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TITLE: NAVIGATING SELF-/FEMALE IDENTITY (& LOSS)

A PORTFOLIO OF THEORY, PRACTICE AND RESEARCH SUBMITTED IN FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY

(TOP-UP DPSYCH – POST CHARTERED COUNSELLING PSYCHOLOGY)

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ACKNOWLEGEMENTS & DEDICATION:

My sincere thanks go to:

1. My supervisor, Dr. Ulrike Schmidt, for taking on the supervision of the research and the wonderful team work that we have been able to continue to engage in, over what has been about 7 years, both during my time at the Maudsley, and in the last two years doing the top-up DPsych. Here the creative process was kept going, with each motivating the other, keeping at it through times of excitement and delight, and times of needing to go back to the drawing board, through all the stages of what has been a wonderful, but most challenging and ambitious, but so rewarding project. She has supported me through the low and highlights (both content and process wise) of all of this, as a true academic, practitioner, colleague, mentor etc, in her so special, interpersonally sensitive, encouraging, driven, enlightening and facilitating manner.

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(previously unbeknown) personal gynae & fertility issues arose and got in the way both at the start of writing up the research full-time and towards the very end of it, away from clinical practice. She showed such special understanding of the issues involved, putting these into words, reflecting on my reflections and the meaning of this, helping me to come to a realisation that I wanted to keep going, notwithstanding, but because of it, and the importance of the work continuing both to others and myself. And, finally, to Julie Quek who was a most helpful, hardworking, loyal and fun colleague to have, who, particularly, encouraged me through the "running the groups" stages of the trial. She has a real devotion to "the cause", which really rubbed off onto me, as did the enthusiasm & love for the field of both Mr. Edmonds & Miss Rose, at a practicing obstetricians & gynaecologists, and an academic interest level, specifically and generally.

3. All the women that I have worked with at the Centre, from whom I learned so much and who helped me & motivated me to crystalise a theory & model to help them help themselves to navigate their predicament, in the absence of such a theory & model.

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personal life story and some of my own personal pain, which was both terribly humbling, painful, and strangely beautiful.

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6. And all the creatures great and small (including human and animal – my family & friends!!!!), who did not possibly always realise, at the very moment that they were, that they inspired me to keep on going in so many tiny and big ways, who seemed to listen to me over coffees/meals, keep me company in the varied cycles that this project went through, and highlighted once more to me the things that matter in life, and that there is a time for everything under the sun….. and that He blesses and that there is value in everything….

This portfolio is dedicated to the memories of my sister Anneke Henriette[1]*, who so well understood many of the issues this thesis deals with, and in thanks to all those people acknowledged above, whose exceptional support & encouragement made this all possible*

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[1] Who died when I just started working at the Centre

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SECTION A PREFACE

SECTION A PREFACE - FROM GIRL INTO WOMAN; FEMALE IDENTITY /ROLES AND LOSSES OVER THE LIFE SPAN - *Loss of girlhood and self in childhood; Loss of a sexual, reproductive, "normal" developing, and future self in adolescence; Loss of a sense of self into an anorexic identity and female thinness in adolescence; Loss of a child and sense of self as a "good mother" in young adulthood & beyond – theory, practice & research*

The various components of this portfolio link together at two levels. Firstly, at a "theme[1]", and secondly at a "professional knowledge and skills' development" level.

LEVEL 1: THEME:

At a "theme" level the varied components of the portfolio allow the reader to look through the eyes of varied girls/women, and the conclusions they drew about their (female) self in varied circumstances. They represent varied women at different ages across the lifespan. They, particularly, consider the experiences that effected these women's female identities negatively. They note the obstacles placed on these girls'/women's female developmental trajectory. Obstacles which stood in the way for the trajectory to take its "normal" course. As a result of which these women's identities, whether at the life stage of childhood, adolescence or young adulthood, could not develop unhindered and unspoiled. Where these women "failed to thrive", resulting in low self-esteem". The theme that binds the various components of the portfolio concerns the pain and losses that can go into being a girl/woman. It concerns the conceptualisations surrounding it; of what makes a woman loveable and acceptable, good, competent, worthy etc in this world. It talks about the aspects of girls'/women's bodies, their shape, the organs of vagina and womb, and sexual and reproductive functioning in relation to

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[1] As the subtitle of the preface, which are the subtitles to the varied sections of the portfolio, tries to capture

that. It talks about women's prospective or actual roles as mothers, partners, and their experiences of these, which seem important and all somehow go to the heart of being a woman. And how, in tandem with this, women's worth as girls/women, can fuse with any of these and go on to define them and contribute to their sense of agency. Here women judge themselves on these aspects and feel judged on them by others. It goes on to outline how, when difficulties cross these women's paths, these are navigated, through varied flights into Anorexia Nervosa (AN), into depression, "denial" etc. It considers the life-stories, however painful, that Counselling Psychologists have the privilege of witnessing. Allowing these women to express their innermost thoughts, feelings and fears. For these women, through a guided process, to revisit the so difficult experiences that had such a great impact on them, and consider and challenge the conclusions drawn from it. To acknowledge their loss and pain, but also look with them for aspects that have gone "unstoried". In order to help these women rebuilt the "picture" of self, others & the world (ie. build alternative, more elaborate beliefs about the self, others, and the world). To bring them back from the sense of failure and despair that they have been surrounded with. To introduce a less narrowly defined "picture" (schema) of the world, others and self. To allow, to some extend, a re-finding or finding of the self, whilst being allowed to mourn the losses incurred and move on and "thrive again" in whatever way appropriate, and possible, considering the person and the circumstances.

SECTION D, presents a case study, taken from **professional practice**. Drawing from theory and research, I conceptualise what is behind the atypical Anorexia Nervosa (AN) that Holly presents with. Listening to her story and attempting to come alongside her.

Looking through her eyes at her experience of childhood sexual abuse, we see that she has been given the message that she will not be protected as a child. That she cannot be a child, and that she is there to satisfy her grandfather's & her grandfather's brother's sexual desires, in a premature confrontation of the self as a sexual being, or rather as a (female) sexual object. Here her needs for love and safety are not met by her carers. This involves a loss of a potentially secure girl-hood. Here the AN serves as a flight into staying childlike and not claiming life as an adolescent, a young adult, and adult woman. Instead she "regresses" to the child she was not allowed to be, reclaiming her lost childhood. She shuts out difficult feelings through starvation, flushing out any food she may have eaten, with laxatives as a cleansing ritual. In order to wash away all the badness that she feels clings to her, in an attempt to alleviate the aversive experiences of herself and body that constantly besiege her. It concerns an identity that is prevented from forming, in its very early stages. Where there seems no self, beyond the self as a (female) sexual object. The varied aspects of self (including the sexual self) and possibilities for healthy loving and relating are not explored in adolescence and adulthood, beyond a part-repetition of the pattern, getting involved with a very needy young man. Stopping physical and emotional growth through starvation and avoiding inter-relating; an all-absorbing Anorexic self is occupied instead.

<u>SECTION B</u>, the **research component** of the portfolio, considers the experience of self in adolescence through the eyes of the girl diagnosed with the Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH). This is a condition where girls are born without a vagina and womb, which does not get diagnosed until puberty, when these young women fail to

menstruate. This is only one gynaecological condition that presents in adolescence. It considers how the self, growing into womanhood and being diagnosed at that particular moment in time, is felt to be jeopardized. It considers the conclusions drawn by these women and their sense of incompleteness, of deficiency and incompetence as a woman. How the sense of self that is often so fragile at the time of diagnosis, ie. in puberty, can be shattered through this experience, leading to a flight into depression, eating trouble, a cutting off and denial etc. It notes these women's experience of a terrible loss of a sense of normality & privacy, being unable to have sexually intimate relationships without medical intervention. The loss of never being able to carry and give birth to a child in future, that she has with the partner whom she loves. It involves a loss of the potential child that these women, as any other woman, assumes that she may one day carry. It involves the loss of a potential carefree teenage-hood, a loss of potential roles, of acceptability/loveability/competence to self and others as a woman etc.

SECTION C, the **critical literature review** component of the portfolio, presents a review of the literature of Cognitive-behavioural therapy of Anorexia Nervosa, looking through the eyes of the adolescent woman with AN. It elaborates on the sense of inadequacy, deficiency, ineffectiveness, impotency and low self-esteem (on a more general level) that young women may experience, through a negative interpretation of circumstances and the self, an inability to deal with interpersonal issues and or intense mood states, with a possible over-focus on their bodies and food. Where these women flee into an idealised female thinness. Through this they seek to obtain a sense of self from an anorexic identity and a sense of relief, control, perfection and achievement that goes with that. In doing so, they avoid facing difficult emotions, thoughts, and relational issues etc. It involves a loss of self, of experienced/expressed teenage "normality". Here the self becomes defined in terms of weight, and is linked to self value; ones' lovability and acceptability as a person, in a similar merging, that also happens in women diagnosed with MRKH, where self becomes defined/judged in terms of the presence/absence of certain body parts and becomes directly linked to ones' value as a woman.

SECTION E, presents a second case study, taken from **professional practice**. It looks at the experience of self of Mandy, a woman who lost her toddler son through accidental death. It considers her interpretation of the events, noting her conclusions of inadequacy as a young mother for failing to protect him. The event shattered her new-found sense of self, security and feeling loveable & acceptable (and able to be loving), that she had gained from marriage and motherhood, what with having experienced neglect and insecurity in childhood and adolescence. She feels that the need to protect her child from accidents has not been met by her, and that she has terribly failed as a mother. This involves a loss of potential "carefree" early motherhood and mothering in young adulthood. This results in her flight into chronic, clinical, reactive depression. Or, alternatively, mechanisms of obsessive over-compensatory activity, to remedy her deficient mothering, to pay for it, and never stop paying for what happened. Trying to make up for it to her other children and husband. Not allowing herself to live and laugh again, sinking with her little Frank in the black mud that he had drowned in, for another 22 years, when she presented for therapy.

LEVEL 2: PROFESSIONAL KNOWLEDGE AND SKILLS DEVELOPMENT:

At a "professional knowledge and skills development" level, the sections link as follows:

SECTION D & E, the **professional practice** component of the portfolio, aims to use theory and research, to in practice, conceptualise what is happening for the two women presenting, and find ways of working with them. To help them start to develop a sense of self that was not allowed to even begin to develop in the first place as in the case presented in section D. Or to re-piece together a sense of self as a good enough mother to the remaining child, and children born subsequently to her toddler's death, as in the case presented in section E. To look at issues of shame, having compassion on the self, and help these women further mourn the losses incurred. This illustrates my skills in translating Cognitive-behavioural knowledge and models for varied presentations in great depth, as well as cognitive trauma theory, and theory on loss and mourning, into practice. Conceptualising the cases and applying and tailoring therapy to suit the individual patient's "illness picture/life story" and needs, through creative, and compassionate pieces of reflective practice as a scientist-practitioner.

SECTION C, the **critical literature review** component of the portfolio, aims to further delve into the varied ways of conceptualizing one presentation of female identity distress, namely Anorexia Nervosa in great detail from a Cognitive-behavioural perspective. Considering the early and more recent contributions of Cognitive-behavioural theories & Cognitive-schema theory of AN to the understanding of the development and maintenance of the most important Cognitive-behavioural aspects of AN; its core pathology. To consider from the models proposed, what their suggested frameworks for focusing on the core pathology and reversing its maintaining factors are. Ie. the application of theory to treatment. To furthermore, look at both empirical evidence that has been collected to test treatment and the different aspects of Cognitive theories of AN proposed. To consider the limitations of existing models, the gaps in knowledge and what conclusions can be drawn.

SECTION B, the **research component** of the portfolio, extends on the type of analysis engaged in, in part D above, though on a different topic. It presents the reader with not only a major review of the literature of the little known area of MRKH, of being diagnosed with this condition and the impact of diagnosis and medical treatment. But, it also puts forward my own theory of what happens when this occurs. This theory draws from the ideas generated by the review, my own professional experience of working with these women[2], and using Cognitive Schema & Trauma theory in an iterative process. It, furthermore, places the conceptualisation within theory on psychosexual differentiation, adolescent developmental stages and tasks, as a context to situate the time of diagnoses in and highlight why and where diagnosis "hits" the way it does these young women. This conceptualisation is then translated into therapy; considering the core problem presentation, its maintaining factors; revisiting and reworking the experience, rebuilding a sense of self, using, amongst others, "Pennebakerian" writing tools. The treatment developed is then evaluated in a randomized controlled trial which I carried out single-handedly. It provides a discussion of (a) the data gathered, including cross-sectional data, (b) associated limitations of the research, suggestions and recommendations for further research, and finally (c) the strengths of the research.

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[2] *from which the idea for the research directly arose.*

SECTION B: RESEARCH

TITLE:

TREATMENT FOR MAYER-ROKITANSKY-KÜSTER-HAUSER SYNDROME (MRKH) – DEVELOPMENT AND EVALUATION OF A GROUP COGNITIVE-BEHAVIOURAL THERAPY PROGRAMME

SETTING:

The National Centre for Adolescent and Adult Women with Congenital Abnormalities of the Genital Tract, Queen Charlotte's & Chelsea Hospital, London, UK

CHAPTER ONE: INTRODUCTION, AIMS AND OVERVIEW[1]

This thesis describes the development and evaluation of a psychological (group cognitive behavioural) intervention for women with Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH). The idea for the studies described here arose directly from my clinical work with women with this condition at the National Centre for Adolescent and Adult Women with Congenital Abnormalities of the Genital Tract at Queen Charlotte's & Chelsea Hospital in London, UK. To set the scene in this chapter I will first give an introduction to the Mayer-Rokitansky-Küster-Hauser Syndrome and its treatment, and, secondly will outline the aims and structure of this thesis.

1.1. WHAT IS THE MAYER-ROKITANSKY-KÜSTER-HAUSER SYNDROME?

The Mayer-Rokitansky-Küster-Hauser Syndrome, abbreviated to MRKH or Rokitansky Syndrome, is also known under the name of Vaginal Müllerian Agenesis Syndrome or Congenital Absence of the Vagina. Though already known by Avicenna (980-1037) and Albucassis (1013-1100) and first described in the contemporary medical literature by Realdus Columbus in 1562 (Ghirardini & Popp, 1995), Vaginal Müllerian Agenesis, was particularly characterised in the German medical literature by Mayer (1829), Rokitansky (1838), Küster (1910) and Hauser & Schreiner (1961). It became referred to as the Mayer-Rokitansky-Küster Syndrome by Hauser & Schreiner in 1961, and to this Hauser's name was added by Vecchietti in 1970. Thus, as Ghirardini & Popp (1995) point out, the name is a "summary of the development of our knowledge on this subject and of medical ideas in the last 175 years".

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[1] The research was undertaken, amongst others, for my (top-up) DPsych (Post Chartered Counselling Psychology) commenced in October 2004.

The condition is characterised by a congenital abnormality of the female genital tract. This manifests itself in a non-formation of the vagina, in association with a complete absence of the uterus, a rudimentary uterus in the midline, or, more commonly, rudimentary uterine horns located on the lateral pelvic sidewalls, but with normal ovaries (Edmonds, 2000). This is pictorially represented in figure 1.1 as follows:

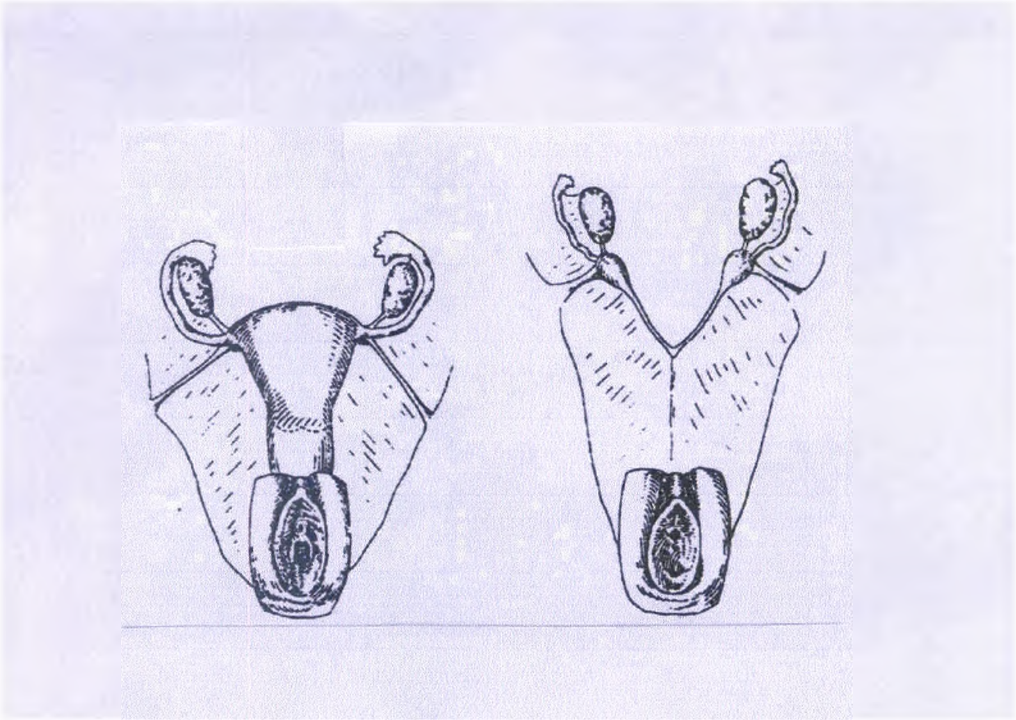

Figure 1.1. **Normally developed internal versus MRKH female reproductive organs,** Hauser & Schreiner (1961) – with permission of EMH Swiss Medical Publishers Ltd.[2]

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[2] EMH Swiss Medical Publishers Ltd. "were pleased to grant permission to J.G. Heller for the reproduction of the figure from Hauser GA & Schreiner WE: Das Mayer-Rokitansky-Kuster Syndrome – Uterus bipartitus solidus rudimentarius cum vagina solida. Schweiz Med Wochenschr 1961, 91, 381-384" in their email of 15/05/2006 - written by Natalie Marty, MD, Director of Publications

A sub-group may also have renal, ear or skeletal abnormalities (Strubbe, Cremer & Willemsen, 1994). Affected women have a normal female karyotype (chromosomal pattern: 46,XX). They have normal external genitalia; i.e. a vulva, including the mons pubis, labia majora and minora, clitoris and vestibule of the vagina. The latter is on a spectrum from being very shallow and blind-ending, to being almost non-existent. Either a mere vaginal dimple can be detected, or a perineum, that on closer inspection, immediately posterior to the urethra and above the rectum, is either slightly depressed, or almost flat. The condition stems from a failure of the Müllerian ducts to develop "in utero". The syndrome may result from a genetic mutation or deletion of genes on chromosome 16. This chromosome has also been linked to renal (mal)formation. However, in the majority of cases the aetiology is thought to be polygenic multi-factorial (Edmonds, 2003). MRKH has an incidence of approximately 1 in 5000 female births (Aittomaki, Eroila & Kajanoja, 2001). It is the second commonest cause of primary amenorrhoea, second only to Turner's Syndrome (Edmonds, 2000).

At puberty the female sexual secondary characteristics of breast development, underarm and pubic hair growth are brought on by normally functioning ovaries. Women with MRKH have a hormonal cycle normal in length, but without menstrual periods, because of the lack of a uterus with its associated pattern of a build up, and eventual shedding of endometrium. Amenorrhoea may be the only outward sign of the problem, apart from a failure at sexual penetration possibly revealing the absence of the vagina. The age of diagnosis of the condition varies widely within and between studies, reportedly ranging from 1 to 28 years. The condition is typically diagnosed when women are well into puberty, with a reported mean or median age at diagnosis ranging from 16.0 to 17.7 years (Fairbairn, 1952; Kaplan, 1968; David, Carmil, Barr-David & Serr, 1975; Hecker & McGuire, 1977; Rock, Reeves, Retto, Baramki, Zacur & Jones, 1983; Poland & Evans, 1985; Weijenborg, van Dijk & van Hall, 1986; Möbus, Sachweh, Knapstein & Kreienberg, 1993; Robson & Oliver, 2000; Weijenborg & ter Kuile, 2000; Holt & Slade, 2003). Often women will have waited, or have been told to 'give it a few years', before undergoing tests, in case they are late developers. Diagnosis is made by clinical examination of the vulva, which reveals a short, blind-ending vagina in a young woman with primary amenorrhoea, normal sexual secondary characteristics, and blood tests which show normal levels of female hormones for that age group. Confirmation is by ultrasound or magnetic resonance imaging, which shows the amount of uterine tissue present. In view of the normal levels of female hormones (from which the presence of ovaries can be inferred) and the ultrasound or magnetic resonance imaging scan findings (revealing the absence of the womb), there is no need for karyotyping (by means of a Buckle smear) of chromosomal make-up. There is also no need for examination under anaesthesia or laparoscopy to confirm the diagnosis. Overall, non-invasive, but sound procedures, best performed in a Centre with expertise in these conditions suffice for making a diagnosis (Edmonds, 2000; Edmonds, 2003). After the first publications on the Syndrome, many studies reported on different surgical and non-surgical methods developed for creating a neo-vagina, with treatment outcome evaluations focusing on anatomical (i.e. in terms of the size of the neovagina) and functional criteria (i.e. in terms of the ability to have satisfactory, e.g. pain free sexual intercourse). The current treatment of choice is the non-surgical method of dilation therapy (Frank, 1938). This involves the patient being taught to put pressure on the vaginal dimple using dilators of gradually increasing size for 20 minutes three times a day (Edmonds, 2000). The whole process takes several months. Success rates in creating a vagina using dilators have ranged from 43 to 100% (Nadarajah, Quek, Rose & Edmonds, 2005)[3].

For many years it was a given that women with MRKH could not have children of their own. However, these women do have normal ovarian function, and with the advancement of reproductive techniques in the last decade, having children of their own has now become possible for women with MRKH through In Vitro Fertilisation using a "carrier mother" (i.e. IVF surrogacy) (Petrozolla, Gray, Davis & Reindollar, 1997; Beski, Gorgy, Venkat, Craft & Edmonds, 2000; Goldfarb, Austin & Peskin, 2000). Importantly, no congenital abnormalities (of the uterus or vagina) have been found in these children (Edmonds, 2000).

Most authors writing about MRKH mention the profound psychological impact being diagnosed with and treated for MRKH has on women with this abnormality, both in the short and longer term (David, Carmil, Bar-David & Serr, 1975; Hecker & McGuire, 1977; Poland & Evans, 1985; Holt & Slade, 2003). Most also mention the need for psychological support or intervention (Mobus, Sachweh, Knapstein & Kreienberg, 1993; Edmonds 2000; Edmonds 2003). Yet very little is known about the specifics and nature

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[3] The low success rate of 43% was reported by Rock, Reeves, Retto, Baramki, Zacur & Jones (1983). The main cause for the frequent failure of the dilator treatment in this series seems to have been iatrogenic in cases who had developed scar tissue following earlier attempts at hymenectomy.

of the psychological difficulties that arise, what a psychological intervention for MRKH should look like and what components it should contain.

1.2 AIMS AND STRUCTURE OF THIS THESIS:

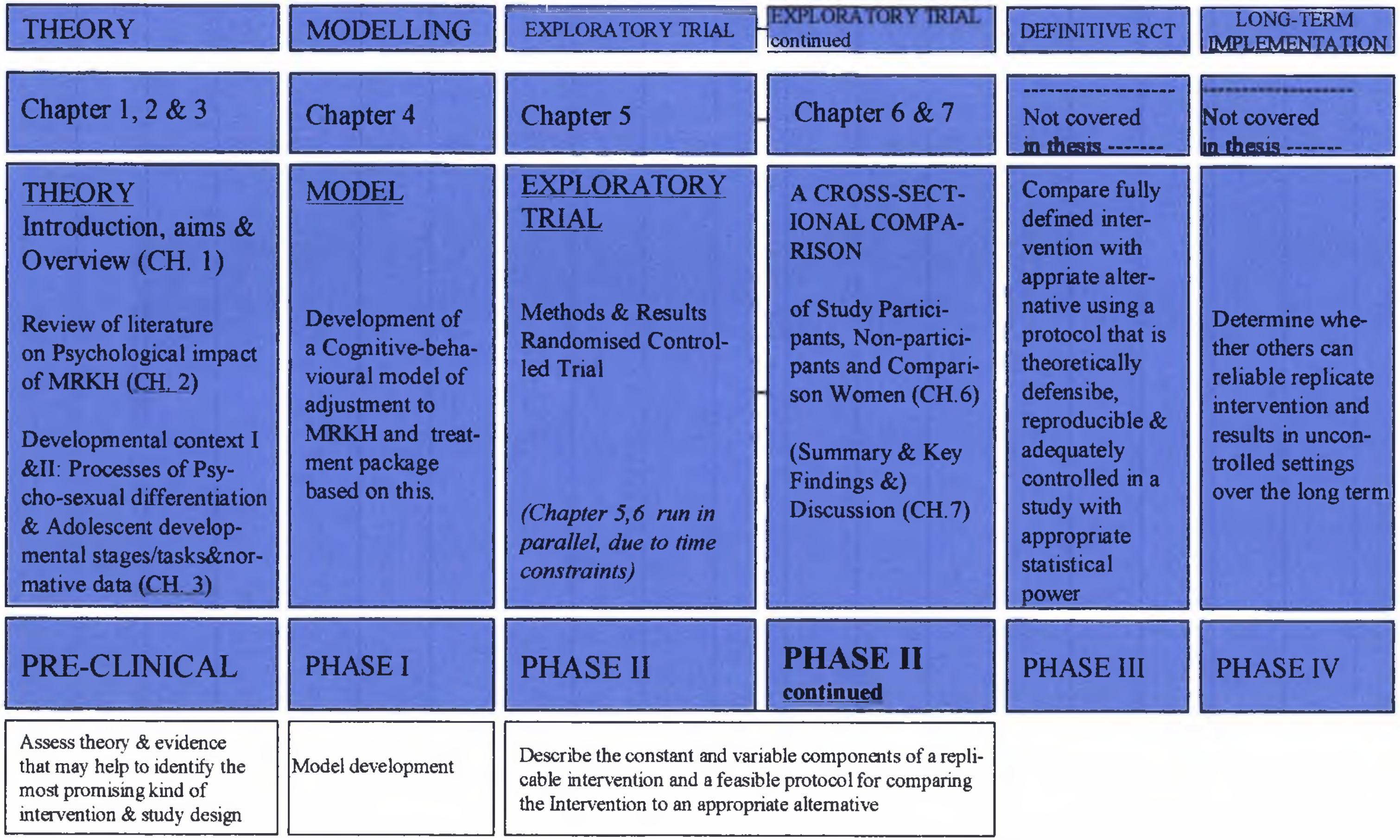
The broad aim of this thesis was to develop and evaluate an intervention addressing the psychological sequelae of MRKH. Given that MRKH is relatively rare, distressing to those affected, and has multiple and diverse psychosocial sequelae it was clear from the out-set that any intervention would have to be multi-faceted and complex. In other words I was less preoccupied with developing a 'pure' intervention consisting of one 'active ingredient' but rather wanted to give it 'my best shot' and devise an intervention which would be able to address a multitude of psychological difficulties arising in the context of MRKH.

A framework for the development and evaluation of complex health interventions has been published by the Medical Research Council (2002). Complex interventions are defined as those "built up from a number of components, which may act both independently and inter-dependently. The components usually include behaviours, parameters of behaviours (e.g. frequency, timing), and methods of organizing and delivering those behaviours (e.g. type(s) of practitioner, setting and loction). It is not easy precisely to define the "active ingredients" of a complex intervention."

The framework suggests a series of five phases of investigation in the development and evaluation of such interventions, ranging from a pre-clinical or theory phase, a model development phase (phase 1), an exploratory trial phase (phase 2), a definitive randomized controlled trial phase (phase 3) and a long-term implementation phase (phase 4). The work presented in the present thesis was conducted with the MRC framework in mind and covers the first three phases. A diagrammatic representation of the MRC framework and how the chapters of the present thesis map onto the different phases is given in figure 1.2. Given the time constraints of producing a thesis, by necessity some of the work on different phases has had to happen in parallel rather than strictly sequentially. The MRC framework acknowledges this point by saying that the framework "should not be read as an inflexible "to do list" but rather as advice to apply to the extent to which it is relevant at each stage" of a given project.

