in this area using a mixed methods design. In particular, the study offers new insights in the consideration of the application of Maudsley in relation to cultural determinates of the family and family dynamics. Many of the current studies in adolescent AN do not account for power imbalances in society and within the family that can also impact upon a family’s ability to effectively resolve complex
problems such as AN, using Maudsley. Despite the growing interest and research base for family based therapy in treating adolescents with AN there are deficits in current literature.

Firstly, there is very little research into contextual factors that impact upon clinical decision-making processes in the treatment setting. The use of Maudsley as the dominant model for treating adolescent AN implies that most of the phenomena associated with treating AN are resolved through this model, and that other ways of intervening with families are of less value. The findings of this doctoral research suggest that clinicians adapt Maudsley because they report that strict adherence to manualised treatment is inadequate in meeting the diverse needs of families presenting to mental health services. Clinicians therefore adapted Maudsley: to suit the specific needs of the families with which they work, and to avoid the negative impact of Maudsley upon familial culture and dynamics. While researchers such as Simmons et al. (2008) contend that practitioners need more training and support to adopt evidence-based treatment for eating disorders, this study asked practitioners adopting or adapting Maudsley, to critically reflect upon the utilisation of this model in practice. Further qualitative research is required, with a larger sample of clinicians, to examine their critical reflections on the application of Maudsley with specific populations, such as culturally diverse groups and families where violence/abuse is present.

Secondly, this research found that the quality of the therapeutic relationship facilitates effective outcomes for the adolescent and family. Further research is needed to understand critical aspects of the therapeutic relationship that might predict and promote enhanced outcomes for parents and adolescents in treatment, particularly given clinical trials suggest at least one third of families do not respond to the dominant model of treatment (Le Grange & Lock, 2005). Further research is needed to examine the knowledge and skills required to effectively engage and maintain families in treatment approaches beyond those that are manualised and to determine what is effective for the third of families for whom Maudsley is not suited.
Given that this study focused on parents and clinicians, it is important that research is conducted with adolescents recovering from AN, on their perception of helpful processes that support recovery. Their reflections could provide a point of comparison with parents’ and clinicians’ views, while broadening possible modes of intervention. Important questions remain about how best to intervene in the social context of the adolescent. Examining adolescents’ views about their context, including school and peers, may also inform treatment.

Lastly, few studies examine helpful coping strategies of parents during AN treatment beyond those connected with improving skills and knowledge in managing illness driven behaviours associated with AN (Treasure et al., 2007; MacDonald et al., 2011). This study suggests parents make use of their values and beliefs as part of managing difficult and challenging behaviours and shows that when clinicians work with family culture or values, treatment is enhanced. Ongoing mixed methods research with a representative sample of parents and clinicians is needed to further examine the role and function of families’ cultural beliefs and values in the recovery process.

10.6. Conclusion

This study makes a unique contribution to knowledge about intervening treatment for adolescents with AN. As a rigorous mixed methods exploration, this research has offered both a breadth and depth of findings that will help social workers and other practitioners to appreciate the contextual factors shaping treatment experiences. This research has shown that it is important to critically reflect upon scientific evidence for practice in treating adolescent AN. Families that present for treatment bring with them an array of experiences that are diverse, complex and varied. This context challenges standardised practice developed on the basis of research evidence using experimental designs. It seems reasonable to question who misses out or what is omitted in treatment when dominant paradigms are reinforced in practice. From a
critical, postmodern perspective, this study has shown that clinicians and families work effectively when knowledge used in treatment is sourced from an understanding and appreciation of scientific knowledge and from individual and cultural experiences. It points to the importance of deconstructing this knowledge and reconstructing knowledge for practice through a process of critically reflective practice.
REFERENCES


Vandereycken, W. & van Deth, R. (1989) Who was the first to describe anorexia nervosa: Gull or Lasegue? *Psychological Medicine, 19*, 837-845.


Appendix A: Non-government eating disorders organisations and forum websites

The Butterfly Foundation
http://thebutterflyfoundation.org.au/

Eating Disorders Victoria (EDV)

The Eating Disorders Association Inc. QLD (EDA)
http://eda.org.au/

Eating Disorder Association of South Australia (EDASA)
www.eatingdisorderssa.org.au/

Women’s Health Works
www.womenshealthworks.org.au

Forum Websites for Parents & Carers

Families Empowering and Supporting Treatment of Eating Disorders (F.E.A.S.T.)
www.feast-ed.org

Around the Dinner Table
www.aroundthedinnertable.org

Maudsley Parents
www.maudsleyparents.org

Eating With Your Anorexic
www.eatingwithyouranorexic.com/
Appendix B: Information sheet for the research project – clinician: experiences of parenting a child with anorexia nervosa undergoing treatment
Information Sheet for the Research Project – Clinician:
Experiences of parenting a child with anorexia nervosa undergoing treatment

Invitation to take part

We would like to invite you to participate in a study looking at effective parental involvement in treatment for adolescent anorexia nervosa. The research will contribute to the ongoing development of family based interventions for adolescents with anorexia nervosa undergoing treatment in Child and Adolescent Mental Health Services.

Why are we doing the research?

Research in the field of anorexia nervosa is in its infancy. Anorexia nervosa is the third most common chronic illness for adolescent girls in Australia (after obesity and asthma). Additionally one in 4 children diagnosed with anorexia nervosa are male.

Recovery from anorexia nervosa can take months or years and families are viewed as active and resourceful in recovery.

We would like to find out about your experiences, as clinician, of effective parental involvement in the treatment of adolescents with anorexia nervosa within Child and Adolescent Mental Health Service (CAMHS) in Hunter New England Mental Health.

We would like to compare similarities and differences in views of clinicians and parents about what is effective to help inform service delivery to families who seek assistance from CAMHS. The study will be used towards a Doctor of Philosophy (PhD) degree with the University of Newcastle by one of the researchers (Cath Wood). Dr Debbie Plath is a supervisor for this PhD.
**Who can participate in the research?**

We are inviting clinicians employed in CAMHS involved in the provision of family based interventions for adolescents with anorexia nervosa. Clinicians will be either: psychiatrists; psychiatric registrars; social workers; psychologists; dietitians; nurses; Aboriginal counsellors or occupational therapists.