Chapters 2 and 3 both relate to the pre-clinical or theory phase. The aims in this phase are to assess theory and evidence that may help to identify the most promising kind of intervention and study design. In chapter 2, I present a systematic review of the literature on psychological sequelae of MRKH addressing questions on the immediate and longer term psychological impact of being diagnosed with this condition and receiving treatment. Chapter 3 contains a narrative review of the literature on adolescent development of identity and sexual milestones with the aim of getting a better understanding of how discovery/diagnosis of MRKH affects normal development. Chapter 4 relates to the model development phase of the framework. Here I describe the development of a cognitive-behavioural model of adjustment to the diagnosis of MRKH and the treatment package based on this. Chapter 5, relates to the exploratory trial phase of the MRC framework. The aims of this phase of the development of a complex intervention are to describe the constant and variable components of a replicable intervention and a feasible protocol for comparing the intervention to an appropriate alternative. The chapter details the (a) design of and setting for the study, (b) participants' inclusion and exclusion criteria, (c) ethical considerations, and (d) recruitment. It also provides descriptions of (i) the intervention, (ii) outcome measures and assessments, (iii) sample size, (iv) randomization, and (v) method of statistical analysis chosen. It, finally, details the findings from the randomized controlled trial, outlining (a) the flow of participants through the study, (b) participants' characteristics at baseline, reports on the (c) quantitative results of primary and secondary outcome measures (including a qualitative component), providing a (d) discussion of the limitations of the research, with suggestions and recommendations for further research, as well as outlining its strengths and noting the issued raised by the study. Chapter 6 reports a cross-sectional comparison study of participants, non-participants and comparison women, which was run in parallel with the trial. Since very little is known from research into MRKH about the psychological functioning of women with the disorder, this chapter aims to identify how these women compare with other women in terms of levels of psychiatric problems, interpersonal problems or self-esteem. Moreover, this chapter aims to address the question of (a) how within the group of women with MRKH those who decide not to take up the offer of psychological treatment compare to those who do in terms of their psychological functioning and the related question of (b) what the characteristics of MRKH women who complete psychological treatment are and how do they compare to those of women who drop out from treatment. Finally, it addresses the question of (c) whether following psychological treatment the psychological functioning of women with MRKH becomes similar to that of women without the disorder. Chapter 7, in closing, summarises the key findings of the research and provides an overarching discussion of the issues raised by the study and goes back to the MRC framework to discuss what the definitive RCT phase and the long-term implementation phase which are not covered in this thesis, might look like.

Figure 1.2 MRC framework for development and evaluation of RCTs for Complex Interventions to Improve Health - Structure of Thesis



THEORY	MODELLING	EXPLORATORY TRIAL	EXPLORATORY TRIAL continued	DEFINITIVE RCT	LONG-TERM IMPLEMENTATION
Chapter 1, 2 & 3	Chapter 4	Chapter 5	Chapter 6 & 7	Not covered in thesis	Not covered in thesis
THEORY Introduction, aims & Overview (CH. 1) Review of literature on Psychological impact of MRKH (CH. 2) Developmental context I &II: Processes of Psycho-sexual differentiation & Adolescent developmental stages/tasks&normative data (CH. 3)	MODEL Development of a Cognitive-behavioural model of adjustment to MRKH and treatment package based on this.	EXPLORATORY TRIAL Methods & Results Randomised Controlled Trial *(Chapter 5,6 run in parallel, due to time constraints)*	A CROSS-SECTIONAL COMPARISON of Study Participants, Non-participants and Comparison Women (CH.6) (Summary & Key Findings &) Discussion (CH.7)	Compare fully defined intervention with appriate alternative using a protocol that is theoretically defensibe, reproducible & adequately controlled in a study with appropriate statistical power	Determine whether others can reliable replicate intervention and results in uncontrolled settings over the long term
PRE-CLINICAL	PHASE I	PHASE II	**PHASE II continued**	PHASE III	PHASE IV
Assess theory & evidence that may help to identify the most promising kind of intervention & study design	Model development	Describe the constant and variable components of a replicable intervention and a feasible protocol for comparing the Intervention to an appropriate alternative			

Continuum of increasing evidence ======>>>>>

CHAPTER TWO: A SYSTEMATIC REVIEW OF THE LITERATURE ON THE PSYCHOLOGICAL IMPACT OF MRKH AND ITS TREATMENT

2.1. AIMS

Most of the literature on MRKH has focused on medical or surgical treatment outcomes. There has been much less interest in the psychological impact of MRKH and its medical/surgical treatment on women with this condition, either straight after diagnosis or in the longer term. The aim of the present chapter is to conduct a systematic review of the literature on MRKH so as to develop a better understanding of the specific nature of the psychological sequelae of MRKH and its treatment and to develop ideas about potential targets for intervention.

2.2. DEVELOPMENT OF QUESTIONS

The questions for the systematic review were developed from reading of the literature and my clinical work with women with MRKH. From the available literature it is often not possible to distinguish between the effects of MRKH per se and the effect of medical or surgical intervention (as many series are of cases seen post-intervention) and it was therefore decided to look at the effects of both together in questions B, C & D. Question E was posed mindful of the fact that the timing, nature and processes involved in medical/surgical contacts themselves may be experienced as difficult:

A. What are the short-term psychological reactions of these women, their families, partners and friends to discovery of the condition or diagnosis of MRKH?

B. What are the longer-term effects of MRKH and its medical/surgical treatment in terms of these women's 'experience of self'?

C. What are the effects of MRKH and its medical/surgical treatment in terms of other longer term psychological and psychosocial outcomes including these women's coping responses?

D. How does MRKH and its medical/surgical treatment effect these women's sexual and romantic relationships?

E. What is the psychological impact on these women of MRKH-related medical/surgical contacts and interventions in terms of the timing and manner in which they are being conducted?

F. Does psychological therapy/counselling improve anatomical, functional and psychological outcomes in MRKH?

2.3. METHODS

PubMed (Science Direct/Medline) and PsycINFO searches were conducted, with hand searches of the reference sections of all articles, books and chapters retrieved. The following search terms were used: vaginal and agenesis, mullerian and agenesis, congenital and absence and vagina (and womb), congenital and malformations and (female) and genital and tract, Mayer and Rokitansky and Küster and Hauser and Syndrome, vaginal and aplasia, Rokitansky and syndrome, Mayer and Rokitansky, Mayer and Rokitansky and syndrome, Rokitansky and Küster and syndrome, psychosocial or psychosexual, or psychological or psychiatric and aspects or impact or effects and of and (the above), medical or surgical and psychological and management and of and (the above). In order to include historical references no data constraints were enforced. All titles, abstracts and the full articles were evaluated by J.G. Heller for potential relevance and subsequently checked by a second assessor, U.H. Schmidt.

Some information is from English translations of works originally published in German, and abstracts written in English for articles written in German, as well as reviews of these German works by other authors. Where available, the original German papers were reviewed. Both J.G. Heller and U.H. Schmidt are fluent in English and Dutch or German. Mr. D.K. Edmonds, Obstetrician and Gynaecologist, and Clinical Director of the National Centre of Adolescent and Adult Women with Congenital Abnormalities of the Genital Tract at Queen Charlotte's and Chelsea Hospital (see also section 5.3), was consulted by J.G. Heller for clarification of medical and diagnostic details of certain case descriptions/series[1].

A total of 479 sources were identified. Sources were included if they discussed diagnosis and/or management of MRKH and reported upon the psychosocial/sexual, psychological or psychiatric aspects of the syndrome either as their main theme or in addition to outlining the anatomical and functional results of creating a neo-vagina. The majority of the sources involved were exclusively of a medical/surgical nature, without reference to psychological outcomes in women with MRKH, and these sources were therefore excluded. Deleting irrelevant titles listed in the searches, cutting out duplicate articles within and between search engines/databases, and taking out the sources of an exclusive medical/surgical nature, the number was reduced to 28 sources. These were judged to include material relevant to the review, providing possible answers to the questions posed above. Four of these were narrative reviews, based on studied opinion and institutional experience with MRKH, rather than involving a study of particular cases (i.e. Jensen & Reiter, 1999; Edmonds, 2000; Croak, Gebhart, Klingele & Lee, 2003; Edmonds, 2003). One source involved duplications of previous work (i.e. Bryan, Nigro & Counsellor, 1949, versus Counsellor, 1948). This leaves 23 sources, of which 16 had a primary focus on psychological, psychosocial or psychosexual aspects of MRKH. These 16 sources consisted of four psycho-analytic case descriptions (two of these involved part-duplications of previous work by the same author: i.e. Kaplan, 1970 vs

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[1] For example, Masters & Johnson's (1961) article described a mixture of cases of women with a potential diagnosis of MRKH and those with other congenital abnormalities of the genital tract, but which had the absence of a vagina in common. Fairbairn's (1952) case study gave rather sketchy medical detail which precluded a definitive diagnosis. On balance, this case was judged unlikely to be a presentation of MRKH (see also footnote 9), but still appeared of interest. Mr. D.K Edmonds was also consulted on some aspects of Kaplan's (1968) writings, which are discussed in footnote 10.

Kaplan 1968, or inclusion of other authors' case descriptions or series in ones' own case descriptions: i.e. Greenacre, 1958; Masters & Johnson, 1961[2]; Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis, 1962[3]; Kaplan, 1968 vs Fairbairn, 1952), nine retrospectively gathered case series (of which one a qualitative study) one case series which combined retrospectively and prospectively gathered cases, one prospectively gathered case series, and one cross-sectional study. The remaining seven sources had a mainly medical or surgical focus (e.g. descriptions of the outcomes of surgical and non-surgical procedures) but with some mention of psychological aspects of MRKH. These seven sources consisted of six retrospective case series, and one retrospective/prospective case series.

The 23 sources report on case descriptions/series ranging from n=1 to n=88 subjects. A data extraction form was created for the purpose of the present review, so as to have a uniform format for characterising the quality and content of the studies included in the review. In devising the data extraction form criteria for the critical appraisal of cohort studies were taken into account (Mamdani, Sykora, Li, Normand, Streiner, Austin, Rochon & Anderson, 2005; Normand, Sykora, Li, Mamdani, Rochon & Anderson, 2005; Rochon, Gurwitz, Sykora, Mamdani, Streiner, Garfinkel, Normand & Anderson, 2005;). A copy of the data extraction form can be found in appendix 2.1.

Details of number of cases per study, setting, focus and other methodological aspects are given in tables 2.1 and 2.2. Table 2.1 lists the 16 articles that had a primary focus on

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[2] For example, Kaplan's (1968) case 16 is the same as Masters & Johnson's case B and Kaplan's (1968) case 17 is Masters & Johnson's case C.

[3] Furthermore, Kaplan (1968) in his case series, including nine patients seen in his own practice and two more unpublished case protocols (plus 6 cases taken from the literature), does only describe 8 out of his own 11 cases fully, see table 2.1.

[6] This article includes case material of Fairbairn's (1952) and Masters & Johnson's (1961) studies.

psychological aspects of MRKH. Table 2.2 lists the seven articles with a mainly medical or surgical focus. Table 2.3 lists the four narrative reviews. Table 2.4 lists the sources involving duplication and part-duplications of papers previously published.

2.4. LIMITATIONS OF THE ARTICLES IDENTIFIED

Most of the findings in the articles tabled, are based on single case studies or small to medium-sized retrospective case series of women with MRKH who were followed up over a period of time. Not all studies explicitly state how they identified their cases, and what pool of potential cases their study participants were drawn from. Where this is stated, the number of study participants is often considerably smaller than the pool of potential participants, suggesting that selection biases may be present. This is not a trivial point as it is likely that women with poorer outcomes (both gynaecologically and psychologically) are perhaps less likely to make themselves available for follow-up. Some studies only include those with complete information from initial assessment through to intervention and post-intervention, again potentially biasing their sample towards those with more positive outcomes. Many studies give little baseline information about their study participants (in terms of socio-demographics, medical/diagnostic information and psychological status). Duration of follow-up periods were highly variable within and between studies and ranged from a few months to more than a decade. Some studies do not specify the duration of the follow-up period. Where women are asked to remember relatively 'soft' information about their emotional response to diagnosis or treatment the reliability of this information may be affected by the passage of many years. Mostly, cases seem to have been obtained retrospectively, often including cases presenting over lengthy periods, i.e. 20 to 30 years, during which time clinical practice and cultural attitudes may have changed considerably. Very few series are based on planned cross-sectional or prospective investigation, and some studies involve both retrospectively and prospectively gathered cases. In terms of diagnostic classification, not all samples are homogenous in terms of the congenital abnormality presented, such as the studies by Bryan, Nigro & Counseller (1949), Turunen (1952), Masters & Johnson (1961), Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis (1962), Kaplan (1968)[6], Hecker & McGuire (1977), and Langer, Grünberger & Ringer (1990) with the diagnosis of Fairbairn's (1952) case remaining uncertain (see footnotes 1 and 9). This is problematic if outcomes are not described separately for cases with MRKH and other disorders. Some writings draw from unpublished data, which are not open to scrutiny (such as Jensen & Reiter, 1999). With the exception of Nadarajah, Quek, Rose & Edmonds (2005) no other study included a comparison group.

The particular aims or focus of a given study often are not explicitly stated and even where these are stated, may not be very specific. Details of other aspects of methodology are also often lacking, including whether and what psychometric measures were used and where patients were followed up by interview what the specific questions asked were. Findings are usually descriptive and are often presented without fully quantifying them (e.g. by saying 'most patients' or 'many patients') thereby making it hard to distinguish between author's impressions and opinions and data obtained from the patients. Where qualitative material is presented this is often mixed in terms of how this was obtained and combines material from case descriptions of psycho-analytic psychotherapy and diagnostic interviews, with unpublished case descriptions, including case descriptions/series previously described by other authors into ones' own case series or duplicating or part-duplicating the author's own previous work, as already mentioned. Methods listed for assessing outcomes are those of observation, self-report questionnaires, semi-structured (pre-/post-operative) interviews (with patients and parents and recorded group discussions), pre-/post-group psychometric measures, physical exam, medical history, clinical case material, descriptions of psychological aspects of the condition, functional/functioning yes/no success ratings of surgery etc. Many writers do not make it clear in their articles, which of their "conclusions" are supported by "hard data" and what is simply their opinion. They often do not link their findings to existing literature or theory. Alternatively, their writings entail a repetition of what they have gleaned from reading previous studies[7], sometimes without going back to original sources, thereby perpetuating misinterpretations or mistakes and presenting them as "fact".[8]

Thus in summary the existing literature on psychological, psychosocial and psychosexual aspects of MRKH is seriously flawed. Bearing in mind these limitations a number of themes emerge from the sources in response to the questions above.

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[7] E.g. Hecker & McGuire (1977) repeat Kaplan's (1968) assertion that diagnosis of MRKH should/could be made in infancy, see also footnote 10.

[8] E.g. Hecker & McGuire (1977) perpetuated the (probably unfounded) assertion that suicide is a risk following diagnosis of MRKH, see also footnote 13.

2.5. RESULTS - QUESTIONS A TO F:

2.5.A. What are the short-term psychological reactions of these women, their families, partners and friends to discovery of the condition or diagnosis of MRKH?

Nine studies, including two psycho-analytic single case descriptions and seven case series provided data that addressed this question.

Fairbairn (1952) drawing from a single psycho-analytic case, states that the woman "welcomed the news of diagnosis aged 21". He notes that she saw it as meaning that "she was granted exemption of the burden of womanhood". "Womanhood" had acquired unpleasant associations for her with connotations of a "vulnerable female body". Being the eldest in a large family, as a child she had seen blood on the sheets after her mother had given birth to one of her siblings, which had frightened her. Fairbairn further writes that his client "dismissed the whole subject of sex and marriage from her mind with a sigh of relief". "She felt now free to devote herself, without hindrance, to a career (as a teacher)".[9]

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[9] An alternative interpretation of the material presented by Fairbairn's client is that she was trying to "block out" her predicament, rather than displaying "relieved" acceptance. This idea is supported by Fairbairn's later descriptions that her "expectations of work and actual experiences left much to be desired". He notes that this client tried alternative career avenues, away from teaching, but never found satisfaction. One could argue that not being given the option of vaginal correction (though Dupuytren had already describe this procedure in 1817), she was precluded from having a fulfilling sexual relationship, and being able to balance work with other activities. This may have led to her continually striving to "fill the gap", and eventually becoming chronically depressed.
As an interesting aside, Fairburn (1952), notes that his client's sisters purportedly shared the condition with her, but were relatively free of "psychopathology". This raises the question as to whether Fairbairn's client may have had Complete Androgen Insensitivity Syndrome (CAIS) as opposed to MRKH, a genetic condition inherited via the female line (Slijper, Frets, Boehmer, Drop & Niermeijer, 2000). CAIS women have a female phenotype (apparent gender) and a XY karyotype (male chromosomal pattern), due to their body's inability to use Androgens pre- and post-natally. An alternative diagnosis in this case is that of Hermaphroditism, with a mixture of 46XY and 46XX chromosomes. There is simply not enough information here to reach a definitive diagnosis.

A further psycho-analytic single case presentation by Greenacre (1958) describes a girl who, at 7 or 8 years of age, in mutual sexual investigation with another girl discovers that "her genital groove lacks an opening". Greenacre notes that the girl "attempted to deny her dilemma and accepted the consolation of her young friend who told her that it would probably come after a time".

Kaplan (1968), based on his series of 11 cases, suggests that even prior to diagnosis "a pervasive and powerful denial might operate", both by the patient and her parents and the physician. He goes on to say that this may arise in the context of "maternal ignorance of the normal anatomy of her daughter". He asserts that the mother's failure to identify the defect, whilst changing nappies and bathing the infant, could be due to "repression of sexual curiosity" or "unconscious refusal to acknowledge the defect". He suggests, furthermore, that "the father may be noting that something is wrong, but keeps it from the patient. The patient may discover the defect during masturbation or sex play, but keeps it from her parents, with the physician not identifying the anomaly, for whatever reason". Kaplan (1968) outlines the parental reactions to include "guilt, anxiety, depression, disappointment, rejection and over-solicitousness". He concludes that "the girl, who does not know what is wrong, gets the message of defectiveness, with a lasting imprint on her self-image". Following from this Kaplan (1968) notes that, "the reaction to diagnosis is replete with painful confusion and shocked misunderstandings"[10]. Specifically, he

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[10] According to Consultant Obstetrician & Gynaecologist Mr. D.K. Edmonds it is questionable that MRKH can be picked up at birth or during early childhood by a parent cleaning their baby daughter's genital area. The appearance of a baby girl's genitalia with or without MRKH would be indistinguishable. Specifically, the appearance of a vagina, closed off by a hymen, is no different from that of a blind ending vaginal dimple. "Painful confusion, shocked misunderstandings, guilt, anxiety, depression and denial", do

mentions that the initial responses included: denial (5/11), depression (2/11), other responses (3/11) e.g. placid acceptance, refusal to be a freak, eagerness for surgery; and was unknown in one case. Referring to Kaplan's (1968) "denial of the anomaly" by parents, Langer, Grünberger & Ringer (1990) report that in 2/11 cases in their series, diagnosis was made in early childhood, secondary to other check-ups being performed, and that one mother kept this secret for 9 years and the other mother "suppressed this knowledge" for about 17 years, till re-diagnosis was made.

David, Carmil, Bar-David & Serr (1975) in their series of 17 cases state that, "reviewing all of the examinations and medications to which these women are subjected after first presenting with a primary complaint, as a rule, the diagnostic process is far too lengthy"[11]. They note that "when at last the correct diagnosis was revealed to them, patients responded with 'shock', 'depression', 'confusion', 'hysteria', and 'a deep feeling of being different' (direct quotations)[12]. They all questioned their femininity with some distress, but most disturbing of all was the knowledge of being sterile." These authors also point out that the young woman's parents typically respond with gentleness, trying to comfort their daughter, although some fathers were not "in the known".

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undoubtedly abound at diagnosis as indicated by Kaplan (1968), but for wholly different reasons than he outlines.

[11] The authors do not note whether this was their conclusion or these women's subjective experiences. They do not provide an overview of what "typically" happens, detailing the timescale of the diagnostic process.

[12] The authors do not state how many women responded with 'shock', 'depression', 'confusion', 'hysteria', and 'a deep feeling of being different'.

Hecker & McGuire (1977) in their series of 23 cases from an original pool of 35 potential cases describe the reactions of women to diagnosis as follows: curious (n=3/23), tragic (n=7/23), moderately upset (n=8/23), indifferent (n=3/23), confused (n=8/23), angry (n=3/23), guilty (n=1/23), relieved (n=2/23), other (n=1/23). Five women in their series indicated that they felt "seriously suicidal at the time". These authors note that "in early papers a high percentage of cases were obtained from autopsy material allegedly following suicide"[13]. All patients in this series described the discovery of the abnormality "shattered" their previous self-image. In terms of how they felt about themselves at the time of discovery these women reported that they saw themselves as "adequate women without a vagina" (n=2/23), "adequate female with corrective problem" (n=9/23), "freak" (n=5/23), and "never be a woman" (n=8/23). Just like David, Carmil, Bar-David & Serr (1975), Hecker & McGuire (1977) note that patients were left too long (2-4 years) without knowing why they did not have periods, before being given the diagnosis. Their patients, when asked, considered age 12 an ideal age to be informed. The authors interpret this to be a reflection of these women's desire to be given what is sexually threatening information at a time when its meaning and impact are less immediate.[14] Hecker & McGuire (1977), like Kaplan (1968) previously, note that

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[13] The authors do not specify their sources here, and it is difficult to guess what they might be. Looking at the earliest papers on the subject, Rokitansky's (1838) descriptions are said to have come from the autopsy material of an unmarried woman who had died aged 60 of gastric cancer, diagnosed 10 years previously. Mayer (1829) made his observations from the autopsy of an unmarried woman who had died at 53 years of age, not stating the cause of death.

[14] Whether early diagnosis at age 12 is possible is questionable, given that the average age at menarche is now about age 12-12.9 – see Chapter 3 table 3.1 (Tanner, 1989; Obeidallah, Brennan, Brooks-Gunn, Kindlon & Earls, 1999). The suggestion of early diagnosis at age 12 does neither take this latter information into account, nor that specialist expertise is required for diagnosis.

the female genitals at the time of delivery should have been examined more closely, by attending medical staff[15].

Poland & Evans (1985) in their case series of n=54 report that in general the young women responded with "shock and denial" following diagnosis. Other commonly noted responses were fear and confusion; feelings of rejection, e.g. feeling like a freak; feeling only part female or incomplete; feeling isolated, as if no-one could ever understand how she felt and concerns about sexual relationships and marriage.

The authors reported that mothers had "concerns about their daughter's future as wives/mothers and carried guilt: wondering whether it was something that they did that caused the anomaly". Fathers, they noted, were "curious re surgery and sexual functioning". They stated that the following questions commonly arose in these women: "1. Why did this happen to me?, 2. How much of a female am I?, 3. What can you do for me?, and 4. How do I tell my boyfriend about the condition?".

Weijenborg, van Dijk & van Hall (1986) in a series of 11 cases, asked women about when and how their diagnosis of MRKH was made. Three of eleven initially went to see their general practitioner and were sent home to wait for another year without a gynecological examination. Five of eleven, when seen by a gynecologist, were not

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[15] Again this goes against expert opinion which says that it is very questionable that MRKH can be picked up at birth, see footnote 10.

initially examined thoroughly (e.g. three of these were treated with hormones[16], in one case a surgical perforation of the hymen was attempted and one had a laparotomy for abdominal pain). Two of six women who were examined and diagnosed had several doctors coming to look at them as they were “an exceptional case”. Only five of eleven cases felt they had received adequate information about treatment options. Women usually reported that the diagnosis was given in a matter-of fact way, but in some cases was accompanied by remarks such as “You can devote yourself to a career because you cannot become pregnant and have children”. In one case the parents were told that their daughter had better become a nun, as marriage was impossible. This is echoed by Langer, Grünberger & Ringer (1990) who noted that 8 of their 11 cases described being given the diagnosis as utterly embarrassing and intrusive, with the doctors’ reaction ranging from bewilderment to curiosity and making them feel like freaks.

A recent qualitative study of 8 women with MRKH (Holt & Slade, 2003) noted that “The new diagnosis seemed to change their perceptions of the self and threatened sexual, social and reproductive functioning. In a literal, physical and symbolic sense it was akin to being given an absence which meant participants no longer felt ‘whole’.” These authors also commented that “...participants had to deal with the tension between appearing ‘normal’ from the outside and yet knowing that hidden inside, they were different” and regarding how these women coped with the diagnosis: “initially this most commonly involved avoidance as participants felt shock and denial around the time of diagnosis and tried not to think about it” .

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[16] As was Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis’ (1962) case, and 2 of 11 of Langer, Grünberger & Ringer’s (1990) cases.

In summary, two key points emerge from the literature: (a) Patients' short-term responses to being given the diagnosis range from positive (including relief, fighting back) through to more negative responses such as shock, confusion, fear, depression and suicidality, feeling isolated, ashamed, or guilty through to more avoidant/cut off responses such as dismissal or denial. These varied and at times mixed reactions are akin to those found in people being diagnosed with major illnesses, such as malignancy (Fallowfield & Jenkins, 2004).

(b) Being given the diagnosis of MRKH and the circumstances surrounding it (e.g. responses of others, how diagnosis is imparted) produces a major threat to these women's sense of themselves as women. The multiple facets and implications of the diagnosis in terms of the woman's reproductive and sexual life and her relationships with partners, family members and friends are associated with these women typically appraising themselves as damaged, defective or incomplete women, or as unloveable, unacceptable, or a freak of nature.

2.5.B. What are the longer-term effects of MRKH and its medical/surgical treatment in terms of these women's 'experience of self'?

Several authors (Fairbairn, 1952; Turunen, 1952; Smolka, 1962; Rock, Reeves, Retto, Baramki, Zacur & Jones, 1983; Folch, Pigem & Konje, 2000; Robson & Oliver, 2000) comment in general terms - without providing data - on these women's persistent low self-esteem and feelings of inferiority, their sense of themselves as odd, defective or deformed, their confusion or anxiety about their femininity and sense of alienation from their body.

Eleven studies provide some data concerning this question including three psychoanalytic case descriptions, one qualitative study, seven retrospective follow-up studies, and one part retrospective/part prospective study. Greenacre (1958) in her single case report, notes that the discovery of the vaginal absence and eventual diagnosis of the condition, led her client to feel as though "she was no good, having no sense of who she was, or just being somebody". Living in a body that she felt alienated from she repeatedly wondered "am I myself, am I me".

David, Carmil, Bar-David & Serr (1975) reported that, most of their series of 17 cases felt different to other girls even prior to diagnosis due to not having their periods. However, until diagnosis they had had no doubts about their femininity, but they now started questioning this because of their knowledge of being sterile. 16 of the cases in this series believed that "full femininity is only expressed by the ability to have children". For many, their sense of inferiority to other women (including those who were functionally sterile) persisted after corrective surgery.

In Poland & Evans's (1985) case series of 54 patients most expressed feelings of rejection, e.g. feeling like a freak, incomplete or part female. 43/54 said in retrospect that not being able to have children was the most difficult aspect for them to accept and 11/54 said that they had thought about suicide because they felt "worthless". These sentiments ('feeling like a freak') are also echoed by the four cases of Sargis, Wylie, Thomay &

Kalani (1960) and by Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis' (1962) case. One of Kaplan's (1970) cases saw herself as "a person, but that not now and never can she be a woman", and two of eleven women in Weijenborg, van Dijk & van Hall's (1986) series noted that they felt "sexually neuter" for years, one even used to say I am "it", "neither man nor woman" (also echoed by Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis' 1962 case, noting she was "neither a boy nor girl"). In addition, eleven of Weijenborg, van Dijk & van Hall's (1986) cases reported feeling continuously different from other women.

Holt & Slade (2003) in their qualitative study describe very similar themes. They also mention that "not being able to have children affected how participants related to other women. Most reported having jealous feelings towards women who could have children but found it hard to accept these difficult feelings as part of themselves."

Several papers present information on how women's view of themselves changes from before to after corrective treatment. Greenacre (1958) in her single case study, notes how the creation and possession of a vagina and the pleasure it can give, from the vaginal orifice, the clitoris and in general bodily contact, allowed her patient to experience the emergence of a "greater sense of being somebody", "and a woman at that". This she concluded was interesting from the "angle of identity". Kaplan (1970) describes the response of one of his psychoanalytic therapy cases to vaginoplasty. Here the woman noted that it "had changed her mind, changed everything about her", and the surgery was experienced as "the death of her "hermaphrodite" self and rebirth as a woman". He notes that despite this she may still be doubting her femininity, inferring this from her behaviour, seeking reassurance in premature and promiscuous coitus, until she was told that both her ovaries were present. This she believed to be essential to "having a woman's feelings" and she no longer had to rely on the reassurance from sexual intimacy alone. Sargis, Wylie, Thomay & Kalani (1960) in their series of 4 patients report a striking reduction of emotional disturbances related to the anomaly after vaginoplasty[17]. Equally, in Langer, Grünberger & Ringer's (1990) case series, 4/11 had postoperatively good self-esteem, and in 7/11 self-esteem was low or fair.

Möbus, Sachweh, Knapstein & Kreienberg (1993) in their case series of 24 asked women to rate their pre-and post-operative self-esteem. 19 of 24 women reported a considerable increase in self-esteem from pre- to post-treatment. In this study four women with poor post-operative outcomes had the lowest scores on self-esteem and a measure of body satisfaction. On a measure of personality functioning the women with poor outcomes were also more likely than the others to be depressed, anxious, sensitive and emotionally labile. It is difficult to know what is cause and effect here. These authors also asked their study participants to rate the psychological impact of their infertility on them on a 0 to 10 scale, with 10 signifying very major negative impact. The median rating was 9, suggesting that infertility is a major source of lasting distress for these women. David, Carmil, Bar-David & Serr (1975) also detailed that 14/17 women in their case series who underwent an operation, experienced no relief of psychological tension, because of their persistent sterility.

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[17] Kaplan (1968), reflecting on Sargis, Wylie, Thomay & Kalani's (1960) findings, notes that "evaluation of Sargis' women in follow-up revealed an abiding sense of defectiveness".

In summary, there is considerable agreement between all sources that following the diagnosis of MRKH there is a major and lasting impact on these women's sense of self both as a person, but particularly as a woman. According to most authors being told that you were born without a womb and vagina goes to the core of these women's gender identity. It draws ones' status as a woman into question, and women diagnosed experience a sense of confusion regarding their gender, bodies, social and sexual roles. The successful creation of a neovagina seems to ameliorate some of these difficulties. Whilst MRKH involves many different losses, the infertility may have the most severe and prolonged impact on these women's defective sense of self. Most of the evidence in this area is qualitative, impressionistic and anecdotal in nature and very little is known about how these women's view of themselves compares with that of other women and precisely how their difficulties evolve over time. We do not know what factors (intra- or interpersonal, medical/surgical) determine greater or lesser negative impact of MRKH on self-image, either in terms of risk or protective factors. No study has formally assessed the impact of MRKH on self-image and identity through validated quantitative measures.

2.5.C. What are the effects of MRKH and its medical/surgical treatment in terms of other longer term psychological and psychosocial outcomes including these women's coping responses?

14 studies and one narrative review provide some information on this topic.

The narrative review by Jensen & Reiter (1999) emphasises how the profound feelings of difference experienced by these women impact on the individual's psychological functioning and create an ongoing sense of sadness and loss.
Fairbairn (1952) in his single case study of a woman who did not have corrective intervention, notes that his client who worked as a teacher held unattainably high standards regarding her work, with high anxiety when these standards were not met. He reported that she became depressed, with difficulty concentrating, and disturbed sleep. She developed a desire to regress to the "paradise" of childhood and the time before the diagnosis, without responsibilities for her family of origin, or her classroom, instead being cared for herself.

Greenacre (1958) in her psycho-analytic case study says that her client had become "fiercely competitive with her brother age 7/8 at initial discovery (that her genital groove lacked an opening), alternated by periods of withdrawal". She developed a phobia of mirrors, since she felt alienated from her body, viewing it as distorted, and felt that she would remain forever untouched and solitary. At actual diagnosis, age 15, which she herself demanded, she remained this way, feeling "no good, having to beat everyone else", to gain any sense of value. Though having developed a normal female body contour and well-shaped breasts helped her to become somewhat less solitary it was not until that she had vaginal surgery, that she developed a sense of being a woman. She then started to work in an Obstetrics Hospital where she "developed a sense of identification with the women she works with. Where she does not feel that she is forever excluded from their knowledge. She gradually comes to the decision to adopt a child".

Other authors have discussed a range of compensatory responses. Kaplan (1968) describes one woman (1/11) "devoting her life to counter feelings of defectiveness by proving that she was as good as anyone else, approximating normality as much as possible". Kaplan (1970), reflecting on Sargis, Wylie, Thomay & Kalani's (1960) findings[18], reports that their patients "strove to approximate normal women to the fullest extent, accepting the presence of the anomaly in its entirety". Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis' (1962) case "could not bear the idea of looking at herself as defective so she pretended that it did not matter and that she could be famous anyhow, deciding to go to college and to devote her life to art and the negro situation – and that was that". However, like in Fairbairn's (1952) case overactive and confident episodes alternated with depressive moods.

The early case series by Bryan, Nigro & Counseller (1949) reports the psychological attitude and emotional stability to be normal in 88 of their patients, fair in 4 and poor in 8, following surgery. However, their sample only included 21 women with MRKH, and they did not report on their criteria for determining patients' mental status.

In contrast, Smolka (1962) in his series of 19 cases mentions that reactive depression and suicidality are common, without specifying the frequency in his series. This he notes is in line with Langer, Grünberger & Ringer's (1990) findings, where 5/11 women judged themselves as depressed, and women saw themselves as socially unattractive and without self-control/agency. In this series 4/11 "coped well", 4/11 featured a "fair balance of denial and acceptance", and 3/11 showed signs of "massive denial and felt sick or

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[18] Though this is not what Sargis, Wylie, Thomay & Kalani (1960) themselves say in these words.

disturbed". Turunen (1952) notes the death of one of his 67 patients through suicide after surgery. However, the reason for the suicide is not given. Kaplan (1968) also mentions that three of his eleven cases suffered from periods of depression post-operatively. Three further patients became sexually promiscuous following intervention, two had other reactions (e.g. a "delusional quest for menses and fertility" and dependence on her mother) and in three no major psychological impact was noted.

Weijenborg and ter Kuile (2000) in their series of 17 cases, most of whom had a functioning neovagina, gave their patients the Symptom Checklist 90 (SCL-90; Derogatis, Lipman & Covi, 1973), a measure of psychiatric symptomatology at two time points (3 to 6 months apart) prior to a psychoeducational group treatment. These women's psychological distress sub-score was intermediate between norms for women in the general population and psychiatric patients.

Other authors have emphasized a minimising/avoidant coping response in these women. Weijenborg, van Dijk & van Hall (1986) in their retrospective series of 11 cases, state that their patients coped by "going back to normal life, working harder to not feel the pain. They minimise the distress experienced, by avoiding thoughts around loss and threat which otherwise would have aroused an emotional response. One woman in their study developed Anorexia Nervosa; not wanting to look feminine either".

Holt & Slade's (2003) in their qualitative study noted that "avoidance of thinking about it might continue for months or even years.....Other styles of thinking which participants used to manage the impact of their diagnosis with included searching for certainty or a sense of meaning with a condition that had not been heard of before by either the participants and sometimes the medical services too." They also noted that "a sense of resignation about their losses seemed to be both a stage that was reached over time but also a style of thinking that for some participants helped them avoid confronting their feelings." Finally, "many participants tried to minimize the significance of their loss by comparing their condition with others which they viewed as worse or by making comparisons with other disabilities."

Poland and Evans (1985) emphasised that "educational and vocational goals of these patients were not affected by their diagnosis. For most the goals for college or work described to us during the first interview were achieved." However, Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis' (1962) case never completed college for fear of failing her exams, having done poorly in school. David, Carmil, Bar-David & Serr (1975) in their case series of n=17, noted that 6 of their 10 married patients considered the idea of adopting a child.

In summary very little is known about longer term psychological outcomes and compensatory behaviours or coping responses in these women. Practically all the available data are anecdotal. There is no solid information on the long-term prevalence of common psychiatric disorders such as depression or anxiety nor is there solid information from prospective studies including pre-and post-intervention measurements about levels of distress and ways of coping and their evolution over time. Nonetheless, we can identify tentatively some common coping or compensatory responses. These include: (a) avoidant responses, i.e. avoiding thinking or talking about MRKH, focusing exclusively on other life areas such as work and avoidance of sexual relationship (see question 2.5.D below), (b) competitive, striving responses i.e. trying to be the best at everything, and (c) trying to fit in and blend in as a woman.

2.5.D. How does MRKH and its medical/surgical treatment effect these women's sexual and romantic relationships?

Thirteen studies report on this, two psycho-analytic case descriptions, nine retrospective follow-up studies, one qualitative study, one cross-sectional study (case-control comparison). In Fairbairn's (1952) single case report, the woman was not offered a neovagina. As she had said "she felt perfectly well", nothing further was done following diagnosis. Fairbairn notes that his case had "dismissed sex and marriage with a sigh of relief and focused on a career" and that, "fortunately, in the circumstances, she had never taken advantage of any opportunity to marry". Yet, "when her career faltered she broke down and her previous attraction to heterosexual men that had been repressed/gone underground, resurfaced in her analysis in middle age".

In Sargis, Wylie, Thomay & Kalani's (1960) series three out of four women were married and following operation had a satisfactory sex life with "normal orgasm and a feeling of pleasure during intercourse". Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis' (1962) case reported, 18 months postoperatively (following her 2nd operation), that the marital sexual relationship was satisfactory for both her and her husband, that she had experienced no bleeding or pain and that the use of dilators had been discontinued.

In Kaplan's (1968) case series six of eleven women (54.5%) got married, two of these later separated or divorced. He notes that a sense of defectiveness or inadequacy in the woman inhibits normal dating, even if genital intimacy is not contemplated, and that low self-esteem, might lead to women to seek "inferior, depreciated men". He writes that "the motives of a man who marries a sterile woman without a vagina certainly deserve scrutiny".[19] In his series four out of nine women chose men they regarded as inferior. Likewise, Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis' (1962) case, who had vaginal correction, married against her parents' wishes, a black artist whom she and her parents considered inferior to her. She ended up living in poverty, completely supporting her husband, who unwilling to get a job, did the housework and cooking. In contrast, Langer, Grünberger & Ringer (1990) reported that 8/11 women had a steady partner at the time of postoperative interview, and that judged by schooling or profession six of the partners were of higher social status than their wife/girl friend, four about equal and none of lower status. They also noted that these relationships seemed more stable than would be expected for this age group. The main post-operative problem for both the women and their partners in this group was the need to have intercourse regularly to prevent shrinkage of the vagina. One relationship broke early in the postoperative phase, with one boyfriend saying that he felt "like an expander". Of the three women who did not have a partner at the time of interview, one lived in a "symbiotic" relationship with her mother and one had several social problems (Langer, Grünberger & Ringer, 1990).

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[19] This comment is likely to reflect the opinions of a male author who is steeped in his time and its values. It is likely that in 1968, forms of sexual expression other than penetrative sex and relationships/marriages without a reproductive focus were not considered valid (see also Chapter 3).

In David, Carmil, Bar-David & Serr's (1975) series, libido was normal in all 17 cases. Among 14/17 patients who underwent vaginal surgery the functional result was good in 71%. Fifteen of their patients got married (88.2%) and five of these divorced. Three husbands did not know of their wife's sterility.

In the study by Hecker & McGuire (1977), 20 of 23 cases (87%) were coitally active. 80% of the 20 reported regular orgasms and all 20 rated themselves as sexually 'satisfied' or 'extremely satisfied'. Patients also rated their partner's sexual satisfaction and in all cases this was rated as equal or higher than their own. Of twelve women in this series who married after treatment, there was no evidence that they chose spouses who differed from the general population. These authors conclude that "Marital stability was equivalent to or better than that of the general population, in as much as there had been only one divorce occurring since treatment." In this series, four of 23 women were considered as treatment failures despite satisfactory anatomical results. The authors noted that these women had in common that "they still considered themselves inadequate and sexually unattractive and described themselves as rather indifferent to or rejective of their newly created vaginas."

In Robson & Oliver's (2000) series of 28 cases, two did not start dilator treatment, and one was lost to follow-up. Fourteen of the remaining 25 cases entered into a sexual relationship at some stage during follow-up which varied between 0.5 to 7 years. Of the eleven patients who did not have any sexual relationship during treatment two developed complications of treatment, four ceased treatment and only two of eleven had adequate vaginal capacity at the most recent examination, in contrast to all 14 of the group with a sexual relationship.

In the case series by Poland & Evans (1985), 42 (78%) of 54 patients got married, five of these later got divorced and 2 remarried. These women were said to have married mostly men of comparable or slightly superior socioeconomic status to that of their fathers. This study also gives some details on sexual satisfaction which was monitored throughout the pre- and postoperative periods in 37/54 patients. Nine of these had experienced orgasms in response to manual stimulation before surgery and 22 described orgasms from masturbation and/or intercourse after surgery.

In the series of Weijenborg, van Dijk & van Hall (1986) seven of eleven women were sexually active, the remaining four had not had sexual intercourse during the time of the study. Two of eleven said they felt sexually "neuter". Most of the women reported being very reluctant to start a relationship with a man and being continually anxious as to when and how to tell him about their problem. In this series "sooner or later all the women wanted to have a vagina and took the decision for treatment … The motive for this decision was often twofold: some actually wanted to have intercourse, others however considered having a vagina as a preliminary condition to feel less hampered in their relations to other people (men as well as women) and to venture on a 'real' relation with a man." "All, at some stage, asked themselves the question: "Why and for whom am I making my vagina?"

Möbus, Sachweh, Knapstein & Kreienberg (1993) in their post-operative follow-up investigation found 20 of 24 women to have a current relationship at the point of follow-up, in 17 of these this was a sexual relationship. All 17 of these described their sex life as excellent. Six of these women were using oral or anal rather than vaginal intercourse. 21 women said they regularly experienced orgasms. Nine patients said they had had little or no fear regarding sexual intercourse after their operation whereas 15 recalled having marked or very marked fear of intercourse following the operation.

Holt & Slade (2003) in their qualitative study noted that "the diagnosis brought the intimate and private issue of sexuality in a more public arena at a time when sexual exploration begins for most young women." and that "most participants had only had one or two sexual partners and it would seem that reducing the number of partners was a deliberate decision in order to avoid the potential difficulties in having to tell someone new." They also mention that "Choosing not to tell people was a way of reducing the number of difficult or rejecting reactions, especially with potential sexual partners."

In the currently largest study, Nadarajah, Quek, Rose & Edmonds (2005) attempted to follow-up all cases who had had dilator treatment for vaginal agenesis in one centre between 1984 and 2001. Out of 145 potential participants 79 responded to the invitation. 15 of these declined to participate (without a reason), two further patients reported that dilators had failed in creating an adequate vagina and two patients failed to adequately complete their questionnaires. The remaining 60 cases (41% of eligible cases) completed a questionnaire assessing sexual function over the previous 4 weeks. This group was compared with a 'super-normal' control group of 131 volunteer women from the general population who had been selected for not having any sexual dysfunction and being in a heterosexual relationship. There were no differences between MRKH women and controls in terms of sexual desire, arousal and sexual satisfaction. The latter consisted of questions concerning the amount of closeness with the partner, satisfaction with their sexual relationship and satisfaction with their sex-life overall. Women with MRKH reported greater difficulty in becoming lubricated and achieving orgasm during sexual intercourse and more pain or discomfort during or after penetration[20].

In summary, whilst the earliest series addressing this topic is rather gloomy about these women's relationship prospects and the kind of men who would be interested in them (Kaplan, 1968), later series do not support this pessimistic view. Whilst women seem to experience considerable anxiety at the start of a new romantic relationship and some may limit the number of relationships, in most studies a high proportion of women do enter long-term relationships. These seem to be with men who - at least judging by their socioeconomic status - are no "lame ducks". The one study that did have a comparison group suggested that relationship satisfaction for women with MRKH is as good as for other women. Having said this, our knowledge of the more subtle interpersonal aspects of these women's romantic/sexual relationships compared to the normal population is as yet very limited.

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[20] This study may have underestimated differences between MRKH patients and controls as the two groups were not matched for age. The mean age of the women with MRKH was 26.6 years whereas the mean age of the controls was 39.7 years. Thus the control group is likely to have included a number of women who were peri-menopausal and may therefore also have had some impairment in their sexual functioning (e.g. in terms of lack of arousal and vaginal lubrication).

2.5.E. What is the psychological impact on these women of MRKH-related medical/surgical contacts and interventions in terms of the timing and manner in which they are being conducted?

Twelve studies offer insight into this question, not always based on data.

Experience of medical and surgical contacts:

As already described above there is anecdotal evidence to suggest that some doctors do not manage the process of imparting the diagnosis to the patient well (Weijenborg, van Dijk & van Hall 1986). Commenting on medical contacts at any stage of the condition, Holt & Slade's (2003) in their qualitative study noted that many of their study participants spoke of "not being able to understand the language the doctors used..." and that medical appointments were characterised by a "lack of accessible and appropriate information exchange" which "left many women feeling isolated, unsupported and unprepared for dealing with the longer-term implications of their diagnosis. Treatment was experienced as focused upon procedures and the physical side to the condition...". In this study, "most participants offered ideas for what they would have liked more of from medical services which included such things as practical facts and advice, to meet other women with similar conditions and to be able to talk about their feelings with someone both after diagnosis and in the longer term."

These difficulties in communication can give rise to misunderstandings and false hopes, as is described by a number of authors: For example, Masters & Johnson (1961) report a case, who had experienced a broken engagement, based on her and her partner's belief that intervention for her absent vagina was not possible. This woman for a period of time refocused her life on educational interests. However, when a (hetero)sexual interest returned in this woman, treatment options were discussed again and surgery was performed, leading to a reduction in distress. This, the authors note, "highlights the need to have clarity as to this and avoid misunderstandings in both the patient and her partner. To not delay intervention when the patient asks for it and is ready for it and facilitate the possibility of "moving on", regarding romantic and sexual relationships". David, Carmil, Bar-David & Serr (1975) report that in their case series most patients believed that the vaginal operation would "solve the entire problem" and were very upset that this did not occur. Likewise, Poland & Evans (1985) point out that despite detailed and careful explanations of what MRKH entailed some patients kept thinking that during the operation a uterus would be found and that they would be made whole again. These authors also describe that all their patients found hospitalization for vaginal surgery difficult and were anxious and worried about things going wrong and embarrassed about their condition.

Timing of corrective intervention:

Many authors discuss the importance of the right timing for any intervention for MRKH based on their clinical experience and opinion. Kaplan (1968) states that corrective procedures for the congenital absence of the vagina, cannot be carried out until the girl is prepared to think of herself as a woman capable of engaging in sexual intimacy and penetrative sex, that to do so any earlier is akin to a "premature confrontation, of an anatomically normal adolescent, with the sexual relationship". Sabbath, Morris, Ludwig, Menzer-Benaron & Sturgis' (1962) case highlights this, where upon gynaecological appraisal under anaesthesia the vaginal anomaly was identified and corrected in the same sitting with the patient waking up to the news of diagnosis and the consequences of vaginal formation with the need for the use of dilators, neither of which she was prepared for. This young woman, who was aged 16, experienced her vagina as "an artificial female organ", dilators as distasteful, unnatural and disgusting and the whole procedure as an assault and did not comply with treatment. She consented to a 2nd operation willingly, when she was ready for it. Langer, Grünberger & Ringer (1990) advocate that in pre-operative counselling the girl's individual psychosexual development has to be taken into consideration, and that a phase of experimenting with non-coital playful sexuality helps to find ones' sexual identity in normal development and should not be shortened in these women. Likewise, Smolka (1962) and David, Carmil, Bar-David & Serr (1975) emphasise that the corrective procedures should be undertaken when the patient is mature enough to understand what is happening and that this may require individual tailoring of the timing. Smolka (1962) gives a "ballpark figure" for intervention of about 20 years of age. Möbus, Sachweh, Knapstein & Kreienberg (1993) note that in the absence of a regular sexually intimate relationship, the vagina needs to be kept patent with molds to prevent it from closing after surgery. They, as Turunen (1952), advocate that surgery seems more practicable around the time of marriage or when the young women is ready for sexual intimacy within a committed long-term relationship. In contrast, other authors consider delay of intervention until engagement/marriage unwise, because an absence of the vagina inhibits normal dating (Counseller, 1948; Smolka, 1962; Kaplan, 1968).

Few studies provide data on the question of optimal timing of any corrective intervention. In one series most patients requested surgical correction within 6 months of diagnosis to feel more complete (Poland & Evans, 1985). In Möbus, Sachweh, Knapstein & Kreienberg's (1993) series 20 of 24 women said that they felt the timing of their operation was optimal, having taken place between age 18 to 20. Those with poorer results had been operated on earlier (age 16 to 17).

Dilator treatment:

Several studies comment generally on the difficulties involved in dilator treatment, both physically and emotionally. For example, Poland & Evans (1985), mention that women often experience pain and fear around the non-surgical intervention of dilators and their size. Kaplan (1968) notes that "the daily use of dilators or of removal, cleaning, and reinsertion of a vaginal prosthesis mobilises disgust and guilt…" Likewise, Weijenborg, van Dijk & van Hall (1986) comment that dilator treatment is painful for women, not only physically, but also emotionally, the difficulty being that "it did not change life radically, as making contact with people required more than having a vagina." Finally, Holt and Slade's (2003) study participants also commented on the experience of using a dilator. "Their use also seemed to have a powerful shaming effect because of associations with sexuality, privacy and intimacy. When referring to using dilators participants' descriptions were scattered with words such as: 'dirty', 'obscene', 'degrading', 'clinical and cold', 'embarrassing' and 'not very nice'."[21]

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[21] Note: Dilator therapy is also needed after surgery, following removal of the mould, to stop the neovagina from closing, in cases where the woman does not have regular penetrative sex. Just like dilator treatment on its own this could equally be experienced as painful and shameful, added to the pain and discomfort

In summary, there is considerable agreement from the available mainly anecdotal evidence to suggest that medical encounters and interventions for MRKH are not straightforward for women, with potential for miscommunication and misunderstandings. Whilst surgical treatment has the potential for giving rise to false hopes, dilator treatment has the potential for being experienced as painful and shameful. There seem to be different views concerning the timing of any corrective intervention, however, more recent opinion seems to converge on ensuring that the time point is decided by the young woman and her family and involves her being developmentally ready for this.

2.5.F. Does psychological therapy/counselling improve anatomical, functional and psychological outcomes in MRKH?

The three psycho-analytic case descriptions by Fairbairn (1952), Greenacre (1958) and Kaplan (1968) provide indirect support for the notion that women with the MRKH may require long-term psycho-therapeutic input. Many other studies advocate ongoing psychological support for women with MRKH (e.g. David, Carmil, Bar-David & Serr, 1975; Hecker & McGuire,1977; Folch, Pigem & Konje, 2000) as do four narrative reviews (Jensen & Reiter, 1999; Edmonds, 2000; Croak, Gebhart, Klingele & Lee, 2003; Edmonds, 2003). These recommendations differ in terms of the nature and focus of the psychological intervention/support, the timing and duration and the best people to deliver the psychological support/intervention. For example, support from mothers and medical staff regarding pain and fear around dilator treatment is advocated by Poland & Evans

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experienced as a result of surgery (including the skin graft) and postoperative course. However, patients may find surgery more acceptable, where a "vagina is made for them, rather than by them."

(1985), whereas Nadarajah, Quek, Rose & Edmonds (2005) advocate close supervision and support from a clinical nurse specialist. Poland and Evans (1985) suggest contact of new patients with 'old' patients, who have undergone intervention around the absence of the vagina. They further outline that women need reassurance and ongoing counselling to help them deal with unresolved losses. Croak, Gebhart, Klingele & Lee (2003), in their narrative review suggest a multifaceted approach to develop strong self-esteem in the patient and a satisfying attitude towards sexuality. Möbus, Sachweh, Knapstein & Kreienberg (1993) emphasises the need for psychological help and guidance following surgery, including regular discussions and detailed explanations about the condition and the intervention and covering the subject of infertility with both patient and partner in this. Rock, Reeves, Retto, Baramki, Zacur & Jones (1983) report that their patients and families receive counselling before surgery, and for up to three years after surgery, by the attending physician and/or psychologist. However, they do not state the content of this counselling. Sabbath, Morris, Ludwig, Menzer-Benaron & Sargis (1962) also advocate counselling and Langer, Grünberger & Ringer (1990) note the need for collaboration between the psychotherapist and gynaecologist from the point of diagnosis, as "all functional failures of surgical intervention were due in their case series to psychological rather than anatomical problems". Robson & Oliver (2000) recommend psychological support through a support group, which in their setting coincides with clinic appointments during the early stages of treatment. This allows women to meet with similar young women and is very popular with patients[22]. The narrative reviews by Jensen & Reiter

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[22] However, the 39 cases who took part in their study were presented over a period of 10 years, which works out as a rate of about 3.9 new MRKH patients presenting each year. Thus, it can be inferred that for these groups to be run, and to coincide with clinics, women with other diagnoses would have had to join these groups, to make up numbers.

(1999), Edmonds (2000) and Edmonds (2003) emphasise that a long-term approach to the psychosocial management of MRKH should be taken with psychological in-put at all stages, from diagnosis, through treatment and thereafter.

To date there is only one study which attempts to evaluate the impact of a psychoeducational group programme of 7 sessions delivered over 14 weeks on these women's emotional wellbeing (Weijenborg & ter Kuile, 2000). In this study, 17 women had two baseline assessments three to six months apart followed by the group programme. The women thus served as their own waiting list controls. The programme covered the themes of diagnosis, reactions, coping, medical information and interventions, sexuality, infertility, female role, and femininity. The two group leaders were a gynaecologist and a female social worker (who herself had MRKH). The topic of each session was introduced by the group leaders. Thereafter, participants could ask questions and share their experiences. Outcome was evaluated on the SCL-90 (Derogatis, Lipman & Covi, 1973) which was administered at the two pre-treatment time points 3 to 6 months apart and post-treatment. There was no difference in SCL-90 scores between the two pre-treatment time points, but from pre-treatment to post-treatment scores on several SCL-90 subscores and the total score significantly improved[23].

In summary, whilst many authors agree that ongoing counselling/psychological support for these women is desirable, this has never been put to the test in a randomized

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[23] However, the stats used to calculate the difference is questionable since it excluded the outcome measures of the women who did not have complete data sets and may therefore have been biased (see also Chapter 5)

controlled trial and it is unclear what is the most effective kind of intervention for achieving what kind of outcomes at what stage of the disorder.

2.6. DISCUSSION

The present chapter aimed to present a review of the literature on MRKH so as to develop a better understanding of the specific nature of the psychological sequelae of MRKH and its treatment and to develop ideas about potential targets for psychological intervention. Below I will present the key findings from the review in relation to each of these aims and will comment on these.

In relation to the first aim of the chapter the following key findings emerge from the review:

(a) Being given the diagnosis of MRKH (and the manifold implications this has for women's relationships, and their sexual and reproductive lives), creates a major threat to these young women's sense of themselves as women, leading them to question their identity as a woman and to experience a sense of confusion regarding their gender, bodies, social and sexual roles. This threat gives rise to the development of negative self-beliefs with many women seeing themselves as defective, inferior or unloveable. Surgical or dilator treatment are often experienced as shameful and may serve to perpetuate or strengthen these beliefs. Whilst the successful creation of a neovagina ameliorates some of these difficulties there is general consensus that MRKH has a lasting impact on these women's negative view of themselves. Whilst MRKH involves many different losses, the infertility in particular may serve to perpetuate these women's defective sense of self.

b) Following diagnosis patients report the full range of emotional responses commonly encountered in response to being diagnosed with major illness, highlighting just how devastating the diagnosis is for these young women. It is known from work on 'bad news consultations' in patients with cancer that people's memory for these kind of consultations is often fragmented and not organised in a coherent narrative, with major misconceptions and confusions about what was said and what is wrong (Fallowfield & Jenkins, 2004). This is analogous also to what happens in the development of Post-Traumatic Stress Disorder following major trauma, when the memory for what happened is poorly elaborated and not incorporated fully into the autobiographical memory base (Ehlers & Clark, 2000). The literature in MRKH suggests that similar processes may be at work here. For example, several authors noted that despite being given careful and detailed descriptions of their condition and its treatment, many young women were not fully able to retain the information and had major misconceptions about this (Masters & Johnson 1961; David, Carmil, Bar-David & Serr, 1975; Poland & Evans, 1985; Holt & Slade 2003).