We will also be inviting parents and their partners who have an adolescent:
- aged between 12-18yrs
- diagnosed with anorexia nervosa within the last 3 years
- within the healthy weight range
- currently receiving treatment from CAMHS or recently discharged

**What is involved in taking part in the research?**

This research is about identifying key elements of parents’ involvement in treatment for anorexia nervosa that enhance recovery. You can participate by completing a survey questionnaire or additionally elect to participate in an interview.

The survey questionnaire has 3 parts and in this research you can participate by completing the survey questionnaire that will take about 30 minutes. You can also choose to participate in a 60 minute interview.

The sort of questions asked in the survey questionnaire relate to basic information about you as well as information about what you found effective and helpful in treatment.

What you have to say in the survey questionnaire will only be seen by the researchers.

The interview can occur either face to face or over the telephone. It is your choice whether you prefer a face to face or a telephone interview. People being interviewed will have contact with the researcher, Cath Wood, and will be interviewed for approximately 60 minutes. The type of questions you will be asked relate to your perception of: experiences of parenting an adolescent with anorexia nervosa; cultural issues within the families you have treated and what you found helpful in treatment.

The interviews will be audio recorded to make sure the researchers have an accurate record of what you have to say. At any time during the interview you can request the audio recording to be stopped and sections of it edited or erased.

A transcript will be made of the interview and it will only be seen by the researchers and the transcriber (who has signed a confidentiality agreement). The transcriber will not have access to your full personal details, they will just be writing the content of the audio recording.
You can be sent a copy of your transcript or survey questionnaire should you wish to review the content. All you have to do is let Cath Wood, the researcher who is collecting the survey questionnaires and conducting the interviews, know you would like this to occur.

All information will be stored in a locked filing cabinet that can only be accessed by the researchers.

**What choice do I have?**

Taking part is entirely your choice. Participation in the research is voluntary in both the survey questionnaire and the interview. Your decision to participate or not will not affect in any way the treatment you currently provide or your working relationship with the researcher. If the researcher is responsible for your supervision you have a choice of being interviewed by a co-researcher.

In this research you can participate by completing only the survey or additionally participate in an interview. Consent to participate in the survey is implied by the completion and return of the survey form. Clinicians who choose to also be interviewed are asked to complete the consent form at the end of the survey questionnaire.

We will only consider you as a participant in the research if you return the survey questionnaire or additionally the consent form indicating that you wish to be interviewed. If you decide to withdraw from the study, you have the option of withdrawing all data relating to you.

**What if I change my mind?**

If you decide to take part and then change your mind, all you will need to do is tell one of the researchers that you no longer wish to be involved.

There are no consequences for you if you decide to withdraw from the research.

**Where will the interviews be held?**

Face to face interviews can be conducted at a CAMHS site. Face to face or telephone interviews will be held at a time and place that is mutually convenient.

**What are the benefits and risks of participating?**

Reflecting on experiences outside of the supervisory or consultative context that may bring undiscovered leanings that enhance family based interventions in the future. Clinicians at CAMHS are keen to participate in evidence based practices and this presents an opportunity to feel a part of contributing to the growing body of literature in this area.
Conversely, reflecting on experiences can be distressing and you can choose not to answer any question and can withdraw from any part of this research at any time you wish. It is recommended that you do not participate in this research if you are dealing with any discomfort related to treating an adolescent with anorexia.

**How will my privacy be protected?**

Each participant is given a code that is used instead of their name for all data supplied in the research. The list of names and codes will be kept on a password locked computer and database, which only the researchers can access. Any reports that we write will only describe experiences of providing treatment and we would also not be using anyone’s names.

The parents that you had seen at CAMHS, or continue to see, will not have access to any information you provide for the purpose of this research.

Coded information will be kept in a locked filing cabinet that only the researchers can open. It will be kept for 5 years, and then shredded. The audio recording of the interviews will also be kept in a locked computer database and will be erased once the study has finished. Transcriptions from the audio recording will be kept in a locked filing cabinet and shredded at the end of the study.

All of your personal information will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002.

**What will be done with the information?**

The information gained from this research will be documented and analysed. It will be the basis of a Doctorate with the University of Newcastle by one of the researchers (Cath Wood) and will be used to add to the knowledge base for working with families who have an adolescent with anorexia nervosa. We will submit our findings to eating disorders and child and adolescent mental health journals so others can learn from what we found out. If you are interested in the results of the study we can send you a summary when we finish – but this will not be for some years.

**What do I need to do to take part?**

Once you have read the Information Sheet and you have decided to take part in the research, please complete the enclosed survey form and return to Cath Wood CAMHS Newcastle via HNE internal mail. If you have indicated at the end of the survey that you would also like to take part in the interview section of the research we will contact you about a suitable time for the interview.
If I have further questions what should I do?

If there is anything that you do not understand, or if you have any questions, you are welcome to ring the Chief Investigator Dr Debbie Plath on (02) 49 215 765 or researcher Cath Wood on (02) 49 257 800.

Thank you for considering the invitation to participate.

Regards,

Dr Debbie Plath                                    Ms Cath Wood

Complaints about this research

This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference number 08/12/17/5.05 and the University’s Human Research Ethics Committee, Approval No H-2009-0057. Should you have any concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or if an independent person is preferred

Dr Nicole Gerrand                                    Human Research Ethics Officer
Professional Officer                                   Research Office
Hunter New England Area Research Ethics Committee     The Chancellery
Hunter New England Area                                 The University of Newcastle
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New Lambton NSW 2305                                    Callaghan NSW 2308
Phone (02) 49 21 4950                                    Phone: (02) 49 21 6333
Email: Nicole.Gerrand@hnehealth.nsw.gov.au               Email: Human-Ethics@newcastle.edu.au
Appendix C: Survey questionnaire - clinicians
SURVEY OF CLINICIANS

Experiences of treating a child with anorexia nervosa
Version 2: 11/06/09

This study is interested in the clinician’s perspective of effective family-based interventions with anorexia nervosa for adolescents. You will be asked about your experience of effective parental involvement in treatment. This is very important to understand because to date there is only some evidence of effective treatment for young people with anorexia nervosa using manualised family-based interventions. However, not all families who attend CAMHS receive manualised treatment as some families are assessed as not in a position to commit to this form of treatment or it is contraindicated due to family circumstances.