(c) Women seem to try to control the sense of threat to their femininity and the accompanying symptoms by using a range of potentially maladaptive strategies such as for example, avoidance (both emotional avoidance and avoidance of relationships), competitive striving, being perfect, being promiscuous or settling for second best in relationships.

(d) There is widespread agreement in the MRKH literature that psychological support or intervention for these women is important, yet there is little detail on what such an intervention might look like.

In relation to the second aim of the chapter several potential targets for psychological intervention emerge from the above findings: (a) Firstly, treatment might usefully revisit the diagnosis and the processes surrounding it. (b) Treatment should help women to examine their self-appraisals and beliefs in the context of their MRKH treatment and relationship history and help them to challenge these. (c) Treatment should address any maladaptive compensatory or coping strategies that may serve to maintain unhelpful self-beliefs.

Some additional ideas about the style, focus and modality of psychological interventions for MRKH have been mentioned in the literature. Holt and Slade (2003) suggest that any psychological treatment of MRKH needs to adopt a collaborative biopsychosocial approach, with flexible provision of information and opportunities to receive support and long term follow-up, beyond the initial treatment period. Moreover, they highlight the importance of women having the chance to communicate with others who have vaginal agenesis, something that has also been stressed by a number of other authors (Poland & Evans 1985; Weijenborg, van Dijk & van Hall, 1986; Robson & Oliver, 2000; Weijenborg & ter Kuile, 2000). In addition, several other authors suggest the involvement of family members and partners in treatment (Kaplan, 1968; Hecker & McGuire, 1977; Rock, Reeves, Retto, Baramki, Zacur & Jones, 1983; Poland & Evans, 1985; Folch, Pigem & Konje 2000; Croak, Gebhart, Klingele & Lee, 2003).

In chapter 4, I will discuss these treatment related aspects in more detail in the context of the description of a cognitive-behavioural model of treatment of MRKH and the rationale for the intervention I designed based on this.

Finally, one other major point is missing almost entirely from the existing literature and this is the developmental context of receiving being diagnosed with MRKH. Diagnosis is typically made in mid-adolescence i.e. at a time when a young woman's emotional, cognitive, social and sexual development is as yet not complete. The immaturity and lack of experience of these young women makes it more likely that idiosyncratic negative appraisals of different aspects of MRKH will arise and that these negative self-appraisals become fully integrated into these women's sense of identity. Thus in order to gauge the full impact of MRKH I will review what is known about the process of psychosexual differentiation and adolescent sexual development.

TABLE 2.1: Articles with a primary focus on psychological, psychosocial or sexual effects of MRKH and its medical/surgical management

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control group**	**Additional comments**
1. Fairbairn (1952) "(1931)"	1 case with ? MRKH/ Hermaphroditism/ Complete Androgen Insensitivity Syndrome	England Psychoanalytic practice		Retrospective case description of extended psycho-analytic p.therapy of a middle aged woman with a physical genital abnormality: familiar & unfamiliar psycho-pathological processes	No measures used. Clinical case material.	Psychotherapy lasting number of years	no	Chromosomal/ Gonadal sex of case not investigated See footnote 9, for an explanation of CAIS
2. Greenacre (1958)	1 case with MRKH	University Department of Psychiatry New York USA		Retrospective case description highlighting early determinants in the development of a sense of identity (psycho-analytic)	No measures. Clinical case material.	Not stated	no	Mainly theoretical paper on sense of identity formation with this case highlighting certain aspects of this.
3. Masters & Johnson (1961)	3 cases, 1 with MRKH (case B), 1 with ? Partial Androgen Insensitivity Syndrome (case A), and 1 with ? Complete Androgen Insensitivity Syn-	University Department of Obstetrics & Gynaecology Washington USA	Cases with VA	Retrospective case series looking at physiological & functioning effectiveness of artificially created vagina in terms of orgasm, lubrication, epithelisation & 4 phases of sexual	Physical exam (length & width of vagina), vaginal smears/biopsy cyclical vaginal PH recordings, detailed history taking; including descriptions of psychological aspects of these conditions	Case A & B 2-4 years Case C no follow-up & detail regarding 4 phases of sexual response	no	Case A & B had surgery, Case C Dilator therapy No conclusive detail of chromosomal/ gonadal sex of case A & C.

TABLE 2.1: Articles with a primary focus on psychological, psychosocial or sexual effects of MRKH and its medical/surgical management

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control group**	**Additional comments**
	drome (case C)			response				
4. Sabbath, Morris, Lud-Wig, Menzer-Benaron & Sturgis (1962)	7 cases, 1 of which had MRKH (case 22) 6 had ovarian agenesis, ovarian dysgenesis/ Turner's	Gynaecology-Psychiatric Unit, Harvard Medical School Harvard USA	Cases with developmental defects of reproductive system effecting internal/ external sex organs alone or both together	Retrospective case series to describe these defects including, clinical/endocrine detail, & treatment & a psychiatric summary, to emphasise the deep emotional content of the indicated treatment on these type of individuals	Review of medical/psychiatric notes	Approx. 5 years in case with MRKH	no	None
5. Smolka (1962)	19 cases with MRKH of 30 who were seen at the Dpt. between 1946-1961	University Gynaecology Department Kiel Germany	Cases with VA	Retrospective case series of women who had vaginal surgery looking at psychosocial indications for surgical intervention	Follow-up Interview not stating type of ? asked	Not stated	no	Article in German No facts.
6. Kaplan (1968)	11 cases with absent vagina seen with 6 cases from literature, 2 of the latter do not have MRKH	The Long Island Jewish Hospital Dpt. Child Psychiatry New York USA	Cases with VA	Retrospective case series on psychiatric aspects of diagnosis & management of VA (psychoanalytic)	Extended interviews (type of ? asked not stated) & psychotherapeutic case material	Variable, often 1 to 87 sessions	no	Duplication of case desciptions of Fairbairn, Greenacre, Sabbath et al (above) & Masters & Johnson (Table II); included into own number of cases presented. Only inclu-

TABLE 2.1: Articles with a primary focus on psychological, psychosocial or sexual effects of MRKH and its medical/surgical management

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control group**	**Additional comments**
								des summary of cases 1-6, 8 & 10, leaving descriptions of case 7/9 & 11 to an overview table
7. Kaplan (1970)	2 cases with MRKH	" "	" "	Retrospective case series & psycho-analytic case discussion	No measures used. Clinical case material.	" "	no	Part-duplication of own work: Case 1 (Alma) in these case descriptions is case 1 in his 1968 paper.
8. David, Carmil, Bar-David & Serr (1975)	17 cases with MRKH	University Department of Obstetrics & Gynaecology Tel Aviv Israel	Cases with MRKH	Retrospective case series on psychological problems associated with knowledge of anomaly & following surgery on anomaly	Interview; focus areas: 1. process of discovery of condition & reaction 2. response to surgery 3. effect on self-image of condition 4. effect on relationships 5. current relationship & reaction to adoption	Not stated	no	Merging of impression with data.
9. Hecker & McGuire (1977)	23 cases with MRKH of 35 who were seen at the Dpt. between 1961-1974 not all of which had MRKH	University Department of Obstetrics & Gynaecology Washington USA	Cases with VA	Retrospective case series on psycho-social & sexual functioning in women treated for Vaginal Agenesis	Questionnaire; with questions around: 1. reaction to initial discovery of condition 2. experience of condition 3. families & partners 4. anatomical outcome vs social adjustment	5 months - 7 years	no	Merging of impression with data
10. Poland & Evans (1985)	54 cases with MRKH with complete pre- &	University Department of Obstetrics & Gynaecology	Cases with MRKH with complete pre- & post opera-	Retrospective case series looking at psychological as-	Pre&Post operative interviews & recorded group discussions regarding emotional impact	Observed from initial diagnosis through to 2-10 years	no	No information on other cases seen during this period

TABLE 2.1: Articles with a primary focus on psychological, psychosocial or sexual effects of MRKH and its medical/surgical management

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control group**	**Additional comments**
	post-operative evaluation	Detroit & Denver USA	tive evaluation	pects of Vaginal Agenesis	of condition on patient & family during diagnosis, surgery & thereafter.	post-operatively		
11. Weijenborg & van Dijk & van Hall (1986)	11 cases with MRKH of 17 who were seen at the Dpt. between 1976-1985	University Department of Obstetrics & Gynaecology Leiden The Netherlands	Cases with MRKH	Retrospective case series looking at psychological, social & sexual consequences of diagnosis & treatment	Semi-structured interview re: 1. how diagnosis was made 2. what did it mean initially, later from psychological, social, sexual point of view 3. what treatment given & how feel about	Not stated	no	In places merging of impression with data.
12. Langer, Grunberger & Ringer (1990)	11 cases with MRKH & 7 with C(V)AH of 26 who were seen at the Dpt.	1st Department of Obstetrics & Gynaecology & Institute of Depth Psychology & Psychotherapy, Vienna Austria	Cases with MRKH & cases with CAH	Retro/prospective case series looking at the effects of surgery on psychosexual function & psychosexual sequelae of & coping mechanisms specific for the 2 different "malformations".	Semi-s. interview: open-ended? & Independent rating of presence or degree of absence of: a. coping with "disease" b. postoperative psychosexual functioning, c. self-esteem & mood, d. body image. Use Giessen Test, & medical assessment of anatomical results of surgery.	Not stated.	No	At the end of paper hard to distinguish impression from fact and what own impression/ other author's impression & fact is. CVAH = Congenital Virilising Adrenal Hyperplasia.
13. Mobus, Sachweh, Knapstein & Kreienberg (1993)	24 cases with MRKH of 27 who were seen at the Dpt. between 1972-1990	University Gynaecology Dpt. Ulm & Mainz Germany	Cases with MRKH	Retrospective case series looking at psychosexual rehabilitation following surgery	Interview, (German) questionnaires on functioning x 2, personality & body image, and a physical exam	Not stated	no	Article in German

TABLE 2.1: Articles with a primary focus on psychological, psychosocial or sexual effects of MRKH and its medical/surgical management

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control group**	**Additional comments**
14. Weijenborg & ter Kuile (2000)	17 cases with MRKH	University Department of Psychosomatic Gynaecology & Sexology Leiden The Netherlands	Cases with MRKH	Prospective study looking at effect of support/information group program on psychological wellbeing in women with MRKH	SCL-90-R Pre&post Repeated measure ANOVA & T-test with Bonferroni correction	None	no	Participants are their own waiting list controls.
15. Holt & Slade (2003)	7 cases out of 40 with MRKH seen In 2 o/p Dpts.	2 Out-patient Gynaecology Clinics England	Cases with MRKH	Retrospective case series looking at living with the experience of an incomplete vagina & womb (qualitative)	Semi-stuctured interview on 1. how understood and thought about vaginal absence 2. how experienced diagnosis & treatment 3. effect on life style, relationships & self-perception. Interpretative phenomenological analysis	None	no	None
16. Nadarajah, Quek, Rose & Edmonds (2005)	79 cases with MRKH of 145 who were seen at Dpt. between 1984-2001 vs 131 without MRKH	The National Centre for Adolescent & Adult Women with Congenital Abnormalities of the Genital Tract Queen Charlotte's & Chelsea Hospital London England	Cases with MRKH	Cross-sectional study looking at sexual function in women treated with dilators for Vaginal Agenesis vs sexual function in women without MRKH (from the general population)	Questionnaire (Female Sexual Function Index - FSFI): Looking at: Sexual desire, arousal, lubrication, orgasm, satisfaction, pain. Student's T comparing two groups	Up to five years?	yes, 60 cases with MRKH, 131 controls	Control group significantly older (mean age 39.7 vs women with MRKH with a mean age of 26.6)

TABLE 2.2: Articles with a primary focus on descriptions of congenital absence of vagina, descriptions of surgical/non-surgical procedures and outcome (with mainly medical/surgical focus):

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control Group**	**Additional comments**
1. Bryan, Nigro & Counseller (1949)	100 cases with absent vagina included of which approximately 21 had MRKH	Division of Surgery, Mayo Clinic Rochester USA	Cases with absent vagina	Retrospective case series comparing various methods of surgical treatment for congenital absence of vagina	Physical exam, medical history, surgical investigative & medical findings, medical interview. No indication of measures used to asses psychological attitude/emotional stability of subjects	Surgical follow-up over 4-8 years.	no	This study is a reproduction of Counseller (1948) Note on psychological attitude & emotional stability of patients.
2. Turunen (1952)	73 cases with absent vagina included, of which possibly 67 had MRKH, who were seen at the Dpt. between 1937-1956	University Gynaecology Department Helsinki Finland	Cases with congenital absence of vagina	Retrospective case series which describes findings of congenital absence of the vagina and it's mostly surgical treatment in women presenting	Not noted. Medical case material	Surgical follow-up up to 20 years post-surgery	no	Article in German
3. Sargis Wylie, Thomay & Kalanie (1960)	4 cases with MRKH	Lakewood Hospital Cleveland USA	Cases with MRKH	Retrospective case series looking at construction of a functional vagina	Physical exam & patients' (interviewed) response. type of ? asked, not stated (possibly regarding sexual pleasure & orgasm)	Not stated for how long following surgery	no	Noting psychosocial indications for surgery
4. Von Hauser & Schreiner (1961)	21 cases with MRKH	University Gynaecology Department Basel & Zurich	Cases with MRK	Retrospective case series look at characterisation & distinction of MRK as a	Medical observation	Not stated	no.	Including some psychological aspects. Article in German.

TABLE 2.2: Articles with a primary focus on descriptions of congenital absence of vagina, descriptions of surgical/non-surgical procedures and outcome (with mainly medical/surgical focus):

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control Group**	**Additional comments**
		Switzerland		Syndrome				
5. Rock Reeves, Retto, Baramki, Zacur & Jones (1983)	88 cases with MRKH seen at the Dpt. between 1950-1980	University Department of Obstetrics & Gynaecology Baltimore USA	Cases with MRKH	Retro/prospective case series looking at functional & anatomical success of vaginal creation	Review medical records & contact by phone. Anatomical failure is classified as further surgery needed: surgeon's assessment. Functional success is classified as sexual satisfaction: patients' assessment Use T-test & Chi-square, where appropriate.	Mean follow-up 8.4 years, range 1-27 years	no	Reference to psychological impact. Writers call it a "historical prospective analysis" Cases with repeat operative vaginoplasty not included, suggests is not consecutive series.
6. Folch Pigem Konje (2000)	2 cases with MRKH	Department of Obstetrics & Gynaecology Leicester Royal Infirmary, England	Cases with MRKH	Retrospective case series on aetiology, diagnosis & management of MRKH	Not stated	Not stated	no	None.
7. Robson & Oliver (2000)	28 cases with MRKH seen at the Dpt. between 1988-1997	Division of Paediatric & Adolescent Gynaecology, Hospital for Sick Children Toronto Canada	Cases with VA	Retrospective case series of long-term outcome of various surgical therapies for vaginal agenesis	Review of patient notes	Not stated	no	Note on psychological impact.

TABLE 2.3: Narrative Reviews

Authors & year of publication	No. of cases	Setting/ location	Inclusion criteria	Type of study & Focus	Methodology	Duration of Follow-up	Control group	Additional comments
1. Jensen & Reiter (1999)	-------	Section of Pediatric Psychology The Cleveland Clinic, Children's Hospital & Department of Paediatrics, Rainbow Babies & Children's Hospital Cleveland, Ohio USA		Chapter in book on congenital malformations of the female genital tract looking at psychosocial aspects of congenital female tract anomalies	--			Based on studied opinion and institutional experience with MRKH - mainly referencing Congenital Adrenal Hyperplasia and an (1998) unpublished study on the experience of women with MRKH
2. Edmonds (2000)	-------	The National Centre for Adolescent & Adult Women with Congenital Abnormalities of the Genital Tract Queen Charlotte's & Chelsea Hospital London, England		Chapter on congenital malformations of the genital tract looking at diagnosis & management, including psychological aspects	--			Based on studied opinion and institutional experience with MRKH
3. Edmonds (2003)	-------	The National Centre for Adolescent & Adult Women with Congenatal Abnormalities of Queen Charlotte's & Chelsea Hospital London, England		Chapter on Congenital malformations looking at their management, including psychological aspects.	--			Studied opinion and institutional experience with MRKH, also includes a review of the literature on the outcome of the creation of a vagina, surgically & non-susurgically, in Mullerian Agenesis.

TABLE 2.3: Narrative Reviews

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control group**	**Additional comments**
4. Croak, Gebhart, Klingele, & Lee (2003)	-------	Section of Urogynaecology & reconstructive pelvic surgery, Department of Obstetrics & Gynaecology Mayo Clinic Rochester, USA		Review of the literature on diagnostic & therapeutic strategies for MRKH	-------	-------	-------	Recommendation of multi-faceted approach; not only surgical management but also psychosocial adaptation needed

TABLE 2.4: Articles involving duplication or part-duplication of papers previously published

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control Group**	**Additional comments**
1. Bryan, Nigro & Counseller (1949)	100 cases with absent vagina included of which approximately 21 had MRKH	Division of Surgery, Mayo Clinic Rochester USA	Cases with absent vagina	Retrospective case series comparing various methods of surgical treatment for congenital absence of vagina	Physical exam, medical history, surgical investigative & medical findings, medical interview. No indication of measures used to asses psychological attitude/emotional stability of subjects	Surgical follow-up over 4-8 years.	no	This study is a reproduction of Counseller (1948) - below Note on psychological attitude & emotional stability of patients.
2. Counseller (1948)	76 cases with absent vagina included, of which possibly less than 21 had MRKH of 100 cases who were seen in Dpt. between 1936-1947/8	Division of Surgery Mayo Clinic Rochester Minnesota USA	Cases with congenital absence of vagina	Retrospective case series to describe a surgical procedure & discuss results of treatment for congenital absence of the vagina	Physical exam & investigations + patients' report/data pre-/ post operatively	Surgical follow-up up to 10 years post surgery	no	Note on psychological benefits of surgery. 4 cases died of intestinal obstruction, following use of ileum to create a vagina. Unclear whether any of these had MRKH
3. Kaplan (1968)	11 cases with absent vagina seen with 6 cases from literature, 2 of the latter did not have MRKH	The Long Island Jewish Hospital New York USA	Cases with VA	Retropective case series on psychiatric aspects of diagnosis & management of VA	Extended interviews (type of ? asked not stated) & psychotherapeutic case material	Variable often 1 to 87 sessions	no	Duplication of case desciptions of Fairbairn (1952); Greenacre (1958); Masters & Johnson (1961) - K's case 16 = M & J case B & K's case 17= M & J case C -; and Sabbath et al's (1962), see Table I, included into

TABLE 2.4: **Articles involving duplication or part-duplication of papers previously published**

Authors & year of publication	**No. of cases**	**Setting/ location**	**Inclusion criteria**	**Type of study & Focus**	**Methodology**	**Duration of Follow-up**	**Control Group**	**Additional comments**
								case series. Of 11 own cases, only 8 are fully described, see table 2.1 for detail.
4. Kaplan (1970)	2 cases with MRKH	The Long Island Jewish Hospital New York USA	Cases with VA	Retrospective case series & psycho-analytic case discussion	No measures used. Clinical case material.	Variable often 1 to 87 sessions	no	Part-duplication of own work: Case 1 (Alma) in these case descriptions is case 1 in his 1968 case descriptions

CHAPTER THREE:THE DEVELOPMENTAL CONTEXT OF MRKH

3.1. INTRODUCTION

In the previous chapter I reviewed what is known about the impact of MRKH and its treatment on the lives of women with this condition, both immediately after diagnosis and in the longer-term. As mentioned before, MRKH is typically diagnosed in the mid-teens i.e. at a time when young women are in the process of transition to adulthood. Thus, in thinking about the psychological sequelae of MRKH one needs to consider the developmental context. In what follows, I will conduct a brief narrative review of what is known about (I) psychosexual differentiation: the development of psychological gender identity, sexual orientation, and gender role behaviour, and (II) adolescent developmental stages and tasks and the timing of sexual milestones in normal adolescents. The aim of this review is to identify the implications of the fact that MRKH 'hits' in adolescence for the development of a cognitive-behavioural model of the condition and its treatment.

3.2 PSYCHOSEXUAL DIFFERENTIATION

3.2.1. Psychoanalytic Theories[1]

According to Freud (1932) at the outset there does not appear to be a male or female person in the psychological sense, but both sexes appear to occupy a

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[1] I will briefly describe these now largely outdated theories simply because several of the earlier MRKH case series came from psychoanalytic practice and the descriptions and inferences drawn about these cases is likely to have been influenced by these theories.

‘bisexual’ position (Mitchell, 1982). Freud (1932) also postulates a process of a ‘shattering of varied complexes’ and working through of ‘oral, anal, and phallic phases’ before sexual organization can take place, and a turning from ‘child auto-erotic interaction to adult-erotic interaction’, resulting in a ‘genital phase’ and an arrival at a female/male position (Kline, 1981). Freud’s theories on psychosexual development are summarized by Greenacre (1950) as follows: “having moved from the ‘oral’ to the ‘anal’, and into the ‘phallic’ stage, both sexes appear to be, at this point, ‘little boys’ - the girls being the littler boys (considered from the angle of body sensations), both enjoying ‘clitoral sensation’, where the vagina is still undiscovered. Here the change to a feminine orientation occurs under the influence of the discovery of a penis by a girl on a boy. A subsequent ‘penis envy’ ensues and a turning away from the mother, who has not given the girl a penis, to the father and, eventually, a partner in adulthood. In adulthood the wish for a penis is substituted with a wish for a child, motherhood and marriage”. Finally, “with this a move from a masculine to a feminine position is arrived at in conjunction with the establishment of vaginal sensations beyond the clitoris being registered in the central body image, and an awakening to its function as an organ. Sexuality establishes itself during an individual’s history in this way” (Freud, 1932).

Greenacre (1950) and Kesterberg (1956 a,b) take issue with Freud by saying that the vagina does not remain undiscovered in childhood. These authors propose that an early “awareness” of the vagina as an organ occurs in young girls, as they react to the tension arising from this area (when constipation in the rectum creates vaginal sensation). However, a young girl will not be able to point to the source of this tension and name it and does not have the same "organ constancy" of her vagina, that a boy has of his penis at this point, because of his early active experience of this organ in urination[2]. The onset of menstrual periods in puberty brings the vagina more in the picture/onto the body map. This process also leads to an identification of young women with their peer group, through this shared "secret" that they have with other women, and adjustment to and integration of that body part into the body schema.

In contrast to the above theorising, Bonaparte (1953) has a very simple thesis for understanding feminine psychology. She states that a woman is a male organism arrested in development between a child and a man.

3.2.2. Contemporary Models

Coming from an experimental and social psychology perspective, Green (1974) postulated three dimensions of psychosexual differentiation which are: (a) psychological gender identity, i.e. one's sense of self as male or female; (b) sexual orientation, i.e. one's preference for a sexual partner of the same or different sex and (c) gender role behaviour, i.e. one's participation in stereotypical masculine/feminine activities. He suggested that these dimensions

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[2] In my experience, women with MRKH suggest, that at some level, they "knew" about their vaginal absence well before diagnosis, not necessarily through exploration, but through some sense of this having registered before.

may be intertwined, construing or constituting each other. Taken together these dimensions of psychosexual differentiation encompass the process of working out where one fits into society.

In relation to the above, Piaget (1952) and Kagan (1970), arguing from a cognitive developmental perspective [3], noted that a sense of self-concept and gender self-concept, is only established in relation to the other, in terms of a gradual distinction between a "me", and "not me".[4] In this process a girl, gradually, builds a picture of herself, the "me", vis-à-vis others, including other girls and boys, women and men, and the "not me", through an internalized representation of her body as she knows it, which Piaget (1952) calls a "body schema". This, he states is the very first schema and it forms the basis on which all future, more sophisticated schemata develop. This internal representation, is a structure that allows a person to screen, code and evaluate incoming information into categories, interpret these and use as a basis for action, both mentally and physically (organizing thinking and simplifying information processing). He goes on to note that experiences which cannot be included within the existing schemata of the "me" (one's body schema) and the schema of the "not me" (other schema) set up a state of anxiety in the child. This tension can only be reduced through a process of either assimilation (when new information is absorbed into the schema without fundamentally changing it) or accommodation (when a schema would accommodate itself to fit new

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[3] of the child, ie. Cognitive-Developmental Theory (CDT) of the child and gender self-concept.

[4] Where previously no differentiation was made in the young child between itself and the outside world, where everything was just a mass of sensations.

information), the motivation for which lays in the achievement of a state of equilibrium in the child. This echos the notion of Greenacre (1950) and Kesterberg (1956 a,b), that the integration of body parts into the body schema, would not happen when a body part remained a source of anxiety.

Weeks (1986), who writes from a social constructionist perspective, builds on the above and asserts the role of an “embodied” self in psychological gender identity development, i.e. the role of one’s physiology, of learning and becoming aware over time of the various parts that there are to one’s body, their functions and, particularly, how these parts make up a whole, visible, embodied person and this sense of self and body in relation to others. He states that a girl comes to see herself as a girl, through constant comparison with other people, male or female. This gives rise at a nascent cognitive level to the concept of gender identity, i.e. being a member of one sex, but not of another, as well as, in part, to that of gender role behaviour.

Linked in with the above is the process of reinforcement of gender difference. This process involves being reared unambiguously as a member of one sex or another (Money, Hampson & Hampson, 1957). Gender difference is reinforced by the name a girl is given at birth, by the way she is dressed, and by the positive feedback that she receives from others, for engaging in certain “feminine” actions/roles, or culturally sanctioned markers of femininity as opposed to masculinity. Closely connected with this are the processes of identification, modeling, and imitation of others, described by Bandura (1977) and other social learning theorists. Through these processes, social expectations and scripts are being internalized, and over time become increasingly idealized and stereotypical. This eventually lead to a sense of psychological belonging to a particular sex, an awareness and recognition of being male or female and a comfortableness with that, which Stoller (1964) called "core (psychological) gender identity".

The above ideas are further developed, by amongst others Bem (1961), Fagot & Leinbach (1989,1993), Bandura & Bussey (1999), and Martin, Ruble & Szkrybalo (2004) with two somewhat overlapping theories of gender development, Gender Schema Theory (GST) and Social-Cognitive Theory (SCT), both of which combine social learning theory and cognitive approaches. According to these theories[5] a girl/young woman, over time learns, comparing herself with grown-up women, that they not only have periods, ovaries and eggs, but that a woman can fall pregnant through vaginal intercourse with a man, and that she can carry a baby in an internal organ that is called a womb and can give birth to this baby and nurture it. In other words she works out, or comes to an understanding of the properties attributed to her sex, the objects with which her sex is typically associated, and the kinds of activities they prefer and she may come to prefer or idealise, beyond mere biological predisposition to these or social reinforcement of these (Fagot & Leinbach, 1989, 1993). This

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[5] The nuances, differences in emphasis and debates within and between these theories are beyond the scope of this thesis

"gender stereotypical" knowledge, becomes eventually organized in an "internal picture", i.e., an increasingly complex gender knowledge structure/gender schema, of what happens to those occupying her gender[6]. From this she can infer what may happen in future to her and what her role in life may be (Bem, 1981). This goes with the division of labour between men and women as an organizing principle of society, playing a role as to the conceptualization of what it means to be a woman and how it is personally experienced and how socialising agents and the broader culture (parents, day care workers, teachers, the media, cultural norms) imbue gender with saliency and functional significance (Bigler, Jones & Lobliner, 1997).[7] According to this being a woman can become equated very early on, by the girl and others, with the ability to have sex, fall pregnant and have children (see also David, Carmil, Bar-David & Serr 1975; Weijenborg, van Dijk & van Hall 1986; Holt & Slade 2003). Values and norms of the environment are thus passed from one generation to the next (Weeks, 1986).

Several recent authors take a biopsychosocial approach and discuss the pre- and post-natal effects of sex hormones on a woman's experience of her body, and the development of a sense of herself as female (Masica, Money, & Ehrhart 1971; Goy & McEwen, 1990; Hines, Ahmed & Hughes, 2003). The rise in oestrogens at puberty sets in motion the "standard" physical feminization process with the development of female secondary sexual characteristics,

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[6] This is a concept central to GST, from which its name has been derived.

[7] I.e. the power of gender, as a processing dimension, is derived from its functional value (Bem, 1981).

activates the propensity for female ways of thinking, feeling, or reacting and for adult type female sexual orientation and behaviour, role development and psychological gender identity.

3.3. ADOLESCENT DEVELOPMENT AND SEXUAL MILESTONES

To understand where exactly in a young woman's development the diagnosis of MRKH "hits", given a typical age of diagnosis at around 16 to 18 years, I will take a life-course perspective and describe the developmental stages and developmental tasks associated with adolescence from a normative point of view, and provide some information on milestones of sexual development.

3.3.1 Definitions and Stages of Adolescent Development

Adolescence has been defined as the period of transition from "puberty to married union", or from puberty to an arriving at "more adult roles/responsibilities and adult sexual health (Elders, 1980)". The onset of puberty is ushered in by multiple changes on several levels (Kipke, 1999). These changes go towards marking the passage from childhood into adolescence and the working towards mature adulthood, i.e. "this gradual coming of age, biologically and more generally, that may occupy much of the second decade of life".

Developmental psychologists and health professionals have categorized adolescence into the three developmental stages of early, middle and late adolescence (for review see Report of the National Commission on Adult Sexual Health; Haffner, 1995). These stages, they note, are key to understanding adolescents' behavioural decisions and adolescent sexuality. The characteristics and key developmental tasks of the three stages are as follows:

A. Early adolescence (females ages 9-13, males ages 11-15):

Puberty as a hallmark

Adjusting to pubertal changes such as secondary sexual characteristics

Concern with body image

Beginning of separation from family

Increased parent child conflict

Presence of social group cliques

Identification with certain social groups over others

Concentration on relationships with peers

Concrete thinking, but start of exploration of new ability to abstract

B. Middle adolescence (females ages 13-16, males ages 13-16):

Increased independence from family

Increased importance of peer group

Experimentation with relationships and sexual relationships

Increased abstract thinking ability

C. Late Adolescence: (females ages 16 and older, males ages 17 and older):

Anatomy nearly secured

Body image and gender role identification nearly secured

Empathic relationships

Attainment of abstract thinking

Defining of adult roles

Transition to adult roles

Greater intimacy skills

Sexual orientation nearly secured

The pursuit of these developmental tasks the report notes, drawing from Scales (1991), answers three psychosocial questions that adolescents ask themselves: (1) Am I normal?; (2) Am I competent? (3) Am I lovable (and acceptable to others) and loving? The report finally states that adolescent behaviours can be attributed to a search for affirmative answers to these questions.

Kipke (1999) notes that the sequence of the varied changes occurring during adolescence in both boys and girls is predictable, but the timing and configuration of these changes may vary across societies and different historical periods. In modern Western society, the period of adolescence is much more prolonged than in traditional societies (Buchman, 1989).

3.3.2. Sexual 'Milestones' of Adolescence

The report of the National Health Commission on Adolescent Sexual Health (Haffner, 1995) states that "adolescent growth and development and adolescent sexuality is not singular or stable. It is plural and dynamic. For most young people, adolescence does not entail an absolutely predictable, consistent set of developmental tasks that is being negotiated, nor does it unfold in a singular, universal fashion". The report goes on to say that "adolescent sexuality emerges from cultural identities, mediated by ethnicity, gender, sexual orientation, class, physical and emotional capacity. Adolescent development is affected by parents, other family members, and other adults, as well as schools, and the peer group". Thus any normative data on the timing of the negotiation of these developmental tasks, hereafter referred to as 'milestones of sexual behaviour', need to be considered in terms of the characteristics of the cohort that is studied and the time period when the data were gathered

Table 3.1 gives an overview of studies that present information on the age at which certain sexual milestones are typically taken in contemporary Western societies.

The onset of puberty is considered as one of the most important developmental milestones for girls to negotiate (Brooks-Gunn & Reiter, 1990; Stattin & Magnusson, 1990). In particular the first menstruation is considered by many to be the "single most critical event marking puberty in girls, signifying and symbolizing feminine identity and maturity, attributes that will constitute the core of the personality in subsequent development towards adult status" (Stattin & Magnusson, 1990). In this context Dubas, Graber & Peterson (1991) state that adolescents' perception that they are developing 'on time' or are later maturing than their peers, may be as important or even more important than actual timing of puberty and related milestones (see also David, Carmil, Bar-David & Serr 1975; Weijenborg, van Dijk & van Hall 1986; Holt & Slade, 2003).

3.4. DISCUSSION

3.4.1. General Points

Both Freud's (1932) and Bonaparte's (1953) theories nowadays may be easily dismissed as being outdated and having little "face value". However, these theories will have informed the thinking and writing of some of the earlier authors' writing about MRKH such as Fairbairn (1952) and others discussed in Chapter 2. More modern theories about psychosexual differentiation, psychological gender identity, sexual orientation and gender role behaviour are biopsychosocial in orientation and take into account such diverse factors as pre- and post-natal hormones and their effects on brain and body development (hormonal sex and phenotype), the impact of embodiment, of anatomical and biological foundations, of social comparison, modeling, imitation, identification, the power of socialisation; shaping and reinforcement, of cognitive, body schema and gender schema development, the sexual division of labour, cultural values and norms, and of adolescent developmental stages and tasks upon the varied aspects of psychosexual differentiation. Thus, there is a complex interaction between nature and nurture in the way any given individual has to negotiate these factors vis-à-vis what it means for them to be a woman or man.

It needs to be borne in mind that writings about psychological effects of MRKH have evolved over the last 50-60 years and during this time thinking about psychosexual differentiation, sexual orientation, and gender role behaviour has changed considerably. Sexual preferences for a same sex partner are now much more accepted in Western society and no longer classified as a sexual aberration, as was the case in earlier decades There has also been a move away from rigid and idealised gender role behaviours. Thus the "female ideal self", of a woman, married to a somewhat older man, with a good income, so that she can afford to become a homemaker and raise a family as the ultimate fulfillment in life, has long since gone. Marriage and comparable committed relationships no longer exclusively have reproduction and raising children as a sole aim and having children is not a requirement for that relationship to survive or to be seen as valid. Furthermore, in current relationships penis-vagina intercourse does not have to be the 'holy grail' of sex (Liao, 2003).

Whilst the above suggest that at least in modern Western society there is an increasingly relaxed view that is more accepting of diversity of sexual expression, it would be naïve to assume that this change in culture has made it substantially easier for young women to be diagnosed with MRKH, as even in this "enlightened" age the physical/psychological capacities for penis-vagina intercourse are still widely seen as prerequisites for being a man or woman and become linked to the acceptability of oneself as a person in some way (Weijenborg, van Dijk & van Hall, 1986; Liao, 2003). Moreover, outside mainstream Western culture, more traditional groups still embrace the idea of (arranged) marriages with a reproductive focus and the inability of the woman to bear a son may prove sufficient reason for a divorce in some cultures, or sufficient reason for taking of a second wife in others[9].

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[9] As an interesting aside, in Chinese culture until the early 20th Century, the prerequisite for being marriageable, and what was taken as a sign of one's femininity lay in an altogether different organ. Here the body part of initial focus, when coming of age, was the presence/absence of thin, delicately pointed and small feet, rather than the presence of a vagina or the capacity for intercourse and reproduction. See (2005) notes, that these feet, "were something for a man to be fascinated by during the most private moments between a man and woman, which would not diminish in value to him even after the couple had children, or the rest of the woman's body was not longer a sexual enticement to do bed-business". However, I state that this initial focus away from the vagina, and capacity for intercourse and reproduction, would eventually lead back to these. See (2005) goes on to outline, that "the size of one's feet served as proof/disproof to any prospective in-laws of one's perseverance, one's ability to endure the most severe of pains (and risks) (of foot-binding in childhood), and so the pains (and risks) of child-birth". In all of this the presence of a vagina and the capacity for intercourse and reproduction, and giving birth (to a son), seemed assumed. All these aspects of the female body appeared to become interlinked, and become ways by which to identify women and give them value (or not).

3.4.2. Specific Implications for Women with MRKH and for the Development of a CBT model

Below, I will place the findings of the review in context and discuss where - developmentally speaking - MRKH "hits" most, why it is such a challenging experience and the implications this has for the development of a psychological intervention. Table 3.2 puts together a range of MRKH related events and difficulties with the developmental context in which they are likely to occur and speculatively (based on my own clinical experience and the literature review in chapter 2) links these with negative appraisals that young women typically develop in these situations.

It can be seen from this table that by the time they are diagnosed most young women with MRKH typically will have had a history of primary amenorrhoea for a good two years or more. This absence of menstrual periods puts them out of step with their peers at a time when being like your peers is of paramount importance. This is likely to lead to alienation, from the peer group with a growing sense of being different. As time passes the amenorrhoea is likely to become seen as an increasingly shameful secret. The uncertainty of not knowing what is wrong will lead to growing anxiety and may explain why some young women respond with some relief when they are finally diagnosed. In terms of their cognitive development these girls are still at the concrete level of processing information and may therefore be more prone to develop extreme negative appraisals of their situation than someone with adult cognitive processing skills would. Given the significance of the onset of menstrual periods as a symbol of 'feminine identity and maturity' (Stattin & Magnusson, 1990) it follows, that even prior to diagnosis the absence of periods poses a significant threat to these adolescents' sense of themselves as young women. Once diagnosis is made the developmentally pertinent questions of "Am I normal?" and "Am I loveable and loving?" may no longer be answered in the affirmative with cues being taken from the environment in relation to this (see table 3. 2; e.g. information given during medical encounters, the response of the doctor, the parents, the opposite sex, their girlfriends, peers, and others).

The timing of diagnosis coincides with the stage when teenagers typically are becoming more sexually active. At this stage the young woman with MRKH will learn that she needs dilator therapy to be able to have penetrative sex. This puts physical and emotional barriers between her and the opposite sex. Diagnosis and treatment therefore are likely to inhibit dating and sexual exploration and will deepen the young person's sense of falling behind her peers and being different. With their (absent) vagina remaining a source of anxiety, it cannot be integrated into their body image. However, even after successful dilator therapy, they may experience a continuing worrying about whether their vagina will work/will be "noticeably" different compared to that of other women, when engaging in sexual intimacy and penetrative sex.

Up until and including the early stages of pubertal development these girls had felt in step with other girls, in their ways of thinking, behaving, and in terms of their physical development (e.g. breast development and pubic- and underarm-hair growth), but the non-formation of their vagina and womb, and their knowledge of this, leaves a big hole in their body picture. This experience does not fit existing schemata (of "me" not "me", "female" or "male"), and is therefore hard to assimilate or accommodate. Thus there is a strong potential for women to continue to experience major anxieties related to this and even a possible shattering of a sense of self, feeling compromised as a woman, and with a threat to becoming a complete person, and attaining adult status.

They may question now how they can fulfill the female adult roles of being a wife and mother, and where they are to fit into society. Associated with this there may be a loss of direction and power, a sense of inferiority to other women who can do all these things, and a sense of incompetence and defectiveness compared to other women.

The emotional and cognitive immaturity and lack of experience of these young women as their predicament unfolds over time makes it more likely that idiosyncratic negative appraisals of different aspects of MRKH arise and that these negative self-appraisals become fully integrated into these women's sense of identity. Thus all developmental tasks are being threatened from completion with all three psychosocial questions that motivate the completion of these tasks, having been disconfirmed.

In the previous chapter I have already identified some potential targets for psychological intervention including: (a) revisiting the diagnosis and the processes surrounding it; (b) identifying, challenging and correcting unhelpful negative appraisals and self-beliefs, (c) addressing any maladaptive compensatory or coping strategies that may serve to maintain unhelpful self-beliefs. From the above it becomes clear that there is a further potential target for therapy. This is to help patients complete and rebuild their sense of self.

Table 3.1. Age at which certain sexual milestones are typically taken in contemporary Western societies.

Milestone	Age	Type of Cohort
Menarche	Mean age: 12 years	Tanner, 1989 UK representative sample
	Mean age: 12.9 years	Obeidallah et al., 1999 Chicago adolescent girls
First masturbation	Median age: 14.3 years	Schmidt et al., 1995 UK University students
First romantic kiss	Median age: 14.4 years	Schmidt et al., 1995 UK University students
First date	Median age: 14.4 years	Schmidt et al., 1995 UK University students
First petting	>50% teenagers by age 14	Coles & Stokes 1985 American teenagers
	Median age: 15.8 years	Schmidt et al., 1995 UK University students
First sexual intercourse	Mean age: 17.1	Schmidt et al., 1995 UK University students
	Median age 17.2 years	ACSF, 1992 Representative survey of young people in France
	Mean age 17	Schalet, 2004 American and Dutch adolescents

Table 3.2. MRKH related events and difficulties, their developmental context and likely negative appraisals
The format of this table was adapted from Ehlers & Clark (2000). The term appraisal here is used to denote any cognitive response to a range of MRKH-related stresses and events.

What is appraised?	**Developmental context**	**Negative appraisal**
Failure to menstruate at the expected time	Age 12 to 16; Early to Mid adolescence, Cognitive development not complete: concrete thinking - start of ability to abstract Girlfriends start to menstruate (mean age menarche age 12); menarche signifies transition to womanhood Importance of being like peers Increasing importance of body image Early sexual experimentation, e.g. first kiss, first date	'I am different to other girls' 'I am not a proper woman'
Diagnosis: Being told you have no vagina and uterus Being told you are infertile Overall	Age 16 to 17; mid to late adolescence Increased abstract thinking ability Increased importance of peer group Experimentation with relationships and sexual relationships First petting; first sexual intercourse	'I am not normal' 'I am not a proper woman' 'I am sexually neuter' 'I am incomplete/a freak/soiled goods 'I am worthless as a woman' 'I am outside of female experiences – there is no place for me in society – the future is bleak' 'If this can happen, anything can happen, the world is a scary place, and worse can happen still'
Doctor's behaviour during consultations: e.g. treating patient like a specimen, emphasising technical and medical aspects of treatment	See above	'I am a freak' 'I am not a proper person'
Parents response to diagnosis: e.g. depression, denial, shame	See above	'I am unloveable' 'I must never mention this' 'I am an embarrassment to others' 'I am all alone'
Boy-friend/partner's (assumed/actual) response to diagnosis:	See above	'Nobody will ever want me' 'I am unacceptable as a sexual partner' 'I am unloveable'

		'I will never find a soul-mate – the future is bleak
Pain/discomfort related to interventions	Age 17-19: Anatomy nearly secured Body image and gender role identification nearly secured Empathic relationships Attainment of abstract thinking Defining of adult roles Transition to adult roles Greater intimacy skills Sexual orientation nearly secured	'Sex is disgusting'' 'I am disgusting' 'I deserve this'
Emotional response to other women: e.g. jealousy about other women's relationships or babies	See above – and at any age thereafter	'I am bad for feeling this way'
Being confronted with other girls'/women's sexuality e.g. hearing friends talk about periods, being asked for a tampon, seeing other women in relationships, or with their children	See above – and at any age thereafter	'I am inferior'
Being rejected by boy-friend (relationship break-up)	See above – and at any age thereafter	'Men will always dump me' 'Men can't be trusted' 'I will never find a soul-mate – the future is bleak' 'I am second best – can only get second best'

CHAPTER FOUR: A COGNITIVE-BEHAVIOURAL MODEL OF MRKH

4.1 INTRODUCTION

In the last few decades the role of cognitions (thoughts, images, ideas, attitudes), and particularly that of maladaptive thinking (distorted ideas about the triad of self, others, the world) in mood and human behaviour have been implicitly recognized (Beck, 1976; Greenberger & Padesky, 1995), that is a person's emotions are influenced by their thoughts, and emotional problems result from particular interpretations of events. This has led to the development of cognitive-behavioural models that aim to provide a means of understanding the development and maintenance of the core phenomena of emotional disorders, Beck's (1976) cognitive-behavioural account of depression being the first of these. More recently, CBT models of a range of other disorders, including for example anxiety disorders, obsessive-compulsive disorder, eating disorders, personality disorder, psychosis and post-traumatic stress disorder have been developed with ensuing improvements in the treatment of such problems (Salkovskis, 1996). A key element of a good CBT-model is an in-depth understanding of the phenomenology of a particular disorder. This then allows for the development of treatment interventions, i.e. devising a set of procedures that focus on the core pathology of the disorder and reversing the factors that keep the disorder in place (Clark, 1997). In turn, such treatment interventions based on a clear model for that disorder, can help inform the understanding of the disorder (Persons, 1989). The most successful psychological treatment interventions seem to have been derived from models that are based on the principle that cognitive-behavioural processes that maintain the disorder are specific to a given disorder. This leads to a specific model of the problem presenting, that proposes what the central aetiology and the cognitive maintaining processes are of such a disorder (Clark, 1986; Fairburn, 1985).

The aims of the present chapter are: 1) to describe the development of a specific model of the core negative impact of MRKH and the factors that keep this in place; 2) to detail the implications for treatment of MRKH following from the model and 3) to set out the structure and procedures of a cognitive-behavioural treatment for women with MRKH and the rationale for using specific treatment components.

4.2. A Cognitive-Behavioural Model of the Psychological Aspects of MRKH

The core psychological issue in MRKH is the major sense of threat to these women's sense of themselves as (fully-functioning, loveable) adult women. This threat arises from various specific events associated with MRKH, from the clinical symptom (primary amenorrhoea) through to discovery/diagnosis and treatment, together with a whole range of interpersonal influences. These MRKH-related events unfold during a developmentally sensitive time from early into late adolescence. Diagnosis is usually made during a narrow developmental window, when these young women are on the cusp between mid- to late adolescence, i.e. at a time when the average young woman is about to have her first sexual intercourse. Diagnosis is typically experienced as a major traumatic event and a watershed, that divides life into a before and after. Women's view of self (the assumed potential or integrity of their bodies), their sense of self vis-á-vis others, and the world is shaken and sometimes shattered. Based on the MRKH literature, my own clinical experience and adapted from the CBT-model of PTSD by Ehlers and Clark (2000) I postulate three mechanisms which lead to and serve to maintain a problematic adjustment to MRKH. These are: (a) a failure to 'process' the diagnosis; (b) the occurrence of idiosynchratic negative appraisals of MRKH-related events which become incorporated into these women's core schemata and sense of identity as women; (c) women's attempts to control the sense of threat to their femininity and the accompanying emotional symptoms by using a range of potentially maladaptive cognitive and behavioural strategies. Below I will give some details on each of these.

4.2.1. Failure to 'process' the diagnosis

In an excellent chapter on 'Cognitive therapy in adverse life circumstances', Moorey (1996) discusses the process of adjustment to a major negative life event, such as being given the diagnosis of MRKH. Whilst earlier writers proposed a stage model of adapting to bad news (Kübler-Ross, 1970), the empiricial evidence for this is not strong (Silver & Wortman, 2001). Others, such as Horowitz (1986) have postulated two phases of adjustment, one which is characterized by avoidance and denial, the other characterized by overwhelming and intense emotions. There is however, widespread agreement that what is needed is some form of processing of the cognitive and emotional significance of a given event and this will take time. This has been referred to as 'working through' or 'emotional processing' by writers from a psychodynamic or cognitive perspective respectively (Sandler, Dare & Holder, 1970; Rachman, 1980)

In my clinical work with MRKH women, when revisiting the negative life event of being diagnosed with these women in individual therapy, even when the diagnosis had happened decades ago, I often noticed that they would remember and zoom into what seemed a lot of, possibly superfluous, detail. For example, they would describe the dress they wore on that day and its colour and pattern, how bright the sun seemed to shine outside as compared to how dark it was in the consultant's office, they could see in their mind's eye, the consultant's face, and the clothes s/he wore, or the size of her/his desk, or the window behind the consultant's head. However, typically also at a certain point of talking about their experiences their mind would go blank and they could not remember and relate what was said, or happened next, unable to sketch the larger "picture", leaving big gaps in information. It was then that some women would start to describe the situation as feeling like they were falling off a huge cliff-face not onto grass, but onto glass, and that in this they could not recognise themselves for the wounds incurred, or falling from a huge building and shattering into a million pieces.

These clinical observations point towards a re-experiencing (in this case of being given the diagnosis) mainly in terms of sensory impressions rather than in the form of a coherent narrative. This is somewhat analogous to what happens in the development of PTSD (Ehlers & Clark, 2000) and points towards incomplete processing of the memories of what happened, as a result of the information being too overwhelming and painful, and leading to having poor intentional recall (and possibly vivid unintentional re-experiencing). As already highlighted in the previous chapters, the relative cognitive immaturity of these adolescents, with a tendency to rule-based black-and-white thinking, is likely to foster such poor processing of these events. It has also been suggested that certain pre-existing beliefs such as the belief that it is weak or unacceptable to show strong feelings may prevent emotional processing following a trauma and predispose to PTSD. From this one can surmise that if the family of a young woman models an emotionally avoidant, embarrassed response to her diagnosis that this might make it more likely for her to be unable to fully process what happened. Or, alternatively, if a family member displays a very strong emotional response to the diagnosis, the patient may infer from this that there is no place for her to have emotions as well, that she now cannot be weak, and needs to be strong, with the same end-result as the previous scenario.

Poorly formed memories and an environment that makes it hard for the person to update and revise and make sense of what happened prevent the incorporation of new information and therefore the ability to adjust to the MRKH diagnosis and to move on.

4.2.2. The development of idiosyncratic negative appraisals of MRKH-related events

Having congenital agenesis of the uterus and the vagina, perhaps combined with other congenital abnormalities e.g. of the kidneys, would be very distressing to anybody. Thus appraisals such as *'I am different'*, *'life is not fair'*, *'my prospects for finding a partner are reduced'* are to some extent realistic. Nonetheless, there will be many appraisals related to the 'events' of MRKH that are overly negative and idiosyncratic. A table of some such appraisals (gleaned from the literature and my own experience) in their developmental context, together with the events that might elicit such appraisals, was shown in chapter 3. The response of others may inadvertently strengthen and reinforce such appraisals. It is the persistence of such appraisals and the fact that in some individuals they may over time come to be elicited by an increasingly greater range of triggers which are only peripherally or not at all related to MRKH, that is noxious and maintains these women's psychopathology.

Given that these adolescents' core identity as a woman at this stage, in terms of their psychological gender identity, sexual orientation and gender role behaviour, is still developing, any idiosyncratic negative appraisals of MRKH-related events are likely to become incorporated into these women's core schemata and their sense of identity as women.

4.2.3. Use of potentially maladaptive cognitive and behavioural strategies for the reduction of threat

Women are likely to attempt to control the sense of threat to their femininity and the accompanying emotional symptoms by using a range of potentially maladaptive cognitive and behavioural strategies. As Ehlers and Clark (2000) have pointed out the strategies chosen are likely to be meaningfully linked with the individual's appraisals of a particular situation. These strategies intended to reduce the threat of MRKH are maladaptive because they maintain the threat associated with MRKH by three mechanisms: (1) directly producing psychological symptoms; (2) preventing change in negative appraisals of MRKH or its sequelae; and (3) preventing change in the processing of the diagnosis. Table 4.1 below illustrates some negative appraisals and the maladaptive strategies connected with them.

4.2.4. Other considerations: Appraisals and emotional responses

Adjustment reactions to bad news are typically characterised by intense and mixed emotions, such as anger, fear, and depression often rapidly alternating (Moorey, 1996). Particular emotions are meaningfully linked to particular appraisals (Ehlers and Clark, 2000). For example, the thought 'I will never be able to have a child' is likely to be linked to regret and sadness. Beyond the early phase of adjustment to diagnosis, one salient feature of MRKH is that many women constantly compare themselves (negatively) against other women and this is associated with appraisals such as 'I am inferior', ' I am not a proper woman'. Emotions aroused by situations involving social comparison where there is a threat to rank prominently include shame, guilt, envy or jealousy (Gilbert, 2001). As Gilbert points out these emotions are generally seen as socially unacceptable emotions and people tend to keep them to themselves. They also have the potential for contributing and intensifying a person's sense of themselves as a bad person and as harbouring something that needs to remain hidden

4.3 Putting It All Together in The Clinical Context

So far I have outlined the development of a problematic adjustment to MRKH during adolescence and have talked about negative appraisals arising directly from the MRKH-related events as they unfold and how these and other mechanisms might contribute to the persistence of a problematic adjustment in the longer term. However, MRKH also needs to be seen in these women's life context and development prior to puberty, particularly as these women often have a sense of life being completely divided into a before and after diagnosis.

By the time they come for treatment women will often have lived with MRKH for a number of years or even decades and so will have had time to incorporate MRKH and all related events (however incomplete this process may be) into their sense of who they are as a woman and a person in this world and will have developed a well-rehearsed set of rules for living and dealing with their MRKH.

Thus in a clinical and treatment context it therefore makes sense to try to formulate MRKH- related psychological difficulties 'longitudinally', i.e. taking into account previous life experiences and socio-cultural context, temperament, and pre-existing beliefs. The account that follows draws on CBT models of disorders of personality development (Beck, 1996; McGinn & Young, 1996; Padesky, 1994). These models distinguish between different types/levels of problematic cognitions (such as schemata, conditional assumptions and negative automatic thoughts), on the grounds that these have different treatment implications. Table 4.2 shows a longitudinal model of the psychological aspects of MRKH.

4.3.1. Core beliefs: the self, others, the world and the future

Core beliefs or schemata about the self, others, the world and future are deeply held beliefs typically formed in childhood. These are organized meaningful wholes, that people develop over time which are being used to screen, code and evaluate incoming stimuli and allow the individual to interpret their experiences in a meaningful way

(McGinn & Young, 1996; Padesky,1994; Piaget, 1952). Prior to the diagnosis of MRKH many of these young women will have had an unremarkable development with positive beliefs about the self and others and a basic belief that the world is a good place and that events that happen within it are meaningful and make sense (Janoff-Bulman, 1992). There may be an added belief that bad things happen only to other people. Until puberty the young woman is also likely to have an intact body schema and an equally intact developing schema of herself as a young woman (Piaget, 1952).

The MRKH diagnosis induces an intense psychological crisis as it is experienced as threatening to the person's physical and emotional integrity. It constitutes a massive assault on the young person's existing schemata about the self, others and the world (Janoff-Bulman, 1992; Rothbaum & Foa, 1996). It is so unexpected and outside the range of these young people's usual experience, so statistically unusual and so extremely difficult to get one's "head around" that many women initially think: "This can't be me, this can't be happening to me, it's a bad dream that I will wake up from". However, gradually the person has to accept that she is not immune to rare, random and traumatic events. As one woman said, "statistically it happens to one in 5000 females born, but I do not take any comfort from statistics, because that statistic can be you, that statistic was me".

Thus the world may no longer be experienced as safe, secure, and predictable, but as malevolent or meaningless. For example, one of my patients noted that after diagnosis she saw the world "as it truly was", i.e. as an insane place, with insane things happening in it, where she had no control, and “where nothing could be trusted”, and her own power to make a difference seemed to have gone.

For many young women with MRKH, their body schema, i.e. their internal mental representation of her body on which - according to Piaget (1952) - all other schemata are built, is shattered. Being given a diagnosis of an ‘absence of a vagina and uterus’ is hard to make sense of. Incoming stimuli that confront her can no longer be coded and matched with what she previously knew about her body and it’s integrity. Learning about other abnormalities that occur in the context of MRKH, such as renal abnormalities, may further compound the threat to the body schema and further alienate her from her body.

In parallel the young woman’s schema of herself as a developing woman who can have sexual and love relationships and children is shattered with the future seeming bleak or at least very uncertain. To this a new MRKH-related schema is added. I say this because many of my patients talk about how the MRKH becomes their major preoccupation and identity, through which all other experiences are filtered and coded.

The body, feminine and MRKH related schemata, which are closely linked, become imbued with a negative meaning of being different, defective, worthless, unloveable, out of control or even outside human experience. The exact nature and cognitive/emotional colouring of this is likely to depend on a number of factors such as other pre-existing experiences and/or schemata. One powerful contributing factor is the meshing of the view of self with culturally derived beliefs about what it means to be a woman, where self-worth or value becomes narrowly linked to the presence of a vagina, the ability to have sex, to have a womb and give birth to children. This could be seen as an interacting cognitive subsystem operating (Teasdale & Barnard, 1993; Teasdale, 1993). In other words; it is not the culturally derived belief about what it means to be a woman *per se* that causes distress but the intimacy of its link to self-worth/esteem (including ones' lovability, acceptability to others, ones' power in society and perceived control over ones' predicament (efficacy), via the intermediary of the body experience (the presence/absence of certain body parts). This is depicted in diagramme 4.1, by the area highlighted in blue.