Aims of the research:

To identify:
1. key elements of effective treatment
2. what factors encourage the engagement of parents/carers in their child’s treatment
3. directions for service development
4. issues for training clinicians

HOW TO COMPLETE THE SURVEY

This survey has 3 sections:

1. Section 1 asks you to rank on a scale of 1 to 5 the importance of different aspects of treatment for anorexia nervosa.
2. Section 2 gives you an opportunity to comment on some aspects of treatment.
3. Section 3 is a basic social profile that provides important background information.

At the end of the survey you will be asked whether you would like to participate in an interview. Only provide personal contact details if you consent to an interview. Otherwise, simply return the survey through HNE internal mail to Cath Wood, Newcastle CAMHS.
**Section 1 - IMPORTANCE of aspects of treatment received at CAMHS**

Q1. Please colour the circle relating to the response which most closely reflects how important you feel each aspect of treatment is in the effective management of anorexia nervosa.

<table>
<thead>
<tr>
<th>Aspect</th>
<th>not at all important</th>
<th>not very important</th>
<th>reasonably important</th>
<th>very important</th>
<th>extremely important</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a) Your relationship or sense of connection with the parent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1b) Providing specific information about the seriousness of the illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1c) Including the parent as someone active in treatment (encouraging active parenting)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1d) Being able to separate the illness (anorexia) from the child</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1e) Assigning the task of decision making about food to parents in the early stages of the illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1f) Treatment that promotes handing decisions about what to eat back to the child once they reached healthy weight</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>1g) Teaching parents how to stand up to the power and influence of anorexic thinking</td>
<td></td>
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</tr>
<tr>
<td>1h) Treatment that addresses adolescent issues once the child has reached a healthy weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1i) Enhancing parental ability to help their adolescent with anorexia towards recovery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1j) Active parenting in assisting with recovery from anorexia nervosa</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 2 - FURTHER INFORMATION

If you would like an opportunity to write some comments related to your experience of treating young people with anorexia nervosa please do so in the following spaces.

Q2. Can you make some general comments on aspects of treatment you think parents find helpful?

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________

Q3. What are your comments on aspects of treatment parents may find unhelpful?

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________

Q4. Can you comment on some of the common experiences of parenting a child with anorexia nervosa?

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________
Section 3 - TELL US ABOUT YOURSELF

Clinicians are advised to complete this survey outside of clinical sessions with families.

Q5. What is your gender?
○ Male ○ Female

Q6. What is your Profession?
○ Aboriginal counsellor ○ Nurse ○ Psychiatrist ○ Psychologist
○ Dietitian ○ Occupational therapist ○ Psychiatric registrar ○ Social worker

Q7. What is your highest level of education?
○ DClinPsych ○ Masters degree ○ Other (please specify below)
○ Bachelors degree ○ PhD

Q8. Employment
○ Employed F/T ○ Employed P/T ○ Employed Casual ○ Employed Temporary

Q9. Are you of Aboriginal or Torres Strait Islander descent?
○ Yes, Aboriginal ○ Yes, Torres Strait Islander ○ Yes, Aboriginal and Torres Strait Islander ○ No

Q10. Were you born in Australia?
○ Yes ○ No

Q11. If No, in which country were you born?

Q12. Were either of your parents born overseas?
○ Yes ○ No

Q13. Duration of employment with CAMHS
○ 0-6 months ○ 12-18 months ○ 2-3 years ○ 5-10 years
○ 6-12 months ○ 18 months-2 years ○ 3-5 years ○ 10+ years

Q14. Years of experience providing family-based interventions for anorexia
○ 0-6 months ○ 12-18 months ○ 2-3 years ○ 5-10 years
○ 6-12 months ○ 18 months-2 years ○ 3-5 years ○ 10+ years
Q15. Types of treatment provided (select all that apply)

- Maudsley family therapy (child and family seen together)
- Started with Maudsley and changed to individual treatment for child
- Parents and child only seen together
- Parents/siblings and child seen together (NOT Maudsley therapy)
- Child seen individually only
- Child/parents/siblings seen together with individual time for child
- Child and parents seen together with individual time for child and separate time for parents
- Child and family seen together with individual time only for child
- Individual time for child and separate time for parents
- Other (please specify below)

In completing this survey could you indicate how easy it was to complete.

Q16. How easy was this survey to complete?

- Very difficult
- Mostly difficult
- Not difficult
- Mostly easy
- Very easy

Thank you for your time in completing this survey. Your participation is of great assistance in helping to shape the delivery of service to young people with anorexia nervosa.

Your completed survey can be returned through HNE internal mail to Cath Wood, Newcastle CAMHS.

OPTIONAL Interview

Opportunity to participate in an interview:

There is now an opportunity for you to indicate your interest in participating in an interview with the researcher at a later date, that is mutually acceptable, to help further understand issues related to your experience of providing a clinical service to young people with anorexia nervosa and your involvement in treatment. Alternatively, you can elect to conclude at this point and provide no further details.

If you would like to participate in an interview please indicate your interest to do so on the attached consent form and return with your completed survey to Cath Wood, Newcastle CAMHS.
Appendix D: Consent form for CAMHS clinicians for the research project
Consent Form for CAMHS Clinicians for the Research Project: Experiences of parenting a child with anorexia nervosa undergoing treatment.

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have kept.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I understand that by ticking one of the boxes below that I consent to participating in:

- a survey questionnaire only □
- or
- a survey questionnaire and in an interview that will be recorded □

I understand that my personal information will remain confidential to the researchers and that I will not be personally identified in the research report.

I understand that I have the right to review and edit the content of the survey questionnaire and of my interview transcript.

I have had the opportunity to have questions answered to my satisfaction.

Print Name: ________________________________________________________________

Address: _________________________________________________________________

Signature: __________________________  Date: __________________________
Appendix E: Information sheet brief follow-up interview - clinician
Information Sheet for the Research Project—Brief follow-up interview Clinician: Experiences of parenting a child with anorexia nervosa undergoing treatment

Invitation to take part

We would like to thank you for your previous participation in this research and invite you to participate in a brief follow up interview looking at how treatments and therapeutic approaches enhance effective parental involvement in treatment for adolescent anorexia nervosa. The research will contribute to the ongoing development of family-based interventions for adolescents with anorexia nervosa undergoing treatment in Child and Adolescent Mental Health Services.

Why are we doing the research?

Research in the field of anorexia nervosa is in its infancy. Anorexia nervosa is the third most common chronic illness for adolescent girls in Australia (after obesity and asthma). Additionally one in 4 children diagnosed with anorexia nervosa are male.

Recovery from anorexia nervosa can take months or years and families are viewed as active and resourceful in recovery.

We would like to find out more about your experiences, as clinician, of treatments and therapeutic approaches used in the treatment of adolescents with anorexia nervosa within Child and Adolescent Mental Health Service (CAMHS) in Hunter New England Mental Health.

We would like to compare similarities and differences in views of clinicians and parents about what is effective to help inform service delivery to families who seek assistance from CAMHS. The study will be used towards a Doctor of Philosophy (PhD) degree with the University of Newcastle by one of the researchers (Cath Wood). Dr Debbie Plath is a supervisor for this PhD.
**Who can participate in the research?**

We are inviting clinicians employed in CAMHS, who have previously been interviewed as part of this research, and are involved in the provision of family based interventions for adolescents with anorexia nervosa. Clinicians will be either: psychiatrists; psychiatric registrars; social workers; psychologists; dietitians; nurses; Aboriginal counsellors; or occupational therapists.

**What is involved in taking part in the follow up interview?**

The interview can occur either face to face or over the telephone. It is your choice whether you prefer a face to face or a telephone interview. People being interviewed will have contact with the researcher, Cath Wood and will be interviewed for approximately 30 minutes. The type of questions you will be asked relate to your perception of treatments and therapeutic approaches used in treating adolescent anorexia nervosa in CAMHS.

The interviews will be audio recorded to make sure the researchers have an accurate record of what you have to say. At any time during the interview you can request the audio recording to be stopped and sections of it edited or erased.

A transcript will be made of the interview and it will only be seen by the researchers and the transcriber (who has signed a confidentiality agreement). The transcriber will not have access to your full personal details they will just be writing the content of the audio recording.

You can be sent a copy of your transcript should you wish to review the content. All you have to do is let Cath Wood, the researcher collecting the survey questionnaires and conducting the interviews, know you would like this to occur.

All information will be stored in a locked filing cabinet that can only be accessed by the researchers.
What choice do I have?

Taking part is entirely your choice. Participation in the research is voluntary. Your decision to participate or not will not affect in any way the treatment you currently provide or your working relationship with the researcher. If the researcher is responsible for your supervision you have a choice of being interviewed by a co-researcher.

Consent to participate in the interview is indicated by the completion of the consent form. If you decide to withdraw from the study, you have the option of withdrawing all data relating to you.

What if I change my mind?

If you decide to take part and then change your mind, all you will need to do is tell one of the researchers that you no longer wish to be involved.

There are no consequences for you if you decide to withdraw from the research.

Where will the interviews be held?

Face to face interviews can be conducted at a CAMHS site. Face to face or telephone interviews will be held at a time and place that is mutually convenient.

What are the benefits and risks of participating?

Reflecting on experiences outside of the supervisory or consultative context that may bring undiscovered leanings that enhance family based interventions in the future. Clinicians’ at CAMHS are keen to participate in evidence based practices and this presents an opportunity to feel a part of contributing to the growing body of literature in this area.

Conversely, reflecting on experiences can be distressing and you can choose not to answer any question and can withdraw from any part of this research at any time you wish. It is recommended that you do not participate in this research if you are dealing with any discomfort related to treating an adolescent with anorexia.
How will my privacy be protected?

Each participant is given a code that is used instead of their name for all data supplied in the research. The list of names and codes will be kept on a password locked computer and database, which only the researchers can access. Any reports that we write will only describe experiences of providing treatment and we would also not be using anyone’s names.

The parents that you had seen at CAMHS, or continue to see, will not have access to any information you provide for the purpose of this research.

Coded information will be kept in a locked filing cabinet that only the researchers can open. It will be kept for 5 years, and then shredded. The audio recording of the interviews will also be kept in a locked computer database and will be erased once the study has finished. Transcriptions from the audio recording will be kept in a locked filing cabinet and shredded at the end of the study.

All of your personal information will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002.

What will be done with the information?

The information gained from this research will be documented and analysed. It will be the basis of a Doctorate with the University of Newcastle by one of the researchers (Cath Wood) and will be used to add to the knowledge base for working with families who have an adolescent with anorexia nervosa. We will submit our findings to eating disorders and child and adolescent mental health journals so others can learn from what we found out. If you are interested in the results of the study we can send you a summary when we finish – but this will not be for some years.

What do I need to do to take part?

Once you have read the Information Sheet and you have decided to be re-interviewed, please complete the enclosed consent form and return to Cath Wood CAMHS Newcastle via HNE internal mail.
If I have further questions what should I do?

If there is anything that you do not understand, or if you have any questions, you are welcome to ring the Chief Investigator Dr Debbie Plath on (02) 49 215 765 or researcher Cath Wood on (02) 49 257 800.

Thank you for considering the invitation to participate.

Regards,

Dr Debbie Plath
Ms Cath Wood

Complaints about this research

This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference number 08/12/17/5.05 and the University’s Human Research Ethics Committee, Approval No H-2009-0057. Should you have any concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or if an independent person is preferred

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Email: Human-Ethics@newcastle.edu.au

Appendix F: Consent for brief follow-up interview - clinician
Consent Form for Re-interview CAMHS Clinicians for the Research Project:
Experiences of parenting a child with anorexia nervosa undergoing treatment.

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have kept.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I understand that by signing this form I consent to participation in a re-interview that will be recorded.

I understand that my personal information will remain confidential to the researchers and that I will not be personally identified in the research report.

I understand that I have the right to review and edit the content of my interview transcript.

I have had the opportunity to have questions answered to my satisfaction.