4.3.2. Conditional assumptions, rules and attitudes

Holding negative schematic beliefs is very distressing. Thus, to avoid the activation of these beliefs and the accompanying emotions, and compensate for them by moving as far towards an opposing state as possible, a person may develop a set of attitudes, conditional assumptions, and 'rules for living', constructed to keep the beliefs at bay. These conditional beliefs relate directly to the schemata they are developed to compensate for. Thus, for women with MRKH they are often around the need for control to compensate for core beliefs around powerlessness and lack of self-efficacy or around achievement, and lovability, in order to compensate for self-beliefs around being an inadequate defective, worthless woman or lacking identity as a woman.

A typical example of beliefs at this level may include the attitude 'if anyone finds out what is wrong with me they won't want anything to do with me', the assumption 'if I pretend to others that nothing is wrong, people might think I'm ok; if I don't, they will reject me' and the rule, 'I should try to present myself to the world as happy, smiling and someone without needs or problems'.

These rules for living which are typically phrased in a conditional, 'if …then…' format or as 'shoulds' and 'musts' usually are closely linked to certain maladaptive ways of behaving that may limit the person's development and maintain the problem. For example, a young woman with core beliefs that the world is totally unpredictable and unsafe and that she herself is powerless, may develop conditional beliefs such as 'If I am out of control I will feel terrible and terrible things will happen.' An associated rule for living might be 'I must always be totally in control of my life'. Behaviourally this might lead to her leaving nothing in her life to chance, being constantly vigilant for problems and dangers and planning everything in her life in great detail.

A young woman with a core belief of 'I am inadequate and defective as a woman' may develop the conditional belief 'I will only be acceptable to people if I present as the perfect woman'. This might make her spend huge efforts to try to improve her appearance and make herself desirable as a woman, in terms of dress, make-up or Western cultural ideals of slimness. At times when this becomes too exhausting she may flip into alternative behaviours, abandoning her striving for perfection and may comfort eat, generally neglect her appearance and abandon efforts to appear feminine. Others might compensate for defectiveness beliefs by trying to gain assurance of their femininity through (multiple) sexual relationships in short succession (with an avoidance of psychological intimacy for fear of “being found out”/rejected), in an attempt to proof to themselves that their newly formed vagina is normal.

4.3.3. Schema Processes

McGinn & Young (1996) tapping into very similar phenomena postulate that schemata are maintained by three processes of schema avoidance, compensation and maintenance. Schema maintenance refers to ‘cognitive distortions and maladaptive behaviour patterns that directly reinforce or perpetuate a schema”. An example would be a woman with MRKH who chooses partners who are unsuitable and allows herself to be used and treated badly by them because she believes "No one else would want me, I am unacceptable and unlovable" . This woman might react with suspicion when a good man would show interest in her and reject him, because she believes “there must be something wrong with him, if he shows interest in someone defective as me”.

“Schema avoidance” refers to the cognitive, behavioral, or emotional strategies by which the individual attempts to avoid triggering a schema and the related intense affect” (McGinn & Young, 1996). An example would be a woman who avoids any relationships because this would be too painful for her.

Finally, schema conpensation “refers to behaviors or cognition that overcompensate for a schema” (McGinn & Young, 1996). Thus a woman with MRKH may strive for academic excellence to gain worth in a field other than her femininity. She may engage in pleasing behaviours to gain acceptance and love, thinking that if she does as others say she can make this happen and become “loveable” to others. She may thus forge a life away from relationships that are mutually giving. She may become a “do gooder”, a self-less creature, a saint, focusing only on others to the exclusion of herself. She may resort to pretending to be all right at all times and more than normal, not sharing parts of herself that she experiences as being shameful, unacceptable to others, for fear of rejection, and/or she may flee into drink and drugs. Diagram 4.1 provides a “map” of MRKH-related negative schematic beliefs about the self and sense of self as a woman that these women develop, and the processes of schema avoidance, compensation and maintenance, associated with them.

4.3.4. Triggers

Schema-level beliefs and conditional assumptions can lie dormant, but become activated by salient triggers. In the case of MRKH triggers or critical events often are relationship break-ups, which bring down a carefully built up "facade" and activate the woman's negative core beliefs about herself. Alternatively, events such as a friend or a sister having a baby may also serve to activate MRKH-related schemata, as may an infection in the newly created vagina.

4.3.5. Maintenance of problematic adjustment to MRKH

The thoughts (idiosynchratic negative appraisals), emotions, and behaviours that arise in relation to MRKH related stressors and maintain the psychological difficulties associated with MRKH have already been discussed above under 4.2.2. to 4.2.4.

4.4. Treatment Implications

From the above model a number of predictions follow:

Firstly in order to reduce the core negative impact of MRKH on these women and the maintaining processes that keep this in place it follows that a cognitive-behavioural Therapy (CBT) for MRKH should cover the following areas:

Firstly, the negative life event of being diagnosed with MRKH needs to be revisited with the aim of helping women to fully process what has happened. According to Janoff-Bulman (1992) such processing of a traumatic event, requires the rebuilding of a stable self and safe assumptions about the self and world. Ehlers & Clark (2000) also point toward the need to elaborate the trauma memory and integrate it "into the context of the individual's preceding and subsequent experience...".

Secondly, problematic appraisals of MRKH related events, i.e. diagnosis and sequelae of MRKH and other related beliefs, such as the conclusions the woman draws about herself and rules for living need to be modified, as they maintain the current sense of threat to these women's sense of themselves (see Ehlers & Clark, 2000).

Thirdly, dysfunctional cognitive and behavioural strategies that prevent processing the traumatic event of being diagnosed, exacerbate psychological symptoms or hinder reassessment of problematic appraisals need to be identified and replaced with other more adaptive strategies for coping with distress (see Ehlers & Clark, 2000).

Beyond this these women need to be helped to develop a more positive view of their own femininity, in other words their body schema and feminine schema need to be rebuilt. This may mean helping women to shift from a narrow, caricatured view of femininity as derived from the possession of a vagina & womb to a broader, more balanced and more accepting view of what makes a woman loveable, acceptable and competent. Secondly, they need to develop a more positive, accepting view of their MRKH as something that is no longer a shameful secret, but something that can be thought and talked about and lived with. This work towards greater acceptance of things that can't be changed needs to include an acknowledgement and mourning of the real losses incurred as a result of MRKH.

4.5. Structure of Treatment

4.5.1 Group versus individual intervention

In planning the design of a treatment intervention for MRKH women the question arose whether this should be an individual or group intervention. Increasingly, in the development of service contracts in the National Health Service, there is the stipulation that patients' evaluation of services should guide service development. The annual audit (NSCAG Report March 2003-April 2004 and March 2004–April 2005) of service users' satisfaction with the provision of care at the National Centre for Adolescent and Adult Females with Congenital Abnormalities of the Genital Tract, suggests the following: Women attending the Centre find the one-to-one therapy offered (which uses the above format), as well as individual therapeutic input at the time of diagnosis, at the time of treatment, and during outpatient follow-up very helpful. However, from the twice yearly support group meeting for women with MRKH held at the Centre it has become apparent how much affected women also value the opportunity of sharing their experiences with others with similar difficulties. Thus it was reasoned that a group therapy intervention could form a welcome and resource effective addition to the Centre's therapeutic repertoire.

Furthermore, it was felt that a group approach would be beneficial as it would be a direct challenge to the commonly held belief by these women that they are 'abnormal' or 'freaks' or 'the only one' to have this condition. In a group format, there would also be more "voices" in the room to generate new perspectives when challenging negative appraisals. To use the group in this way it needed to be small enough to be intimate and for people to feel safe, but not so small as to become uncomfortable, making people feel put on the spot or pressurised to talk all the time, or not generating sufficiently varied views. There had to be a balance between giving each participant space to talk, whilst others listened, and taking the time to think and respond. Groups of 5 to 8 people in total were seen as ideal for this.

4.5.2 'Dose' of therapy

It was thought that the above programme could be delivered in seven once weekly sessions, lasting three hour each (with a small break in-between), organized around a range of relevant themes or topics with one further session at 3-month follow up. This would amount to a total of 24 hours of therapy time. This is a pretty standard 'dose' of therapy time in one-to-one CBT therapy. Other factors played a role in deciding the number of sessions for the programme. These included ethical constraints posed by the research, such as not wanting to keep the waiting-list control group waiting for longer than 3 months, before they could access therapy, Moreover, considering the distance patients would have to travel to the Centre, the time and financial commitment had to be manageable for women from all walks of life and a longer therapy might just have been unrealistic and have led to high drop-out.

4.6. Procedures of Cognitive-Behavioural Group Therapy for Women with MRKH

A full session-by-session account of the contents of the therapy will be given in chapter 5. Here I will look more broadly at the therapeutic procedures used over the course of the therapy and how they map on to the aims of therapy.

4.6.1. A formulation-based approach

The intervention centres around a cognitive-behavioural case conceptualisation (see table 4.2) which serves as an overall working model and template, and is used to explain the CBT model and to guide the therapy. Over time each woman produces her own formulation which gets updated and revised to tailor it to her particular circumstances as therapy progresses. Each session focuses on a different key MRKH related event or topic.

4.6.2. Re-processing diagnosis

The treatment starts with a focus on the central life event of being diagnosed, and aims to help women move from a poorly processed patchy memory full of gaps and misconceptions to a more manageable and coherent evaluation of the experience. This work involves getting women to expose themselves to feared and avoided emotions and thoughts, identifying and challenging unhelpful appraisals, and systematically confronting and reappraising the event, challenging the negative conclusions drawn about themselves, others and the world, and core beliefs and assumptions developed from it, or earlier beliefs about the self that are reinforced by it.

4.6.3. Cognitive restructuring

Later sessions focus on other MRKH related events and problems such as having dilator treatment, issues around sexual and romantic relationships and mourning the losses of MRKH including infertility. These topics are used to get women to process previously avoided thoughts and feelings, and to identify and challenge unhelpful beliefs and behaviours and - over time – to develop a more adaptive view of themselves, the world and their future (Janoff-Bulman, 1992; Rothbaum & Fao, 1996). Finally, there is also an attempt to help women find meaning in their experience. This involves acknowledging the real possibilities of both good and bad things happening, of disaster in spite of human effort, of triumph despite human limitations, of MRKH being a source of strength, not of weakness in oneself, of personal triumph and mastery, of relishing the good life has, notwithstanding it's shortcomings, appraising what is there and what is important, and emerging from the experience somewhat sadder but wiser (Janoff-Bulman, 1992). It also involves letting go of the maladaptive schemata about the experience and regaining a sense of wholeness, and integrity, through a process of reassembly, where the confusion regarding the self is cleared and the interruption to body image, psychosexual differentiation and its varied parts, is overcome and the body, the self, the condition etc. cease to be an ongoing source of anxiety.

Much of this work is done in the sessions using the different perspectives, life experiences and strengths of the group participants to brainstorm new ways and perspectives of looking at, making sense of, and dealing with particular MRKH related events and their appraisals.

4.6.4. Dealing with maladaptive coping strategies

Therapy also focuses on coping with difficult situations or distress away from overcompensation, or denial and avoidance. Participants were taught to identify unhelpful coping strategies that often make a person feel better in the short-term (e.g. starving or comfort-eating, promiscuity, pleasing, pretending that everything is "more than normal", or using drink or drugs) but have negative longer-term consequences and replace them with more adaptive techniques. These included expressing difficult thoughts and feelings through sharing them with a close other, writing about them or using self-soothing strategies (including a relaxation tape, the script of which can be found in appendix 4.1). Moreover, there was also a focus on building interpersonal skills particularly in romantic and sexual relationships, e.g. how to mention MRKH to a new partner, when and what to tell, how to look after one's interpersonal needs in a relationship, and how to have mutually satisfying sexual experiences.

4.6.5. Therapeutic writing tasks

In between sessions this work is supported by specifically designed homework tasks using the tool of therapeutic writing. There is a large and sound body of research supporting the use of writing about a traumatic or negative life event as a tool for processing these. Such writing has been shown to produce positive outcomes in a broad range of areas including diverse indicators of physical and emotional health (for review see Pennebaker 1997, 2004; and also see Nicholson 1995; Lange 1994, 1996; Schoutrop, Lange, Duurland, Bermond, Sporry & de Goederen 1997). Writing seems to be most beneficial in situations where the traumatic event had not previously been much thought or talked about. Studies on therapeutic writing have shown that this only produced health improvements where there is evidence of one of the following things happening: (1) a development of a coherent narrative over time, (2) a shift in the person's perspective, as evidenced by (a) a shift in pronoun use, i.e. a move from a mainly "I, me and my" perspective to one that incorporated the perspective of others, (b) a shift from using more emotional to more cognitive language or vice versa and (3) an expression of some positive emotion in the context of describing difficult or upsetting events. Thus where it is helpful writing seems to allow people to reappraise upsetting life events by considering their implications from a number of different perspectives, integrating thoughts and feelings into a coherent story and finding meaning in what has happened.

Pennebaker's original writing paradigm (1997) was unstructured and simply invited people to write on 3 or 4 occasions about a difficult or traumatic experience expressing their innermost thoughts and emotions about the negative life event. However, more recently and based on the above research findings he has developed more structured writing exercises guiding people to consider a life event with its impact on themselves and others, to deliberately take varied perspectives on the event they are writing about, such as writing from another person's perspective or writing for or from the perspective of different audiences such as a trusted friend, a fair authority figure or another person involved in a particular incident. These and a number of additional exercises are detailed in a workbook for patients (Pennebaker, 2004).

As MRKH is often a shameful secret for women that they do not find easy to talk about, it was thought that writing might be a useful way of helping them process and make sense of what had happened to them. Writing has the added advantage of being under the control of the writer with the writer determining the rate and degree of confrontation with the memory of particular aspects of a particular experience and the writer also determining how much of their writing they wish to share with others.

With this in mind a number of MRKH related writing exercises were constructed (for full details see chapter 5). Women were asked to write about each topic for between 20-45 minutes on 4 consecutive days as is suggested by Pennebaker (2004) for maximum effect. Writing exercises included writing about diagnosis and the conclusions drawn about herself from this, writing about experiences that tell the woman a different story about herself, away from feeling different, incomplete, useless, powerless, or unloveable/unacceptable; writing from the perspective of on older wiser self who looks back at the experience, giving advice, instruction and comfort to her current younger self and suggesting the most helpful way of looking at and mastering any current difficulties (Lange, 1994). The final writing task in the shape of a good-bye letter instructed people specifically to reflect not just on their experience of therapy and each other, but to look towards the future. The therapist also wrote a goodbye letter to each group giving a narrative account of participants' experiences and their ways of processing and reappraising these in the context of the group. The idea was that participants would be able to refer back to this whenever they wanted.

Each new writing task was introduced towards the end of a session with women starting some of their writing in the session and being asked to complete this at home. In the next session there would be an initial discussion about what the process of writing had been like and women would then share some of their writings reading them aloud and facilitating discussion about different ways of processing and appraising their difficulties.

4.6.6. Building new and more adaptive self-schemata

To help participants strengthen the alternative/more adaptive self schemata developed in therapy guided imagery was used: At the end of each session a guided imagery tape was played which followed the following steps of: tuning into the body, creating a wise and compassionate figure, letting go of the negative images, reinforcing the alternative self schema, as described in Garner & Garfinkel (1997), the script of which can be found in appendix 4.1[1].

Furthermore, participants were asked to keep a positive data log of observed events or activities that they had engaged in that were in keeping with/reinforcing of their newly formed schema of themselves. The aim was to focus on the positive, away from the negative, and to slowly make this newly acquired "head-knowledge", a "heart knowledge", i.e. something that they really believed in about themselves and could feel in their hearts, without needing to question it.

4.7 Summary and Conclusions

In the above I have put forward a cognitive-behavioural conceptualisation and therapy of adjustment to the diagnosis and treatment of MRKH. The model was derived from a number of sources including the literature on MRKH, but also by looking for analogies with other conditions, such as adjustment to bad news and PTSD. The model thus is as yet speculative and empirical support for its components, such as the postulated different maintenance factors of problematic adjustment to MRKH is lacking. In what follows I will describe the evaluation of the model and therapy and also adduce some empirical support for some of the components of the model based on patients' therapeutic writing.

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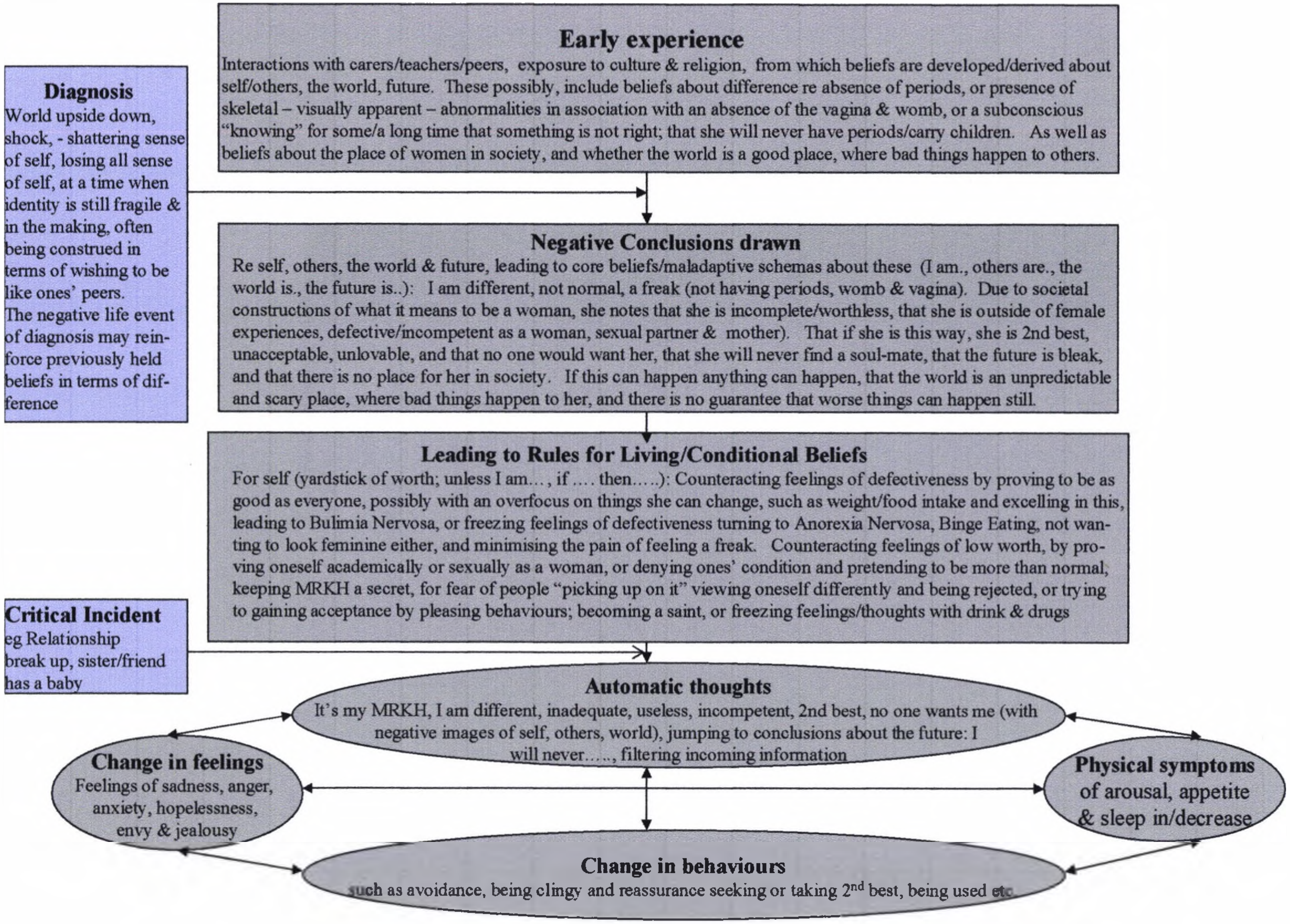
[1] The content of this tape/script is gone through and checked with patients in therapy to ensure that the image of the "beach" and the "sound of seagulls" etc. are indeed seen as safe and non-aversive. Furthermore, it is ascertained whether patients like this way of working, and want to/can use it, as the use of this tape is optional.

Table 4.1: Negative Idiosyncratic Appraisals and Connected Maladaptive Strategies in Response to MRKH-Related Triggers (Gleaned from the Literature and Own Clinical Experience)

Negative appraisal	Maladaptive strategy
If mum/the nurse is doing the crying then there is not enough space for me to express my emotions as well…..	Try hard not to think about MRKH, keep busy at all times, drink alcohol, take drugs
If the doctor/mum/dad have no emotional response to diagnosis then I am not allowed to have any feelings about it either…..	As above
If I think/talk about MRKH then I will 'loose it'/'go mad'. Talking is not going to change anything about it so…..	As above.
If I cannot have a child, then I can devote my life to an alternative course such as teaching/advocating a worthy cause, and then I can gain some value, use as a woman, and possibly obtain sainthood status	No life/work balance, all energies put into chosen activity
If I dress as unwomanly as I can, no guy will approach me, and I will not need to get involved, particularly, as I am not a full woman anyway I might as well stop trying……….	Avoid attracting sexual attention, appear dowdy
If I sleep with guys, then they will love me, as that is all I am there for, or they want from me, and I am not worthy of their love for me anyway…….. If I sleep with many different guys then I can check out whether they will notice anything different about me and my vagina, and whether I really have a normal vagina, can satisfy others and myself and can have a normal sex life…….	Be sexually promiscuous
If I cannot have children, then no man would want me………	Settle for 2nd best in relationships with men
If I go out with a bloke, then I will need to tell him about my MRKH at some point, and then he will reject me and I	Avoid dating, intimacy and relationships with men

will feel worse than I already feel…….	
If I am with other women who talk about their periods, sex and how to fall/not fall pregnant, then I have nothing to say, then they will notice, and I will be found out to be different to them, so I better…….	Avoid female friends
If I do not talk/think about MRKH and anything associated with it, then it will go away in and of itself and I won't feel so bad, so I better …….	Avoid reminders of MRKH
If things like MRKH can happen to me then anything can happen and the world is much less safe then I had assumed, and I have no control and no agency over anything in life, then I cannot plan and dream, forge a particular direction in life or other……	Let life pass by, not plan – live day to day, not take control of the things one can have an impact on

Table 4.2: Longitudinal Cognitive-behavioural Formulation of MRKH



Early experience

Interactions with carers/teachers/peers, exposure to culture & religion, from which beliefs are developed/derived about self/others, the world, future. These possibly, include beliefs about difference re absence of periods, or presence of skeletal – visually apparent – abnormalities in association with an absence of the vagina & womb, or a subconscious "knowing" for some/a long time that something is not right; that she will never have periods/carry children. As well as beliefs about the place of women in society, and whether the world is a good place, where bad things happen to others.

Diagnosis

World upside down, shock, - shattering sense of self, losing all sense of self, at a time when identity is still fragile & in the making, often being construed in terms of wishing to be like ones' peers. The negative life event of diagnosis may reinforce previously held beliefs in terms of difference

Negative Conclusions drawn

Re self, others, the world & future, leading to core beliefs/maladaptive schemas about these (I am., others are., the world is., the future is..): I am different, not normal, a freak (not having periods, womb & vagina). Due to societal constructions of what it means to be a woman, she notes that she is incomplete/worthless, that she is outside of female experiences, defective/incompetent as a woman, sexual partner & mother). That if she is this way, she is 2nd best, unacceptable, unlovable, and that no one would want her, that she will never find a soul-mate, that the future is bleak, and that there is no place for her in society. If this can happen anything can happen, that the world is an unpredictable and scary place, where bad things happen to her, and there is no guarantee that worse things can happen still.

Leading to Rules for Living/Conditional Beliefs

For self (yardstick of worth; unless I am…, if …. then…..): Counteracting feelings of defectiveness by proving to be as good as everyone, possibly with an overfocus on things she can change, such as weight/food intake and excelling in this, leading to Bulimia Nervosa, or freezing feelings of defectiveness turning to Anorexia Nervosa, Binge Eating, not wanting to look feminine either, and minimising the pain of feeling a freak. Counteracting feelings of low worth, by proving oneself academically or sexually as a woman, or denying ones' condition and pretending to be more than normal, keeping MRKH a secret, for fear of people "picking up on it" viewing oneself differently and being rejected, or trying to gaining acceptance by pleasing behaviours; becoming a saint, or freezing feelings/thoughts with drink & drugs

Critical Incident

eg Relationship break up, sister/friend has a baby

Automatic thoughts

It's my MRKH, I am different, inadequate, useless, incompetent, 2nd best, no one wants me (with negative images of self, others, world), jumping to conclusions about the future: I will never….., filtering incoming information

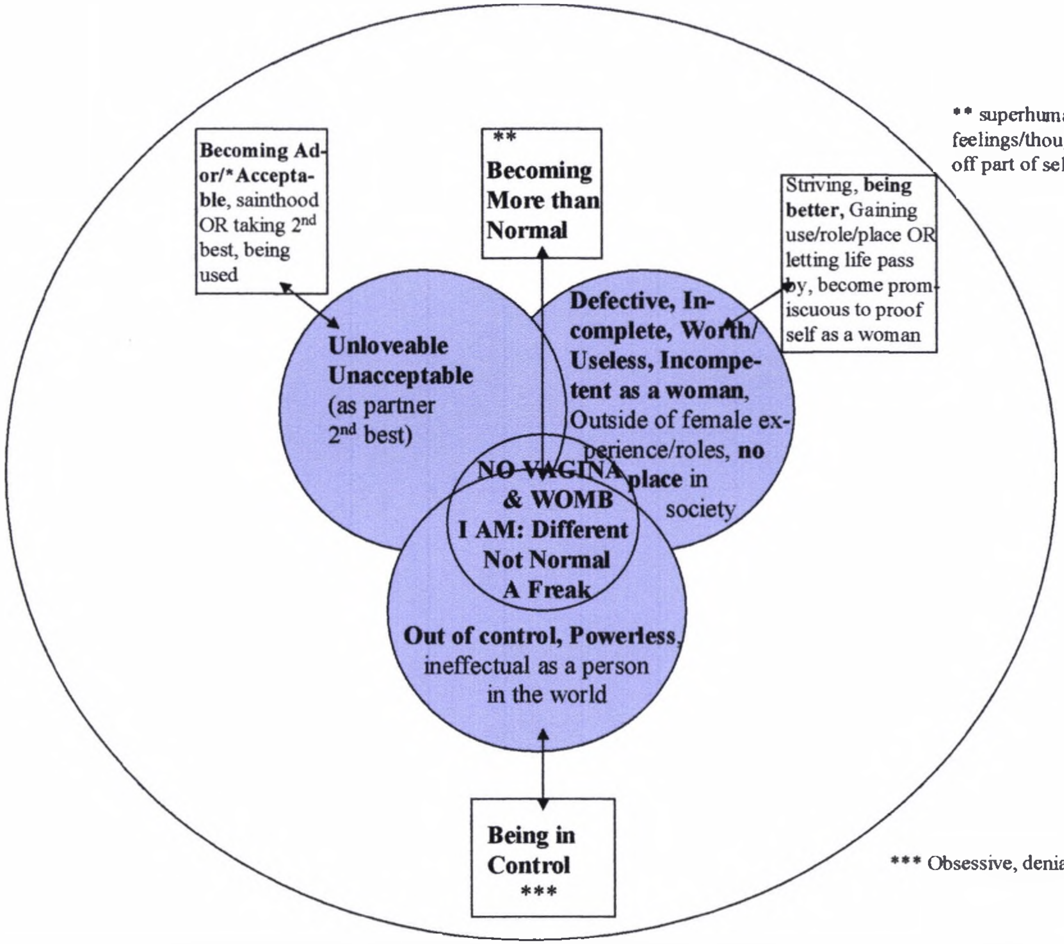
Change in feelings

Feelings of sadness, anger, anxiety, hopelessness, envy & jealousy

Physical symptoms of arousal, appetite & sleep in/decrease

Change in behaviours

such as avoidance, being clingy and reassurance seeking or taking 2nd best, being used etc *goody goody placating, doormat



** superhuman, not open honest re feelings/thoughts/experiences, close off part of self, hide/secret/shame

*** Obsessive, denial real issues

Diagram 4.1: MRKH Negative Schematic beliefs about Self and Sense of Self as a Woman & Processes of Schema Avoidance, Compensation & Maintenance

☐↘ = processes of schema avoidance, compensation & Maintenance (– Rules for living)

○ = Negative schematic beliefs about sense of self, and sense of self as a woman

CHAPTER FIVE: A RANDOMISED CONTROLLED TRIAL OF A GROUP CBT INTERVENTION FOR MRKH VERSUS WAITING-LIST

5.1. Introduction

This chapter describes an exploratory trial of the CBT model and intervention for MRKH in line with the MRC framework described earlier (MRC, 2002). The aims of this phase of the development of a complex intervention are to describe the constant and variable components of a replicable intervention and a feasible protocol for comparing the intervention to an appropriate alternative. The chapter details the (a) design of and setting for the study, (b) participants' inclusion and exclusion criteria, (c) ethical considerations and (d) recruitment. It also provides descriptions of (i) the intervention, (ii) outcome measures and assessments - with a flowchart of measurement points, (iii) sample size, (iv) randomization, and (v) method of statistical analysis chosen. Finally, it reports the findings from the randomized controlled trial detailing (a) the flow of participants through the study, (b) participants' characteristics at baseline, (c) the quantitative results of primary and secondary outcome measures (including a quantitative component), and finishes with a discussion of the key findings, the strengths and limitations of the research, and the clinical and research implications of the research.