Print Name: _______________________________________________________________

Address: _________________________________________________________________

Signature:______________________________  Date:_____________________________
Appendix G: Information sheet for the research project – parents and partners
Information Sheet for the Research Project - Parents and Partners: Experiences of parenting a child with anorexia nervosa undergoing treatment

**Invitation to take part**

We would like to invite you to participate in a study looking at effective parental involvement in treatment for adolescent anorexia nervosa. The research will contribute to the ongoing development of family based interventions for adolescents with anorexia nervosa undergoing treatment in Child and Adolescent Mental Health Services.

**Why are we doing the research?**

Research in the field of anorexia nervosa is in its infancy. Anorexia nervosa is the third most common chronic illness for adolescent girls in Australia (after obesity and asthma). Additionally one in 4 children diagnosed with anorexia nervosa are male.

Recovery from anorexia nervosa can take months or years and families are viewed as active and resourceful in recovery.

We would like to find out about your experiences, as a parent or partner, of treatment within Child and Adolescent Mental Health Service (CAMHS) in Hunter New England Mental Health for your adolescent with anorexia nervosa.

We would like to compare similarities and differences in views of parents and clinicians about what is effective to help inform service delivery to families who seek assistance from CAMHS. The study will be used towards a Doctor of Philosophy (PhD) degree with the University of Newcastle by one of the researchers (Cath Wood). Dr Debbie Plath is a supervisor for this PhD.
Who can participate in the research?

We are inviting parents and their partners who have an adolescent:
- aged between 12-18yrs
- diagnosed with anorexia nervosa within the last 3 years,
- within the healthy weight range,
- currently receiving treatment from CAMHS or recently discharged.

We will also be inviting clinicians employed in CAMHS involved in the provision of family based interventions for adolescents with anorexia nervosa. Clinicians will be either: psychiatrists; psychiatric registrars; social workers; psychologists; dietitians; nurses; Aboriginal counsellors; or occupational therapists.

What will I be asked to do?

This research is about identifying key elements of parents’ involvement in treatment for anorexia nervosa that enhance recovery. You can participate by completing a survey questionnaire or additionally elect to participate in an interview.

The survey questionnaire has 4 parts and in this research you can participate by completing the survey questionnaire that will take about 30 minutes. You can also choose to participate in a 60 minute interview.

The sort of questions asked in the survey questionnaire relate to basic information about you and your adolescent as well as information about what you found effective and helpful in treatment.

What you have to say in the survey questionnaire will only be seen by the researchers.

The interview can occur either face to face or over the telephone. It is your choice whether you prefer a face to face or a telephone interview. People being interviewed will have contact with the researcher, Cath Wood and will be interviewed for approximately 60 minutes. The type of questions you will be asked relate to your experiences of parenting an adolescent with anorexia nervosa; cultural issues within your family; what you found helpful in treatment; and your experiences of treatment.

The interviews will be audio recorded to make sure the researchers have an accurate record of what you have to say. At any time during the interview you can request the audio recording to be stopped and sections of it edited or erased.

A transcript will be made of the interview and it will only be seen by the researchers and the transcriber (who has signed a confidentiality agreement). The transcriber will not have access to your full personal details they will just be writing the content of the audio recording.
You can be sent a copy of your transcript or survey questionnaire should you wish to review the content. All you have to do is let Cath Wood, the researcher collecting the survey questionnaires and conducting the interviews, know you would like this to occur.

All information will be stored in a locked filing cabinet that can only be accessed by the researchers.

**What choice do I have?**

Taking part is entirely your choice. Participation in the research is voluntary in both the survey questionnaire and the interview. Your decision to participate or not will not affect in any way the treatment your child receives or the manner in which you are treated by Hunter New England Health or Child and Adolescent Mental Health Service.

In this research you can participate by completing only the survey or additionally participate in an interview. Consent to participate in the survey is implied by the completion and return of the survey form. Parents and partners who choose to also be interviewed are asked to complete the consent form at the end of the survey questionnaire.

We will only consider you as a participant in the research if you return the survey questionnaire or additionally the consent form indicating that you wish to be interviewed. If you decide to withdraw from the study, you have the option of withdrawing all data relating to you.

**What if I change my mind?**

If you decide to take part and then change your mind, all you will need to do is tell one of the researchers that you no longer wish to be involved.

If you decide to withdraw from the study, you have the option of withdrawing all data relating to you. Withdrawing from the research will not change the treatment that you would usually receive or your relationship with Child and Adolescent Mental Health Service or Hunter New England Health.

**What if my child relapses?**

Should your child relapse, that is fall below healthy weight range, during your participation in the research, it is suggested that you postpone your involvement in the research until your child returns to a healthy weight range. This is to ensure that you can give your full attention to the needs of your child and family at this time. When your child resumes a healthy weight, you are invited to contact us again to let us know whether you would like to resume your participation in the research.
If you decide to withdraw from the research at that point it will not change the treatment that you would usually receive or your relationship with Child and Adolescent Mental Health Service or Hunter New England Health.

**Where will the interviews be held?**

Face to face interviews can be conducted at a CAMHS site, either the one you have attended for treatment or another site; your home or at an independent location. Either face to face or telephone interviews will be held at a time and place that is mutually convenient.

**What are the benefits and risks of participating?**

Sharing your experiences of parenting a young person with anorexia nervosa can be an empowering process as it will give you the opportunity to reflect upon your family’s ability to navigate a path through treatment towards recovery. The reflections you provide will also help shape ongoing services for families who seek treatment for their adolescent with anorexia nervosa through HNE child and adolescent mental health services.

It can also be distressing to reflect upon the challenges anorexia poses to families. If participating in the study causes unanticipated distress you can choose not to answer any question and or withdraw from the study at any time.

**How will my privacy be protected?**

Each participant is given a code that is used instead of their name for all data supplied in the research. The list of names and codes will be kept on a password locked computer and database, which only the researchers can access. Any reports that we write will only describe experiences of parenting and treatment and we would also not be using anyone’s names.

The treating clinician(s) that you had seen at CAMHS, or continue to see, will not have access to any information you provide for the purpose of this research.

Coded information will be kept in a locked filing cabinet that only the researchers can open. It will be kept for 5 years, and then shredded. The audio recording of the interviews will also be kept in a locked computer database and will be erased once the study has finished. Transcriptions from the audio recording will be kept in a locked filing cabinet and shredded at the end of the study.

All of your personal information will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002.
What will happen to the information that is collected?

The information gained from this research will be documented and analysed. It will be the basis of a Doctorate with the University of Newcastle by one of the researchers (Cath Wood) and will be used to add to the knowledge base for working with families who have an adolescent with anorexia nervosa. We will submit our findings to eating disorders and child and adolescent mental health journals so others can learn from what we found out. If you are interested in the results of the study we can send you a summary when we finish – but this will not be for some years.

What do I need to do to take part?

Once you have read the Information Sheet and you have decided to take part in the research, please complete the enclosed survey form and return to us in the reply paid envelope. If you have indicated at the end of the survey that you would also like to take part in the interview section of the research we will contact you about a suitable time for the interview.

If I have further questions what should I do?

If there is anything that you do not understand, or if you have any questions, you are welcome to ring the Chief Investigator Dr Debbie Plath on (02) 49 215 765 or researcher Cath Wood on (02) 49 257 800.

Thank you for considering the invitation to participate.

Regards,

Dr Debbie Plath                                     Ms Cath Wood

Complaints about this research

This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health reference number 08/12/17/5.05 and the University’s Human Research Ethics Committee, Approval No H-2009-0057. Should you have any concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or if an independent person is preferred:

Dr Nicole Gerrand                                      Human Research Ethics Officer
Professional Officer                                      Research Office
Hunter New England Area Research Ethics Committee       The Chancellery
Hunter New England Area                                      The University of Newcastle
Locked Bag 1                                             University Drive
New Lambton NSW 2305                                         Callaghan NSW 2308
Phone (02) 49 21 4950                                        Phone: (02) 49 21 6333
Email: Nicole.Gerrand@hnehealth.nsw.gov.au                Email: Human-Ethics@newcastle.edu.au
Appendix H: Consent form parents and partners
Consent Form for Parents and Partners for the Research Project:
Experiences of parenting a child with anorexia nervosa undergoing treatment.

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have kept.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I understand that by ticking one of the boxes below that I consent to participating in:

a survey questionnaire only ☐

or

a survey questionnaire and in an interview that will be recorded ☐

I understand that my personal information will remain confidential to the researchers and that I will not be personally identified in the research report.

I understand that I have the right to review and edit the content of the survey questionnaire and of my interview transcript.

I have had the opportunity to have questions answered to my satisfaction.

Print Name: __________________________________________________________

Address: ____________________________________________________________

Signature: ___________________________ Date: __________________________
Appendix I: Survey questionnaire - parents and partners
SURVEY OF PARENTS/CARERS

Experiences of caring for a child undergoing treatment for anorexia nervosa
Version 2: 11/06/09

This study is interested in your experiences of the treatment your child has received from CAMHS. It is very important for clinicians and health services to know what families of young people with anorexia have found useful in order to guide ongoing development of services.

Aims of the research:

To identify:
1. key elements of effective treatment
2. what factors encourage the engagement of parents/carers in their child’s treatment
3. directions for service development
4. issues for training clinicians

HOW TO COMPLETE THE SURVEY

We are interested in getting feedback from each parent/partner who has attended treatment at CAMHS with their child. Please find enclosed 2 copies of the survey. Ideally, each parent/partner in the household who is involved in attending treatment for their child at CAMHS should complete a survey. If only 1 parent attends treatment please disregard the second survey.

This survey has 4 sections:

1. Section 1 tells us about the young person involved in the treatment.
2. Section 2 asks you to rank on a scale of 1 to 5 the importance and effectiveness of different aspects of treatment for anorexia nervosa, based on your own experiences at CAMHS.
3. Section 3 gives you an opportunity to comment on some aspects of treatment.
4. Section 4 is a basic social profile of the parent and partner.

At the end of the survey you will be asked whether you would like to participate in an interview. Only provide personal contact details if you consent to an interview. Otherwise, simply return the survey in the reply paid envelope.
Section 1 - TELL US ABOUT YOUR CHILD

Q1a. Gender:
☐ Male       ☐ Female

Q1b. Date of Birth:

Day / Month / Year

Q1c. Birth Order
☐ First       ☐ Second       ☐ Third       ☐ Fourth or more

Q1d. Country of birth:

Q1e. Diagnosis within last:
☐ 0-6 months ☐ 6-12 mths ☐ 12-18 mths ☐ 18mths - 2 yrs ☐ 2-3 yrs ☐ more than 3 years

Q1f. Duration of treatment with CAMHS:
☐ 0-6 months ☐ 6-12 mths ☐ 12-18 mths ☐ 18mths - 2 yrs ☐ 2-3 yrs ☐ more than 3 years

Q1g. Duration of illness - how long has anorexia been in the life of your child:
☐ 0-6 months ☐ 6-12 mths ☐ 12-18 mths ☐ 18mths - 2 yrs ☐ 2-3 yrs ☐ more than 3 years

Q1h. From the following list, please select the MAIN form of treatment your child has received since attending CAMHS. (select one response only)

☐ Maudsley family therapy (child and family seen together)
☐ Started with Maudsley and changed to individual treatment for child
☐ Parents and child only seen together
☐ Parents/siblings and child seen together (NGT Maudsley therapy)
☐ Child seen individually only
☐ Child/parents/siblings seen together with individual time for child
☐ Child and parents seen together with individual time for child and separate time for parents
☐ Child and family seen together with individual time only for child
☐ Individual time for child and separate time for parents
☐ Other (please specify below)

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PLEASE CONTINUE TO PAGE 3
Section 2 - IMPORTANCE and EFFECTIVENESS of treatment received at CAMHS

In relation to the MAIN form of treatment selected in Question 1h (previous page), consider each of the following aspects of treatment.

For each aspect (2a to 2k) please select two responses - how IMPORTANT the aspect of treatment is for you, by filling in one of the circles on the left hand side, and how EFFECTIVE the treatment was for your child, by filling in one of the squares on the right hand side.