5.2. Hypotheses

5.2.1. In women with MRKH, compared to waiting list a group cognitive behavioural intervention will lead to significant improvements on a range of psychosocial outcomes at the end of treatment.

5.2.2. Improvements will be maintained at follow-up.

5.3. Design & Setting for the Study

A randomized controlled trial (RCT) of group CBT for MRKH versus waiting list was carried out.

The study was conducted at the National Centre for Adolescent and Adult Women with Congenital Abnormalities of the Genital Tract at Queen Charlotte's and Chelsea Hospitals. UK based general practitioners and Gynaecologists can refer women to the Centre for assessment and treatment. The team at the Centre consists of two Gynaecologists, who each run a weekly specialist 'female reproductive congenital abnormalities' clinic, a full-time clinical nurse specialist, a half-time counselling psychologist (JHB), and a specialist radiographer. The Centre provides a range of services including diagnostic services, information and support resources, such as leaflets, a helpline, a website (www.mrkh.org.uk), twice yearly support group meetings and a protected chat-room on the website inter alia. These services/facilities are there to promote understanding of the condition and facilitate contact between women with the condition. The team provides medical treatment such as dilator therapy on an in- and out-patient basis, under the supervision of the clinical nurse specialist. The counselling psychologist provides one-to-one intervention at the time of diagnosis, during dilator therapy and at any other time when help is needed.

The study was done in the researcher's own time, i.e. group CBT was offered over and above the researcher's weekly clinical session time as a Counselling Psychologist at the Centre and did not affect the provision of other psychological services available at the Centre.

5.4. Participants:

5.4.1. Inclusion criteria:

Women aged 17 or above with a diagnosis of MRKH (Type I: “simple” MRKH or Type II: “complex” MRKH, i.e. including other congenital abnormalities) made or confirmed at the National Centre were eligible for the study.

5.4.2. Exclusion criteria:

Exclusion criteria to the study were minimal. These consisted of: (1) being already in therapy, (2) being unable to speak English sufficiently well to complete assessment tools or participate in groups, (3) experiencing suicidal ideas or engaging in repeated self-harm, and (4) being under 17 years of age. The rationale for these exclusion criteria is given below.

5.4.2.1. Being already in therapy:

There were clinical and research reasons for excluding those who were currently engaged in psychological therapy from the study. Firstly, it was considered to be confusing and potentially counterproductive for the patient, to engage with more than one therapist, and work according to more than one therapeutic model, at the same time. Secondly, it was felt that if study participants engaged in another therapy alongside the study treatment this would create a confound within the research, as it would not be discernable what effects would be due to the study treatment, or to the other therapy. All women, engaged in treatment elsewhere, had an open invitation to contact the researcher in case of any queries.

5.4.2.2. Being unable to speak English:

Those with major difficulties in speaking English (i.e. unable to complete assessments or participate in a group) were advised to engage in one-to-one therapy. Here the services of an interpreter could be called upon if needed, which is impractical in a group setting.

5.4.2.3. Experiencing suicidal ideas or engaging in repeated self-harm:

Those who experienced serious suicidal ideation and engaged in self-harm, were encouraged to seek one-to-one therapy. They were assured that they could be reconsidered for group therapy once they were no longer actively suicidal/self harming and had established sufficient distress tolerance skills to tolerate engaging in group CBT for MRKH.

5.4.2.4. Being under 17 years of age:

Women under 17 years of age, were excluded. The reason for this was that the Centre has only a handful of women with MRKH in this age group on its books (as in most cases the diagnosis is only made at about age 17 or 18). Moreover, it was felt that it was not developmentally appropriate to mix the small number of younger adolescents with the older participants, given the very different issues experienced by them. The likelihood of large numbers of additional adolescents younger than 17 years being recruited via the Centre's MRKH website "News flash", was considered minimal. Those who have come through to the Service via this route in recent years, typically have been women who have lived with MRKH for many years, and who are from areas where no designated services for this condition exist.

5.5. Ethical considerations:

A number of ethical considerations were taken into account in designing the study, in obtaining informed consent from potential participants and in the practical conduct of the study. These are discussed below and were: 1. Treatment of the control group, 2. Informed consent and right to withdraw from treatment, 3. Confidentiality, and 4. Accessibility of treatment and travel cost.

5.5.1. Treatment of the control group:

It was seen as unethical to have a no-treatment control group. Therefore a waiting list control group was used where participants who drew waiting list had the option of receiving the group intervention after the 3 months follow-up.

5.5.2. Informed consent and right to withdraw:

Having a good understanding of and being able to weigh up the advantages or benefits and potential disadvantages, costs or harms of participating in treatment research forms the basis of giving informed consent. Potential advantages and disadvantages of participating in the treatment and the research (completion of questionnaires) were detailed in the participant information sheet (see appendix 5.1) and were also discussed with potential participants in person by the researcher. Potential disadvantages included: (a) that the group intervention was a new intervention not previously tested. However, CBT in general and many of the techniques and components used here have a solid evidence base in many other disorders; (b) the potential for suffering short-term distress as a result of the intervention (this is specifically mentioned in the therapeutic writing literature - see Pennebaker, 2004). However, this was thought to be a temporary effect only; (c) patients' additional time investment due to having to complete questionnaires at three time points. This was thought to be a minor imposition as the time investment was thought to range from between 30 to 40 minutes only on each occasion.

Balanced against this were potential advantages or benefits of participating in the study such as (a) the likelihood of experiencing improvement in clinical symptoms and well-being; (b) being able to meet other people with the same condition; (c) being able to contribute to the research effort in MRKH, i.e. being able to do something useful for the community of MRKH sufferers at large.

It was made clear to participants at the point of first contact that they were under no obligation to take part in the study. They were assured that if they decided to take part, they were free to withdraw from treatment at any stage, without giving a reason and that this would not affect their future care at the Centre.

5.5.3. Confidentiality:

Participants were assured that all information collected would be handled with the utmost respect and personal identifiers avoided. Data would be safely stored at the hospital where the research was taking place in accordance with NHS data protection regulations. Participants' research records including copies of their therapeutic writings would be destroyed, once the term for the storage of data from the trial had expired. Participants were told how the results of the study would be disseminated and assurances were given that individual participants would not be identifiable in any write up or publications.

5.5.4. Accessibility of treatment and travel cost

It was felt that a lack of money to pay for travel should not impede those who were less well off, but wanted to take part from participating. For those unable to join the treatment study for financial reason due to the cost of travel involved, a small fund from previous patients' donations of money to the Centre was made available to reimburse them. Those on benefits could use the usual NHS form of reimbursement of travel costs available to them.

No financial incentives were given to participate. The study was self-funded, without grant funding or recompense. It was hoped that participants would gain from participation in the emotional sense, and that this would compensate for any lack of financial gain.

5.6. Research Ethics Committee Approval & Recruitment

Research ethics committee approval was obtained from the Hammersmith and Queen Charlotte's and Chelsea Hospitals Research Ethics committee (Reference number: 04/Q0406/116) and from the City University Research Ethics Committee. Confirmation of compliance of the research with all the necessary clinical and research governance requirements was obtained from the Hammersmith Hospitals Trust (reference HELJ3002). The trial was registered with the National Research Register (NRR Pub ID N0016152852; ISRCTN ID ISRCTN97327133; ISRCTN Link http://www.controlled-trials.com/isrctn97327133).

Recruitment took place between October 2004 and January 2005. Women over 16 years of age, who were on the National Centre's mailing list with a diagnosis of MRKH, were informed of the study by post, sending them a participant information sheet to the study, a consent, and reply form (See appendices 5.1 and 5.2 respectively). Furthermore, a "News flash" about the study was put onto the Centre's MRKH web site (www.mrkh.org.uk). The "News flash" said that a Group Therapy Study for Women with MRKH was being run at the Centre, and asked those interested to contact the team Psychologist (JHB) via the Centre's help line.

Any woman who enquired about the study via the helpline, was advised to obtain a referral from her general practitioner or Gynaecologist to the service. On receipt of such a referral, an appointment could then be offered in the Centre's specialist clinic for confirmation of her diagnosis by one of the Gynaecologists. She would also be made aware of the varied nurse led service provisions. Finally, she would meet the team Psychologist (JHB) for a discussion of the study and alternative psychological interventions open to her. She would then be provided with the participant information, consent, and reply forms to the study.

When women indicated that they were willing to take part in the study by returning the reply form attached to the participant information sheet, they were contacted by telephone by JHB to confirm receipt of the form, to be screened for in- and exclusion criteria, and to discuss any queries that had arisen.

5.7. Intervention

Study participants were randomly allocated to one of two groups.

a. Group Cognitive-behavioural therapy for MRKH: This intervention was designed, as noted in Chapter 4, with the aim of (a) reducing any post-traumatic sequelae of diagnosis, the processes surrounding it and its medical or surgical treatment, such as fragmented or intrusive memories and misconceptions of what happened and what is wrong, (b) identifying and learning to challenge unhelpful appraisals of MRKH-related events (c) identifying and correcting maladaptive compensatory strategies, (d) building more positive self-schemata in particular concerning the self as a woman and increasing acceptance of MRKH.

Participants were offered 7 weekly sessions of group therapy (of three hours, with a 15 to 20 minutes comfort break within this, and a further session at 3 months follow-up. The groups consisted of 5, 7 and 7 participants each. Groups took place between November 2004 and June 2005 on Saturdays or Sundays between 11.00 a.m. to 2.00 p.m. or 12.00 a.m. to 3.00 p.m. over seven consecutive weeks with the follow-up session at 3 months. Each group session had a particular theme and homework writing assignments associated with these, all of which related to the immediate and longer term impact of MRKH and its treatment on the woman and her life. A full summary of the session-by session programme, is shown in table 5.1. In brief themes included: revisiting the circumstances of and personal and family reactions to discovery/diagnosis of MRKH; revisiting experiences of MRKH-related care, including dilator therapy and surgery; the effect of MRKH on the person's life and coping; the conclusions drawn following diagnosis and/or treatment about oneself, others, the world and one's future; learning to identify and challenge extreme and unhelpful self-beliefs, exploring societal scripts regarding women's roles and views on femininity; exploring and mourning losses incurred through MRKH; gains and goals for the future; and intimate and sexual relationships.

Groups were led by a female psychologist (JHB), who introduced the themes of the session, educated the women about the model of therapy used and guided the interactions. Between sessions women were instructed to complete homework tasks consisting of expressive writing. These tasks were specifically constructed to enhance emotional processing of previously avoided material, to develop a coherent narrative of what had happened to them and to learn to adopt different and more balanced perspectives on how they viewed themselves. At the end of therapy patients were asked to produce a written good-bye letter with the aim to get them to reflect on what they had learned. (A copy of the letter advising the GP of the participant's participation in the study can be found in appendix 5.4).

(b) Waiting list: Women allocated to this group were offered the opportunity to have group CBT intervention after completing the follow-up period.

5.8. Treatment fidelity

A patient manual for the intervention was produced, including an overview of the session content, an explanation of the model of therapy, the theory and rationale behind it, with handouts on distress tolerance skills, assertiveness, and relationships (with self and others) (appendix 5.9) and the writing assignments and reflection sheets. All participants received a therapy pack including the manual together with an audiotape, with a relaxation exercise on side A and a guided imagery exercise (on side B). They also received a writing pad and pen. Sessions were tape-recorded and patients' writings were collected at each session. Regular supervision for the study therapist (JHB) was provided.

5.9. Outcome measures/Assessments & Primary Outcome Measure:

Participants in both the treatment and waiting list control group completed a number of self-report measures at baseline prior to treatment, at post-treatment (week 7) and at 3 months follow up (week 19). Figure 5.1 shows a flow chart of the design of the study with measurement points.

The following measures were included: the Symptom Checklist 90, the Impact of Event Scale, the Rosenberg Self-Esteem Scale, The Inventory of Interpersonal problems and the Eating Disorders Inventory. All of these "tap" into different aspects of the CBT conceptualisation of MRKH, as outlined in Chapter 4. For a copy of the psychometric measures described below, see appendix 5.7.

The Symptom Check List, SCL-90-R (Derogatis, 1992) was used as the primary outcome measure as it assesses a broad range of psychological symptoms, is highly sensitive to change and therefore lends itself for the assessment of treatment outcome. Moreover, it was previously used in the only previous treatment study in MRKH (Weyenborg & ter Kuile, (2000)[1]. The SCL-90-R has previously been extensively used in many different populations, involving medical outpatients (Brophy, Norvell, & Kiluk, 1988; Spinhoven & van der Does, 1999; Schmitz, Kruse, Heckrath, Alberti & Tress, 1999; Schmitz, Hartkamp, Kruse, Franke, Reister & Tress, 2000). It has good reliability (test-retest and internal consistency) and validity (convergent and discriminant) (Kiger & Murphy, 1987; Brophy, Norvell & Kiluk, 1988; Derogatis, 1992; Martinez, Stillerman & Waldo 2005)

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[1] I.e. an earlier version of it: (a Dutch translation of) the SCL-90 (Derogatis, Lipman & Covi, 1973).

The SCL-90-R is a self-report questionnaire consisting of 90 items. The SCL-90-R is scored on a 5-point scale, indicating the frequency with which the person was bothered/distressed by symptoms during the preceding week (including the day of self-report), from “not at all”, “a little bit”, “moderately”, “quite a bit”, to “extremely”. The SCL-90-R is scored and interpreted in terms of nine primary symptom dimensions and three global indices of distress labeled as follows. Primary symptom dimension: Somatisation (SOM), Obsessive-Compulsive (O-C), Interpersonal Sensitivity (I-S), Depression (DEP), Anxiety (ANX), Hostility (HOS), Phobic Anxiety (PHOB), Paranoid Ideation (PAR), Psychoticism (PSY) and Global Indices: Global Severity Index (GST), Positive Symptom Distress Index (PSDI) & Positive Symptom Total (PST). There are 7 items (items 19, 44, 59, 60, 64, 66, and 89) on the SCL-90-R that are not subsumed under any of the primary symptom dimensions. These items actually load on several of the dimensions but are not ‘univocal’ to any of them. They contribute to the global scores on the SCL-90-R, and are clinically important. They are intended to be used ‘configurally’, i.e. communicating useful information to the clinician (Derogatis, 1992). Derogatis (1992) explains this by means of an illustration, saying that “a high ‘DEP’ score with ‘early morning awakening’ and ‘poor appetite’ may mean something quite different from a similar score with these symptoms absent”.

Raw scores are derived by first summing the values (i.e. 0-4) for the item responses in each of the nine symptom dimensions and the seven additional items. The sum of each symptom dimension is then divided by the number of endorsed items in that dimension, except for the additional items (Derogatis, 1992).

Derogatis (1992) suggests that a "Global Severity Index (GSI) can be computed by first summing the scores on the nine symptom dimensions and the additional items. The sum is then divided by the total number of responses (i.e. 90 if there are no missing responses). Derogatis (1992) notes that the GSI is "the best indicator of the current degree of distress, when one simple summary score is needed, and that it combines information concerning the number of symptoms reported with the intensity of perceived distress".

For more detail on the subscales of the SCL-90-R, and or varied types of calculations of scores see appendix 5.8.

5.9.1. Secondary outcome measures:

5.9.1.A. Impact of Event Scale (IES; Horowitz, Wilner & Alvarez, 1979)

The impact of event scale is designed to assess the current impact of traumatic life happenings on a person and measures current subjective distress, related to a specific event. It has been very widely used to assess post-traumatic stress in different trauma samples. Clinicians have found, and a review by Sundin & Horowitz (2002) supports this, that the scale is useful in following the trajectory of a person's current subjective distress in response to a specific traumatic life event over a long period of time, since it can be used repetitively and anchored to the same psychological trauma (here being diagnosed with MRKH) over an entire time span. From this it follows that measuring where the person currently is on this trajectory can be done at any time following the trauma, but is preferably done when "some" time, rather than a "long" time, has elapsed since the event took place to be able to "map" the impact of the event at varied time-points, since its origin, and obtain its "full trajectory picture" from this point onwards. In the original sample reported on by Horowitz, Wilner & Alvarez (1979), administration of the IES took place 1-136 weeks following the event, whereas in Weiss & Marmar's (1997) sample the average time since the event at administration was 3.1 years, with measurement thereafter taking place at intervals of six months. It could be assumed that having the person self-report many years following the event would mean that they could have moved from the initial stages of the trajectory that they were on, such as experiencing the commonly reported oscillating patterns of intrusive symptoms, being followed by avoidance – following trauma, to these symptoms/experiences becoming less frequent over time, as the implications of the stressor event are digested, - provided that these are digested (Sloan, Rozensky & Kaplan, 1994; Kelly, Raphael & Smithers, 1995). However, Hendrix, Jurich & Schumm (1994) report that over time the distinction between these commonly reported symptoms of intrusion and avoidance blur and the two merge into an overall pattern of stress reactions or general distress levels. They note that this general distress appears to contain both these intrusive and avoidant symptoms, as measured by the IES, and its levels appear dependent on where the person is vis a vis processing the traumatic event experienced, regardless of how long ago it happened.

The IES has good validity and reliability and is highly sensitive to change and thus forms a good outcome measure for brief therapy (Horowitz, Wilner & Alvarez, 1979; Zilberg, Weiss & Horowitz, 1982; Schwarzwald, Solomon, Weisenberg & Mikulincer, 1987; Kulka, Schlenger, Fairbank, Jordan, Hough, Marmar & Weiss, 1990). Critics have suggested that the measure may be limited by its exclusive emphasis on avoidance/numbing and intrusion following a traumatic event (Newman, Kaloupek & Keane, 1996).

The Impact of Events Scale (IES) consists of 15 items listing, as referred to above, the commonly reported experiences or symptoms of intrusion or avoidance after a major traumatic life event or life change. Participants indicate how frequently the statements made in each item were true for them in the past 7 days, scoring each on a 4-point continuum from “not at all”, “rarely”, “sometimes” to “often”. Each item is scored 0, 1, 3 or 5 points, with the higher scores reflecting more stressful impact. The sum of the items scored is the total stress score.

In the present study participants were asked to complete the IES in relation to being diagnosed with MRKH.

For more detail on the subscales of the IES, and or varied types of calculations of subscores see appendix 5.8.

5.9.1.B. Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1965)

The Rosenberg Self-Esteem Scale is a brief measure of global self-esteem (i.e. it measures overall feelings of self-worth or self-acceptance). It has been extremely widely used across a large range of different populations of adolescents and adults and is generally considered the standard against which other measures of self-esteem are compared. It is regularly used in treatment outcome studies (Baker & Gallant, 1984, Blascovich & Tomaka, 1991).

The RSE includes 10 items, half of which are positively keyed in terms of a favourable attitude towards the self (items 1, 3, 4, 7, and 10) and half of which are negatively keyed (items 2, 5, 6, 8, and 9). Each item is scored on a 4-point continuum from strongly agree, agree, disagree, to strongly disagree.

Items are scored from 1 to 4 in the direction of negative self-esteem. Two forms of scoring have been used, but Rosenberg (1965) has found the Likert method to be superior. The Likert score is the sum of the item scores as presented on the scale giving a range from 10-40. Low scores indicate high self esteem. Scores are negatively skewed, that is they tend towards low self-esteem (Rosenberg, 1965).

5.9.1.C. Inventory of Interpersonal Problems, IIP-32 (Barkham & Hardy & Startup1996)

The Inventory of Interpersonal Problems (IIP) was originally developed by Horowitz, Rosenberg, Baer, Ureno, & Villasenor (1988) to measure interpersonal distress experienced by psychiatric patients and evaluate the change over the course of out-patient psychotherapy. Barkham, Hardy & Startup (1996) developed a short version of the IIP, the IIP-32, bringing the original item number down from 127 to 32. They argue that the IIP-32 sacrifices little in terms of psychometric properties compared to the original 127- items version, whilst being considerably more convenient in clinical practice (Barkham, Hardy & Startup, 1996). The IIP-32 has been widely used as a sensitive outcome measure by therapy researchers and clinicians, that easily detects change between pre- and post-treatment scores (Mohr, Beutler, Engle, Shoham-Salomon, Bergan, Kaszniak & Yost, 1990, Muran, Segal, Wallner Samstag & Crawford, 1994, Barkham & Hardy, 1996). The IIP-32 has supplemented existing standard measures of change, e.g. the SCL-90-R (Derogatis, 1983).

The IIP-32 comprises 19 items with the stem: “It is hard for me to…”. And 13 items with the stem: “The following are things that I do too much”. The IIP-32 has 8 subscales: “Hard to be assertive”, “Too dependent”, “Too caring”, “Too open” “Too aggressive”, “Hard to be supportive”, “Hard to be involved”, and “Hard to be sociable”.

Items are scored on a 5-point scale from 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit), to 4 (extremely), in response to the item stem “How much have you been distressed by this problem?”

The total IIP-32 score is simply the sum of all encircled responses (i.e. 32 items rated 0-4), however, scale item 10 and 17 need to be reversed (i.e. 0=4, 1=3). When scoring the mean item total, calculated as the sum of scores of the 32 items divided by 32, these 2 items are not reversed, as this overall level focuses on the extent to which any of these items are rated positively, i.e. experienced as a difficulty.

In order to obtain a score for each of the 8 subscales the appropriate items are added and the mean is calculated (Barkham & Hardy, 1996).

For more detail on the subscales of the IIP-32, and or varied types of calculations of subscores see appendix 5.8.

5.9.1.D. Eating Disorder Inventory, EDI (Garner, Olmstead, & Polivy, 1983)

The EDI was included as there is anecdotal evidence in the MRKH literature (see Chapter 2) that development of eating disorder symptoms were a common response to being diagnosed. Moreover, the EDI includes a number of sub-scales (see appendix 5.8) such as “perfectionism”, “ineffective(ness)”, “body dissatisfaction”, “maturity fears”, and “interoceptive awareness”, that were thought to be of relevance in MRKH in general.

The EDI is a forced choice 64-item, self-report, multi-scale standardized measure, designed for the assessment of psychological traits/attitudes and behaviours common in Anorexia Nervosa and Bulimia Nervosa. It is a well regarded outcome measure, with good reliability, validity and sensitivity to change (Garner, Olmstead & Polivy, 1983).

Each item on the EDI is scored on a 6-point continuum from “always”, “usually”, “often”, “sometimes”, “seldom” to “never”, with the most extreme “anorexic” response (always/never depending on the keyed direction) being given a score of 3, the immediate adjacent response 2, the next response 1, and the three opposite choices to the most extreme “anorexic” response receiving no score (0). Scale scores are the summation of all item scores for that particular scale.

5.10. Sample size:

Power calculations were based on the Weijenborg & Ter Kuile (2000) study, where the effect size for the change in the SCL-90 from baseline to follow-up was 0.8. Using the sample size programme NQuery the following sample size calculation was conducted. A sample size of 21 per group would give 80% power to detect an effect size of 0.8 using a 2-group t-test with a 0.05 one sided significance level.

5.11. Randomisation:

Participants were randomly allocated to group CBT for MRKH versus the Waiting list condition. This process involved preparing a list of random treatment assignments using a table of random digits 0 to 9 as described by Pocock (1983). The list is started at an arbitrary point in the table, and A (CBT for MRKH) assigned for digits 0-4 and B (waiting list) assigned for digits 5-9. Randomisation was stratified according to (a) age: dividing women into two groups, age 17 to 25 and age 25 upwards, to ensure that women with different post-diagnostic intervals were equally distributed across treatment and waiting-list conditions; (b) complexity of

MRKH presentation, to ensure that participants with MRKH with or without other congenital abnormalities were equally distributed across treatment and waiting-list conditions. The reason for stratifying by age and complexity of disorder were that (a) younger women (with a more recent diagnosis) were thought to be likely to experience higher levels of psychological distress, (b) those born with multiple congenital abnormalities such as defects to their heart/limbs, as well as diagnosed with MRKH in puberty, could well experience the latter as a "double whammy" in terms of adding to already existing feelings of "difference" and thus leading to an increase in already existing levels of psychological distress, (c) that it would be helpful to ensure representation/randomisation of these varied levels of distress at baseline due to these factors into the conditions, (d), so that these were equally distributed across the groups, avoiding over-representation in one or the other and thus creating confounding variables, and (e) allow for a better mix of these factors in the therapy groups, within that, which could be beneficial therapeutically, bringing a mix of experiences and levels of distress and coping to these. The two factors of age and complexity of condition were categorized as follows, resulting in four strata of participant types: 1. under 25 years of age with MRKH type I (simple), 2. over 25 years of age with MRKH type I, 3. under 25 years of age with MRKH type II (complex), 4. over 25 years of age with MRKH type II. Four separate randomisation lists, one for each stratum were prepared. Randomization was conducted using the above method with randomly permuted blocks of four (see also appendix 5.3). The method used would allow for replication of the order of assignment. The alternative method of coin flipping was seen as unacceptable, because of its non-replicability (Meinert, 1986).

Potentially eligible participants were registered by the researcher for the trial, after it had been verified that they fulfilled the inclusion and none of the exclusion criteria and after completion of baseline questionnaires. Registration involved writing down the date of entry into the trial, the initials of the participant, their date of birth, age in years at that time, and complexity of condition (MRKH type I or II). This information was passed on to a second independent researcher (DB) who identified which stratum the new participant was in, and then carried out randomisation accordingly.

Thus treatment assignment could not be anticipated by or be influenced by the researcher (JHB). It is worth noting that the researcher did not have a special interest in, or would gain benefit from participants being allocated either way, since the whole trial was run by that one researcher, inclusive of running the treatment groups that the waiting list controls were eventually receiving. 19 participants were allocated to the treatment (group therapy) and 20 to the control (waiting list) condition.

5.12. Statistical Analysis:

The data collected in the trial entailed longitudinal data, which according to Landau & Everitt (2004) is a special case of repeated measures. These data involves repeated measures, with time as the single within-subject factor, which has the following features. They are repeated measures of the outcome taken on each patient post treatment, along with a baseline pre-treatment measurement. The data arise from participants being measured on the same five measures (response variables) on several occasions. The latter measures arose solely from "the passing of time". They are repeated measures that furthermore have the likely feature of having missing values, caused by patients dropping out of the study. The main question in relation to these data is whether there is an interaction between treatment group and time in terms of any of the key outcome variables.

Landau & Everitt (2004) go on to say that the special structure of longitudinal data, as a special case of repeated measures, makes the condition of "Sphericity" which says that variances of differences between all pairs of repeated measures are equal (as applied to other repeated measures situations that are not longitudinal), difficult to justify, as in longitudinal data it is very unlikely that the measurements taken close to one another in time will have the same degree of correlation as measurements made at more widely spaced intervals. An analysis of longitudinal data requires application of a model that can represent adequately the average value of the response at any time in terms of covariates such as treatment group, time, baseline measures (and also account successfully for the observed patterns of dependences in those measurements). A powerful method for analysing longitudinal data is the Linear (Mixed Effects) - Random Intercept Model. This is made up of two components; a regression model for the average response over time and the effects of the covariates on this average response; and a model for the pattern of covariances or correlations between the repeated measures, with the former being of most interest, which is applied here.