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<th>Important</th>
<th>Effective</th>
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<td>not at all effective</td>
</tr>
<tr>
<td>not very important</td>
<td>not very effective</td>
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<tr>
<td>reasonably important</td>
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<tr>
<td>extremely important</td>
<td>extremely effective</td>
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2a) Your relationship or sense of connection with the therapist

2b) Receiving specific information about the seriousness of the illness

2c) Being included as someone active in treatment (helping you help your child)

2d) Being able to separate the illness (anorexia) from your child

2e) Being given the task of making decisions about food on behalf of the child in the early stages of the illness

2f) Handing decisions about what to eat back to your child once they reached healthy weight

2g) Learning how to stand up to the power and influence of anorexic thinking

2h) The treatment in addressing adolescent issues once your child reached a healthy weight

2i) Taking an active parenting role in assisting with recovery from anorexia nervosa

2j) The overall treatment in enhancing your ability to help your adolescent with anorexia towards recovery
### Section 3 - FURTHER INFORMATION

*If you would like an opportunity to write some comments related to your experience of parenting a young person with anorexia nervosa please do so in the following section.*

**Q3a** Can you make some general comments about what it has been like for you to parent a child with anorexia nervosa or be a support person to a parent who has a child with anorexia?

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**Q3b** What have you found to be helpful in the treatment process?

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**Q3c** Are there any aspects of treatment which could be improved?

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Section 4 - TELL US ABOUT YOURSELF

Q4a. What is your relationship to the child:
○ Parent
○ Partner of parent
○ Grandparent
○ Carer
○ Other (please specify below)

Q4b. What is your gender?
○ Male
○ Female

Q4c. What is your age?
○ 30 years or less
○ 30 to 39
○ 40 to 49
○ 50 to 59
○ 60 or over

Q4d. Relationship status:
○ Single
○ Married
○ De-facto
○ Divorced
○ Widowed

Q4e. What is your highest level of education?
○ School Certificate or similar
○ TAFE (or similar)
○ Bachelors Degree
○ Masters Degree
○ PhD
○ Diploma/Certificate
○ Other (please specify below)

Q4f. Employment
○ Employed F/T
○ Employed P/T
○ Employed Casual
○ Employed Temporary
○ Unemployed
○ Student
○ Voluntary work
○ Retired
○ Unable to work - permanently/temporarily
○ Other (please specify below)

Q4g. Did you need to make changes to your employment while your child was undergoing treatment?
○ Yes
○ No

Q4h. If Yes, how did your employment status change?

Q4i. Are you of Aboriginal or Torres Strait Islander descent?
○ Yes, Aboriginal
○ Yes, Torres Strait Islander
○ Yes, Aboriginal and Torres Strait Islander
○ No

Q4j. Were you born in Australia?
○ Yes
○ No

Q4k. If No, in which country were you born?

Q4l. Were either of your parents born overseas?
○ Yes
○ No

Q4m. If Yes, birthplace of your mother/female carer?

Q4n. If Yes, birthplace of your father/male carer?

Q4o. Number of other dependent children you have living with you.
○ one
○ two
○ three
○ four or more
Finally, how easy was this survey to complete?

- Very difficult
- Mostly difficult
- Not difficult
- Mostly easy
- Very easy

Thank you for completing this survey and helping to add to improving service delivery for young people with anorexia and their families through CAMHS.

Your completed survey can be returned in the reply paid envelope provided.

---

**OPTIONAL Interview**

*Opportunity to participate in an interview:*

There is now an opportunity for you to indicate your interest in participating in an interview with the researcher at a later date, that is mutually acceptable, to help further understand issues related to your experience or parenting a young person with anorexia nervosa and your involvement in treatment. Alternatively you can elect to conclude at this point and leave no further details.

*If you would like to participate in an interview please indicate your interest to do so on the attached consent form and return with your completed survey in the enclosed reply paid envelope to: * Cath Wood

CAMHS
621 Hunter Street
Newcastle NSW 2300

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Office Use Only

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0025593699
Appendix J: Interview schedule-parents and partners
Parents and partners: Interview questions.

Experiences of parenting a child with anorexia nervosa undergoing treatment

Parenting a child with anorexia:

1. Can you tell me about your child’s eating disorder and what it has been like for you?

Areas to cover:

- Thoughts and feelings when they first became concerned in relation to eating;
- Any examples of occasions they recall that illustrate the impact on them as parents.
- Thoughts and feelings when your initial suspicions were confirmed by clinical diagnosis of anorexia;
- Any changes in their life they have had to make either positive or negative.
- Parenting skills they have drawn on to help their child or that have been tested by the illness.
- Impact on their life.

2. In summary if you had to describe what having a child with anorexia means to you what would you say?

Areas to cover:

- Explore positive and negative experiences
- Areas of life most impacted upon
- The consequences of the sum of these experiences

Culture:

3. In the family(s) you grew up in what were the values and beliefs about eating in the family?
Areas to cover:
- Religious or spiritual beliefs about food or eating
- Examples of what was expected of them as children in their family in relation to eating
- Examples of how their parents managed meals or meal times

4. How do you think this experience may have influenced you during treatment?

5. In thinking about the parenting you received as a child what aspects of this parenting do you now see in yourself as a parent of a young person with anorexia?

Areas to explore:
- Any examples of times when they saw their childhood experiences influencing current parenting a child with anorexia.

Helpfulness:

6. Could you describe examples or instances within the treatment process that has been helpful?

Areas to cover:
- What was needed and provided?
- When and how did this happen?
- What they notice that was helpful
- Instances when they felt empowered in treatment.

7. Could you describe aspects of the treatment that has been unhelpful?

Areas to cover:
- What was felt to be needed but not provided?
- Examples or occasions where treatment that was unhelpful – what was it that made it unhelpful
- Instances where parent felt on reflection that treatment was unhelpful

8. If you were asked to be a part of a team that provided education to clinicians about helping parents of a child with anorexia nervosa what would you say to those clinicians?
Parents’ experience of treatment:

9. Could you tell me about the treatment you have received through CAMHS in relation to your child’s anorexia?

Areas to cover:
- When first thought treatment was required
- Examples that illustrate what parents thought would happen and what actually happened – were they the same or different than expected?
- Examples of anything they did not expect in treatment
- Examples of how sessions were conducted
- Did sessions change over time?
- How it felt to be in therapy
- How parents were involved in treatment
- Comments about the clinicians style in incorporating them in treatment process
- What parents thought was being asked of them and their reaction to this.

10. What did it mean to you to undertake treatment through CAMHS to help your child towards recovery from anorexia?

Areas to cover:
- From the perspective of the rest of the family such as siblings and or child’s grandparents.
- From the perspective of the hope and expectations you had or have for yourself.
- From the perspective of the hope and expectations you had or have for and your child.
Appendix K: Interview schedule - clinicians
 Clinician: Interview questions

Experiences of parenting a child with anorexia nervosa undergoing treatment

Clinicians’ perceive parental experience of treatment:

1. Can you tell me how you think parents might describe the treatment they receive through CAMHS for their child with anorexia?

Areas to cover:

- CAMHS commitment to including parents in treatment – what is being asked of parents?
- Instances of any feedback parents have provided
- Examples of any feedback about service that has come from other sources
- What happens in sessions? How you include parents in treatment?
- Perception of how parents may feel to be in therapy
- Comments about the clinicians style in incorporating them in treatment process.
- Perception of parents reaction to treatment.

2. What do you think it means to parents to undertake therapy through CAMHS to help their child towards recovery from anorexia?

Culture:

3. With the parents you have worked with what did you learn about the values and beliefs they had about eating and where those values and beliefs may have come from?

Areas to cover:

- Religious or spiritual beliefs about food or eating
- Examples of what was expected of them as children in their family in relation to eating
- Examples of how their parents managed meals or meal times
5. With the parents you have worked with how do you think their experience of their own parenting effects how they then parent their child with anorexia?

Areas to explore:
- Any examples of times when parents talked about their childhood experiences influencing current parenting a child with anorexia.

**Helpfulness:**

6. Could you describe, by example, aspects of treatment process that you think may be helpful to parents?

**Areas to cover:**
- What is needed and suggested?
- Examples of occasions they feel they empowered parents
- Examples of instances that parents have given feedback that something has been helpful
- Occasions when the young person in treatment has told the clinician that advice or suggestions made to parents have been helpful in their recovery.

7. Could you describe any aspects of treatment process that you think may be unhelpful for parents?

**Areas to cover:**
- What was felt to be needed but not provided?
- Occasions where parents or young people have provided feedback that particular forms of intervention or ideas were unhelpful
- What was it about those instances that made them unhelpful
- Examples of instances where clinician has reflected on practice and thought they could have done something different – explore.

8. If you were asked to be a part of a team that provided education to parents about how best to help their adolescent diagnosed with anorexia nervosa what would you say?
Parenting a child with anorexia:

9. Can you tell me what you think it might be like for a parent who has a child with an eating disorder like anorexia?

Areas to cover:

- Thoughts and examples of parents recollections in sessions about first recognition their child had anorexia
- How parents may have felt about this
- Examples of what parents may have said to clinicians
- Thoughts once diagnosed with anorexia
- Any changes in their life they have had to make either positive or negative
- Parenting skills they have drawn on to help their child or that have been tested by the illness
- Aspects of care drawn from previous experience in working with parents.

10. In summary if you had to describe what having a child with anorexia means to a parent what would you say?
Appendix L: Additional interview questions - clinicians
Clinician: Additional interview questions

**Preface:** Treatments and therapeutic approaches are often adapted and modified by clinicians to best meet the needs of the people they are treating.

**Maudsley clinicians:**

1. Do you ever adapt or shift from the manualised Maudsley approach?
2. Under what circumstances would you do this?
3. Could you give me some examples from your clinical practice?
4. Are there aspects of Maudsley that you tend to avoid or modify because it doesn’t really fit with your own experience of what works best with clients? If so can you give some examples?
5. How do you think manualised Maudsley family therapy, as a treatment for adolescent anorexia nervosa, has influenced CAMHS service delivery in addressing adolescent anorexia nervosa?

**Non – Maudsley clinicians:**

1. What approach would you typically use when treating an adolescent with anorexia nervosa?
2. Do you ever adapt or shift from this approach?
3. Under what circumstances would you do this?
4. Could you give some examples from your clinical practice?
5. How do you think manualised Maudsley family therapy, as a treatment for adolescent anorexia nervosa, has influenced CAMHS service delivery in addressing adolescent anorexia nervosa?
Appendix M: Hunter New England Human Research Ethics Approval
12 February 2009

Dr D Plath
Senior Lecturer in Social Work
School of Humanities
University of Newcastle

Dear Dr Plath,

Re: Experiences of parenting a child with anorexia nervosa undergoing treatment (08/12/17/5.05)

HNEHREC reference number: 08/12/17/5.05
HREC reference number: HREC/08/HNE/413
SSA reference number: SSA/08/HNE/414

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- Child & Adolescent Mental Health Services, Hunter New England Health

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

Dr Nicole Gerrand
Research Governance Officer
Hunter New England Health

Hunter New England Human Research Ethics Committee
(Room 231, Building 23)
New Lambton NSW 2305
Telephone (02) 49214 960
Fax (02) 49214 818
Email: hrehrec@health.nsw.gov.au
Nicole.gerrand@health.nsw.gov.au
Appendix N: University of Newcastle Human Research Ethics Approval
HUMAN RESEARCH ETHICS COMMITTEE

Notification of Expedited Approval

To Chief Investigator or Project Supervisor: Dr Deborah Plath
Cc Co-investigators / Research Students: Dr Jill Gibbons, Ms Cath Wood
Re Protocol: Experiences of parenting a child with Anorexia Nervosa undergoing treatment
Date: 17-Mar-2009
Reference No: H-2009-0057

Thank you for your Initial Application submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under Expedited Review of External Approval review by the Chair/Deputy Chair.

I am pleased to advise that the decision on your submission is External HREC Approval Noted effective 10-Mar-2009.

The full Committee will be asked to note this decision at its next scheduled meeting. A formal Certificate of Approval will be available upon request. Your approval number is H-2009-0057.

Associate Professor Alison Ferguson
Chair, Human Research Ethics Committee

For communications and enquiries:
Human Research Ethics Administration

Research Services
Research Office
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 18999
F +61 2 492 17164
Human-Ethics@newcastle.edu.au