The data set collected contained a number of participants who failed to complete all three sets of measurements, and non-complete data sets, are a source of problems in the analysis of longitudinal data. Approaches such as "complete-case analysis", which uses only data of participants who have complete data sets, excluding participants who dropped out without fully completing these sets, are flawed and can lead to biased results. Also flawed is the often used approach of "last observations carried forward", which assumes that participant's scores do not change over time.[2] However, the Linear (Mixed Effects) model with Random intercept used, basically uses all the available data on each participant, by transforming the data set into long format (rows=observations). Here missing data are not imputed, rather the information from correlational observations (e.g. from the same participant at different time points) is used to estimate model parameters. The model provides "asymptotically" unbiased estimates under the assumption that the data are Missing At Random (MAR), that is in the longitudinal design missingness can be predicted by covariates included in the model or earlier values of the response variable but not by the missing values themselves (i.e. missingness does not depend on the missing values, but may depend on other observed characteristics of the individuals in the study). The model is valid under weaker assumptions than complete case analysis, has the above outlined reasonable assumption regarding missing data, but is even robust to violations of those assumptions such as when data are not MAR after all

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[2] if one value carried forward was really adequate, then the value was never missing, besides the fact that this would defeat the point of doing repeated measures, i.e. measuring any change comparing baseline vs post-intervention scores, thus ascertaining treatment outcome.

(Everitt & Pickles, 2000; Mallinckrodt, Scott Clark, Carroll & Molenberghs, 2003). Finally, according to Mallinckrodt, Scott Clark, Carroll & Molenberghs (2003) the model, particularly, provides an appropriate analytic framework for assessing response profiles in randomized controlled treatment trials that entail longitudinal data (of which repeated measures is a special case) and which feature, associated, participant drop out and incomplete data sets, under which descriptions the study described in this portfolio would fall.

Questionnaire measures were scored, and entered in SPSS 13 using the method of Double Data entry (cross referencing hand calculated and computed scores against each other), and then analysed, using the Linear (Mixed Effects) Random Intercept model described above. Baseline measures were used as covariates in the analysis. All available data were included in the analysis. Thus the analysis was intention-to-treat.

Effect sizes were calculated by computing a new variable, which consisted of the change score between baseline and follow-up on all 5 measures individually (baseline score minus follow-up score). Mean change scores for the CBT group and the waiting list group were calculated. Finally, the pooled standard deviation of both groups, i.e. the standard deviation of the mean change score for the total sample (i.e. CBT and waiting list group combined) was calculated. The effect size, Cohen's d (1988) could then be calculated as (mean change score for CBT minus mean change score for Waiting list) divided by pooled standard deviation. The same was done for the change score between baseline and end of treatment on all the measures.

5.13. Results

5.13.1. Flow of participants through the study:

Figure 5.1 shows a CONSORT diagramme detailing the flow of participants through the study (Consort group, 2001). No participant sought contact via the "News flash" on the Centre's MRKH web site. Of a total pool of 335 women with MRKH on the Centre's register, 4 women with MRKH who were 16 years of age or under, were excluded for reasons of age (see also section 5.4.2.4). Of the remaining 331 women contacted, 203 did not respond, and 11 envelopes were returned as undeliverable. 117 responded, and of these 39 volunteered to take part in the study (i.e. 33% of the responders or 12% of those approached). The remaining 78 did not want to take part. 57.7% of these cited practical reasons for non-participation such as 'work commitments' (16.7%), 'other commitments/priorities' (29.5%), and 'distance' (11.5%). The remainder cited reasons such as 'am doing/have done/prefer one-to-one therapy' (6.4%), 'therapy is not for me' (7.7%), 'I am OK now' (9.0%), 'I am not ready' (3.8%), and, 'I am having other health problems currently and am too unwell to travel/participate' (3.9%), and 'no reason volunteered' (11.5%) (see also figure 5.1).

Of the 39 women who agreed to take part 19 were randomized to group CBT for MRKH and 20 to waiting list.

Treatment uptake and attendance in the trial was as follows: In the CBT group, one participant did not commence treatment, three attended 1 to 3 sessions only, the remainder completed therapy. The mean number of sessions attended for all 19 participants allocated to group CBT for MRKH was 5.7, out of 8 possible sessions. Of the 4 women in this group, who did not start or complete treatment, 3 participants completed baseline measures only, one completed all three sets of measures, the other 15 participants completed all outcome measures fully. Of those who completed therapy, one woman needed one additional one-to-one session, to deal with a stressful situation in her life. In the waiting list group 4 women dropped out, after having completed baseline measures only, (for details see figure 6.1). Thus altogether, seven participants completed baseline measures only (three in CBT for MRKH and four in the waiting list group), with the remaining participants completing all study assessments.

5.13.2. Patients' Characteristics at Baseline:

Study participants were from a range of ethnic groups, including: Asian or Asian British (4), Black or Black British (5), Mixed (1) and White Caucasian (29). Their age range was 18 to 56 years (median age 25 years, mode 22 and 23, and mean age 28.2 years). Two thirds of the participants were either married, cohabiting or in a relationship. Patients in both the CBT for MRKH and the waiting list groups were very similar in terms of socio-demographic and medical characteristics, suggesting that the randomisation was successful (for further details see table 5.2).

5.13.3. Characteristics of Non-Participants

The age range of potentially eligible women on the register who did not respond to the invitation to participate in the study was 16-52 years (median age: 28, mode 21, and mean age 28.4 years).

The age range of women who actively opted out from the study was 16 to 64 years, (median age: 24.5 years, mode 21 and 22, and mean age 27.1 years).

All of those who took part, did not want to take part, or did not respond, came from all over the UK, at short distances as well as very long distances from the National Centre in London.

5.13.4. Primary and Secondary Outcomes:

Treatment outcomes are depicted in table 5.3, including questionnaire mean scores and standard errors at baseline, post-treatment and follow-up. Participants in the cognitive-behavioural group intervention had significantly reduced psychological symptoms on the SCL-90-R, and a trend (p=0.07) for improved self-esteem. Scores on the Impact of Events scale, Inventory of Interpersonal Problems and EDI were non-significantly improved at the end of treatment and at follow-up, whereas those on the waiting list remained unchanged. Effect sizes (at follow-up) were all between 0.74 and 1.14, i.e. mostly large (Cohen, 1988). Table 5.3 also shows that the estimated group difference on the SCL-90-R between treatment group (CBT for MRKH) and waiting list was that, for a given post treatment measurement and baseline SCL score, group CBT for MRKH was estimated to decrease the mean SCL-90-R score by 0.40 points more (p = 0.03, 95% CI from a 0.03 decrease to a

0.77 decrease), than the waiting list group did, whilst the estimated decreases on the RSE/IES/IIP-32/EDI were 2.3, 8.4, 5.7 and 8.8 points respectively, with respective p values and 95% confidence intervals as indicated in table 5.3.

Figures 5.2 a to e display differences between group CBT for MRKH and waiting list in graphic format on the primary outcome measure (the SCL-90-R), and secondary outcome measures (the RSE, IES, IIP-32, EDI respectively).

5.14. Some illustrative quotes, case vignettes, group vignette of collage posters and text

Table 5.4 shows some illustrative quotes of what participants shared about their experience of therapy and what they learnt, taken from their goodbye letters. The table is made up out of participants' verbatim quotes, which have been shortened to make individual participants unidentifiable. These quotes suggest that participants valued the group support and sharing of their stories, but also the specific techniques used, such as the expressive writing tasks and the cognitive restructuring of extreme and unhelpful beliefs. The quotes illustrate the marked changes these women experienced in terms of their views of themselves and their MRKH.

Recently high quality journals such as the American Journal of Psychiatry have advocated the use of case vignettes or similar materials to capture participants' subjective experiences of participating in a clinical trial (APA, 2005). Table 5.5 presents two case vignettes of women who can be seen as representative of the participants in the study, in the way they thought about themselves and their MRKH.

Case 1 is 23 years of age, is with no partner and a 'student'. Case 2 is 49 years of age, is with a current partner and classified in the 'medium to low' social class bracket. The material in the table reflects these participants' perspectives, taken as verbatim quotes from all their therapeutic writings (not only their goodbye letters) about their experiences and the group therapy

Finally, figure 5.3 (1-3) provides a group vignette of collage posters and text (Table 5.6) about the same topic. These group vignette posters and text were generated for and presented at the Centre's Support Group meeting, which was held in October 2005. At this meeting the study participants shared their experiences, their reflections on therapy and what they learned with other women with MRKH who had not taken part, as also referred to in section 5.15 below. These vignette posters and text are typical of the group experience of women who took part in the trial.

Overall the above cases and group vignettes, illustrate the marked changes in these women experienced in terms of their views of themselves and their MRKH through therapy. These qualitative materials seem to support the negative/idiosyncratic appraisals and connected maladaptive strategies related to "events" of MRKH that were proposed to occur in these women (as depicted in table 4.1, Chapter 4 as well as those outlined in table 3.2, Chapter 3), and illustrate the changes in these through therapy.

5.15. DISCUSSION

This study is the first randomised controlled trial investigating a psychological therapy in women with MRKH. It is based on a clear theoretical model derived from a systematic review of the literature. The results of this small preliminary trial are encouraging in that the intervention led to lasting and large improvements in psychiatric symptoms, traumatic impact of diagnosis, self-esteem, interpersonal relationships and eating disorder related symptoms. Thus both hypotheses were confirmed.

The study has a number of limitations which are listed below:

The first of these relates to the generalisability of the findings and to the question of how appealing this kind of intervention is to the majority of women with MRKH. Participants were recruited from what is the largest pool of women with MRKH in the UK, but only a relatively small number of women (12% of those approached) chose to take part in the project, with a large number not responding at all (see figure 5.1: Consort diagram). Having said that the register includes women from all over the UK, many of whom stated that it was impractical for them to attend the groups on a weekly basis. Some interesting additional information was gleaned at one of the biannual support group meetings at the Centre in October 2005, when women who had taken part in the study shared their experiences with women who had not taken part. It became apparent that some non-participants were unfamiliar with the idea of therapy and endorsed beliefs such as "you have to be mad" to be needing therapy. Some expressed fears surrounding the idea of therapy opening up traumatic, and thus often avoided, issues and they questioned how opening up this wound could possibly be helpful to them. These thoughts and fears had played an important role in the decision of the latter group not to take part. Interestingly, women who did take part in the group said that these thoughts had also crossed their minds before taking up treatment, but had not stopped them. These thoughts and feelings were present even though the participants information sheet for the study had contained detailed information designed to counter these as had the Centre's twice yearly newsletters, which contained education on the psychological services offered at the Centre. This raises the broader issue of needing to make therapy even more accessible (see below) to overcome some of these misconceptions, possibly in terms of motivational and one-to-one work being added to the group therapy program. However, it seems that the most effective way of reducing fears and misconceptions about therapy was for women to hear first-hand accounts from other women with MRKH about therapy before they could begin to believe that it might be useful to them too. At the end of the support group meeting, there was an unanimous call from all women (including study participants and non-participants) for the Centre to offer to run a group therapy programme, once every year, so that women could join this whenever year they were ready for it (see also point 8.4 below).

A second limitation of the study is the small sample size, which made it impossible to conduct any sub-group analyses of women with simple or complex MRKH or younger versus older participants.

A third limitation of the study is that study participants varied considerably in terms of age and how recently they had been diagnosed, ranging from 1 to 39 years since diagnosis. This suggests that women may have been at different stages of adaptation to MRKH. However, the women who took part noted that this was both a difficulty as well as a help. Some of the younger women felt initially “dwarfed” by women who were “older” – with an expectation that they were coping better. However, as long as women of their own age were represented in the group, women felt that they learned from each other, having both shared and also somewhat different experiences. As for the women who were “older” and perhaps in a somewhat different stage, it may have been helpful to them to remind themselves of their own ‘journey’ with MRKH, thinking of the place they had been in and where they were now, listening to the younger participants in the study and their stories and sharing their own. Having varied ages and stages of adaptation to MRKH represented, added to the range of perspectives brought to the group. Furthermore and related to this, it deserves attention that “older” participants were not necessarily in a more advanced stage of adaptation to MRKH than younger participants were. Although it is a natural assumption to make (as it was by the younger participants in the study) that “older” participants would be better ‘adjusted’ to their predicament, the opposite can also be true. This is due to the fact that the longer these women carry their “awful” secret around, without being able to share this with others, the longer they have had to hide it and live with it, and the more engrained their negative beliefs about their unloveability, unacceptability or incompetence as a women can become (and which are then harder to “reverse” in therapy).

Notwithstanding the above, one question remains and that is whether a more targeted early intervention, e.g. for those who had recently been diagnosed, would have yielded even better results.

A further limitation arises in relation to outcome measurement. All measures used were self-report measures and it would have been desirable to include some investigator-based measures. Related to this, administration and scoring of all outcome measures was conducted by JHB, who also conducted the therapy, and was thus not blind to group allocation. The lack of independence of the outcome assessment from treatment may also have meant that participants reported more favourable outcomes, as they wanted to please their therapist. The involvement of a counselling psychology trainee with a special interest in this area to administer the outcome measures was considered at the start of the study, but for a number of practical reasons did not come about.

A fifth limitation of the study was that the design does not allow to identify what the effective components of the intervention were, i.e. whether improvements were due to specific techniques based on the model or whether they were due to non-specific factors such as having group support or therapist factors. However, the quotes from participants (table 5.4) about their experiences of therapy and what they learned, taken from their goodbye letters go some way in addressing this point. The participants' reflections on their individual journeys of therapy in the context of the group, suggest that they attributed their improvements to a number of causes, including the value of group support and the sharing of their stories, but also the specific techniques used, such as the expressive writing tasks and the cognitive restructuring of extreme and unhelpful beliefs, with a marked change in these women's experience in terms of their view of themselves and their MRKH.

Due to time constraints no formal qualitative analysis of participant's experience of the program as expressed in their goodbye letters, using thematic analysis, or grounded theory, was conducted (Glaser & Strauss, 1967; Rennie & Brewer, 1987). Such an analysis might have generated an even more detailed picture of what participants perceived to have been the components of the intervention that were important to them in terms of helping them change. This might have allowed for the generation of a tentative theory of the therapeutic experience of change, and the linking of these findings with psychological theory.

One important omission is the lack of an additional placebo control group. Thus the addition of a third group to the present study in the shape of an unstructured support group, would have helped to disentangle the effects of the specific CBT intervention from non-specific group support. However, one needs to bear in mind that the study performed was not an experimental psychology design on normal volunteers, but a preliminary RCT of a complex intervention in a population with complex difficulties. So it made sense to start off with the best possible intervention (combining all the ingredients that were thought to give maximum change) before considering a dismantling design at a later stage.

The study also has a number of strengths: Firstly, the client group under review is clearly a traumatised and distressed group (see also chapter 6)[3]. As indicated in chapter 2 the existing evidence-base in this area is poor and the study therefore bridges an important gap in our knowledge, by understanding and conceptualising the condition in therapeutic terms, and demonstrating the efficacy of an intervention developed for this group. The study describes a phase II exploratory trial with a theoretical and model development phase having led to the intervention in an iterative process. The intervention and its components are clearly defined and its content and delivery was standardised and reproducible. Through its inclusion of expressive writing, the study also contains a qualitative component. We have highlighted above participants' views about their experience of therapy as expressed in their goodbye letters. These writings point towards major positive changes in women's view of themselves and a re-evaluation of their difficulties and the significance of MRKH in their lives. It will also be possible to use these women's writings to shed further light on aspects of the CBT model described in chapter 4, but due to time constraints this has not been included here.

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[3] As explained in that chapter, particularly, their mean GSI (General Severity Index) scores on the SCL-90-R (which places these women between a non-patient population and a psychiatric outpatient population, when compared to their norms), and is highlighted in this chapter looking at their baseline IES scores, as depicted in table 5.3, which are 29.1/27.3. This according to the following dimensions: score of 0-8 Sub-clinical range; score of 9-25 Mild range; score of 26-43 Moderate range; and a score of 44+ Severe range, can be interpreted as follows, which is that these women experience a Moderate Impact of Event/of levels of current subjective distress in response to being diagnosed with MRKH at baseline (Corcoran & Fischer, 1994). This goes down to a Mild impact of event at end of treatment and follow-up in the treatment group (whereas the waiting list group does not experience this level of improvement).

The study raises broader questions about the development, evaluation and dissemination of complex interventions for relatively rare disorders such as MRKH and how a small study as this one can inform clinical practice and further research.

First, although the incidence of MRKH is "only" one in 5000 female births, and the area seems highly specialised, it is important to consider that the model and psychological treatment developed here may serve as an exemplar for the development of interventions in other areas of gynaecological-psychological medicine. It could easily be adapted for other congenital abnormalities of the genital tract that exist, such as Turner's syndrome, Ovarian Dys - or Agenesis, Complete Androgen Insensitivity Syndrome, and multiple congenital abnormalities including the genital, urethral and anal tract. It might also be applicable to non-congenital gynaecological conditions such as premature ovarian failure (POF) or early onset gynaecological cancers (e.g. Endometrial or Ovarian cancer) where the genital tract is surgically removed or damaged by radio-therapy. All of these may have a psychological impact not dissimilar to MRKH. This gives the above model far wider applicability. Having said this if applied to other conditions, the model might need some tailoring to include specific issues pertinent to the particular condition. For example, in POF the menopausal symptoms need to be considered, the distress at entering this phase of life at an early stage and the negative (societally reinforced) connotations that this may hold for the woman, and her loss of reproductive function (unless IVF egg donation is considered). In early onset Endometrial cancer, the impact of the removal of the womb and ovaries needs to be considered, the loss of reproductive function and the entering of a premature menopause and its associated symptoms, and the impact of cancer as a potentially life threatening disease[4].

Finally, the MRC framework for complex interventions discussed in chapter 1 suggests that following a phase II exploratory trial, in phase III a definitive RCT is mounted. The aims of phase III would be to compare a fully-defined intervention to an appropriate alternative using a protocol that is theoretically defensible, reproducible and adequately controlled, in a study with appropriate statistical power. The aims of Phase IV would be to determine whether others can reliably replicate this intervention and in other clinical settings over the long term. Phase III and IV will be exceptionally difficult to mount in this area of study, mainly because of the rarity of the conditions involved. If potential participants were recruited only from one specialist Centre such as the one where the present study was conducted, large numbers of women might effectively be precluded from participating as regular attendance at psychotherapy sessions may be impractical for women living at a distance from the treatment Centre. Thus, a large phase III study could only be conducted if several Centres (perhaps in different countries) would collaborate.

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[4] The reason why the current study and the model developed and tested, exclusively focused on women with MRKH, was because in terms of the congenital abnormalities presenting at the Centre which range from mild (such as having a surgically correctible vaginal septum or incomplete formation of the vagina, with typically only transient emotional distress), to highly complex presentations (medically and emotionally) such as CAIS (including a chromosomal and genetic component). MRKH lies somewhere in the middle in terms of its physical and emotional impact. Moreover, as it is the most common congenital abnormality of the genital tract that present at the Centre it was therefore thought possible to recruit sufficient numbers of participants for the research.

Table 5.1: Session Contents of CBT for MRKH Group Therapy Program

Session 1	Getting acquainted Participants' previous experiences of groups "Ground rules for the group": including confidentiality and limits of this in case of major risk to self or others and therapist's supervision. Overview of the programme and model used. Life before the diagnosis Introduction to writing assignment 1 and to distress tolerance techniques
Homework	Complete writing assignment 1 Read hand out on distress tolerance skills
Session 2	Group reflection on homework: the process of writing – how did participants get on with this Developing further coping/distress tolerance strategies, including an introduction to relaxation tape 1, as well as problem solving skills, whilst discerning "what is what", ie. what is the MRKH and what are other issues. Discussion of contents of homework exercise 1; different participants' experience of becoming aware that something might be wrong, seeking help, investigations, diagnosis, own/other's reactions, understanding of MRKH, who/what told, what support asked for
Homework	Writing assignment 2, reading assertiveness handouts, listen to tape 1.
Session 3	Feedback on the assertiveness handouts and querying of anything participants recognised, found helpful, want to put in place. Reflection on writing in general, using page 49 of Pennebaker's Writing to Heal (2004). Discussion of contents of homework assignment 2: different participants' experience of MRKH; how is this affecting their life (self, relationship with others etc) and how are they coping.
Homework	Writing assignment 3
Session 4	Reflection on writing in general. Discussion of writing exercise (homework session 3): meaning of diagnosis, conclusions drawn re self, others, the world. Challenging misconstruing, addressing possible feelings of guilt and shame. Perspective from self: from the vantage point of self when you have grown mature and wise - looking back at the experience; from the perspective where you look at experiences that tell you a different story about yourself. Moving beyond societal scripts of female roles and femininity: what does a woman consist of, what makes a person lovable and acceptable, makes you loveable and acceptable. Acknowledging similarities, differences, a variety of roles, bodies, qualities etc.
Homework	Writing assignment 4.
Session 5	Any thoughts from the previous session? Reflection on writing in general. Discussion of writing assignment: what has been lost as result of the experience, how are you mourning these losses?, what alternative avenues are you pursuing?, what were your old life goals?, and what are the new ones' that you are developing?, what is your view of the role of time in the above?, with a discussion of a process of adjustment to MRKH over the life-span; and crossing bridges when you get there, taking one step at a time. Discussion of what has been learned or gained re self, others, and life from your experiences. Discussion of responses to pregnancy in siblings, mother, friends and looking after one's own needs in these situations.
Homework	Time to reflect on what looked at in this session, what will look at in session 6 and 7, advance homework assignment for session 7 (to start thinking about writing the goodbye letter, gather thoughts).
Session 6	Discussion of participants' experiences and concerns around the creation of a new vagina, natural stretching/dilator therapy/surgery. Considering

	relationships, when/what to tell (told), love of/commitment to/trust of self/others. Talking about "love languages (ie. what makes you feel loved?)", standing up for these needs (referring back to the assertiveness handouts), and discussing sexual intimacy and particular needs within this.
	Handout on relationships (with self and others) and completion of exercises on the handout.
Session 7	Reflections on group ending. Discussion of process and contents of homework. Putting it all together, goodbye letters (reading out your writings to the group and reflecting on what you found helpful participating, what you learned and like to keep doing, what you found difficult, how you see yourself now, the future and you might deal with any issues arising – both by participants and therapist): review and looking ahead. Tape 2 from negative to positive thoughts/feelings/images
	Homework: trying tape 2 at home. Look for, buy and bring a card you like to receive yourself, to follow-up session 8.
(Follow-up) session 8:	How did you get on, any issues arising, further consolidation of experiences, and talking about going away from here (acknowledging concerns and how to deal with these, discussing plans, considering strengths to fall back on). Writing onto each others cards any sentiments/ thoughts of appreciation vis-à-vis the others and the group, with an opportunity for exchange of contact details, for those who would like to keep in touch with each other after the group.

Figure 5.1: Consort diagram: Flow of Participants through the Study

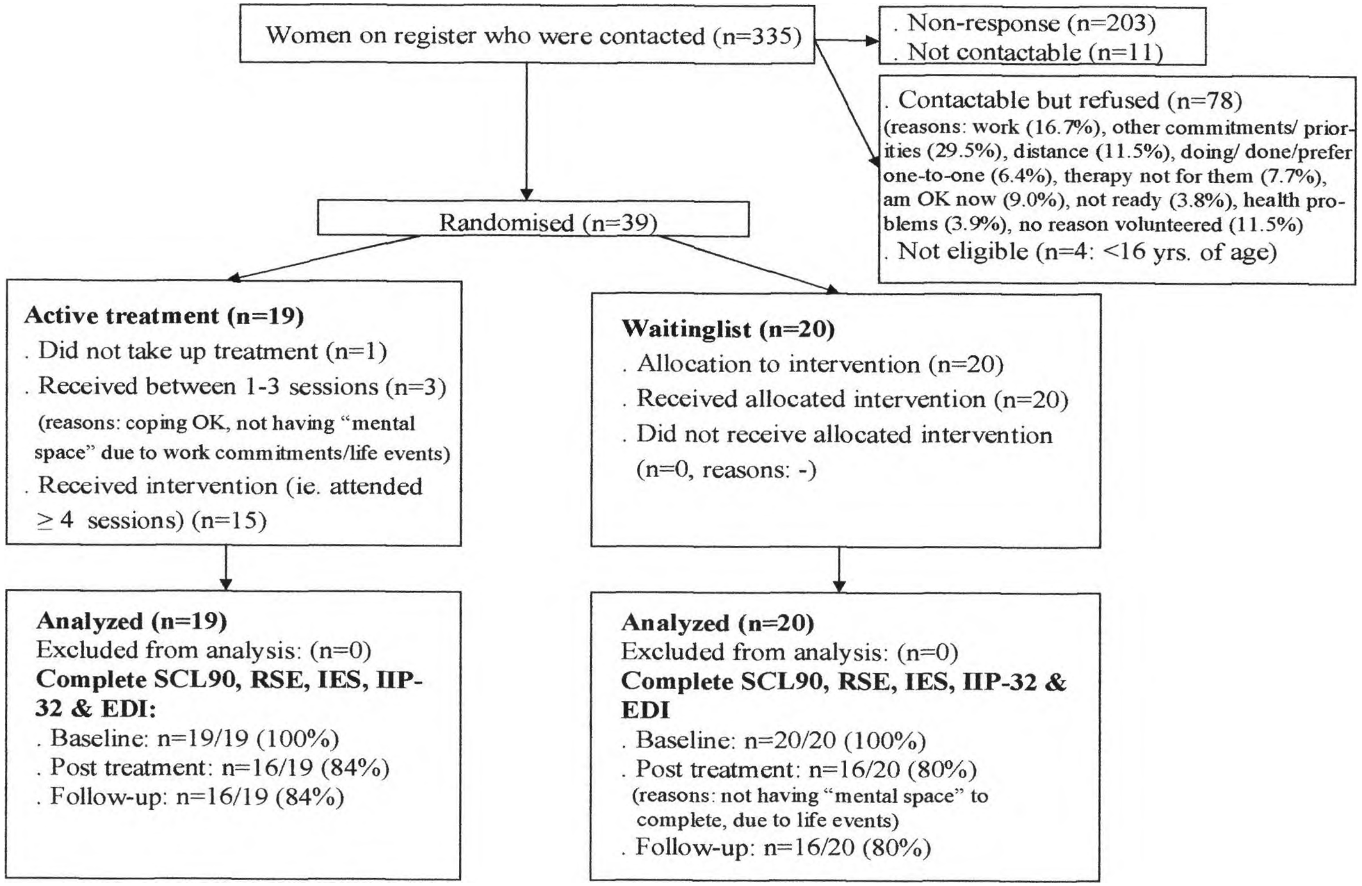

Table 5.2: Baseline Sociodemographics & Medical data

	Active treatment n= 19		Waiting-list n=20		Total n=39	
Age **(mean, (SE))**	28.9	(SE=2.3)	27.6	(SE=1.6)	28.2	(SE=1.4)
Age of Diagnosis **(mean, (SE))**	17	(SE=0.5)	18	(SE=0.4)	17.6	(SE=0.3)
Years since Diagnosis **(mean, (SE))**	11.4	(SE=2.4)	9.3	(SE=1.6)	10.6	(SE=1.4)
MRKH type						
- "simple"	17/19	(89.5%)	18/20	(90%)	35/39	(89.7%)
- "complex"	2/19	(10.5%)	2/20	(10%)	4/39	(10.3%)
Social class						
- High	4/19	(21 %)	3/20	(15%)	7/39	(17.9%)
- Medium to low	9/19	(47.4%)	11/20	(55%)	20/39	(51.3%)
- Student	5/19	(26.3%)	6/20	(30%)	11/39	(28.2%)
- Housewife	1/19	(5.3%)	-	-	1/39	(2.6%)
Relationship status						
- with current partner	13/19	(68.4%)	11/20	(55%)	24/39	(61.5%)
- no partner	6/19	(31.6%)	9/20	(45%)	15/39	(38.5%)
Children (adopted/step)						
- yes	2/19	(10.5%)	3/20	(15%)	5/39	(12.8%)
- no	17/19	(89.5%)	17/20	(85%)	34/39	(87.2%)
Ethnicity						
- White caucasian	13/19	(68.4%)	16/20	(80%)	29/39	(74.4%)
- Other	6/19	(31.6%)	4/20	(20%)	10/39	(25.6%)

Variable	CBT Baseline N=19	CBT Post N=16	CBT Fol-low-up N=16	Wait list Baseline N=20	Waitlist Post N=16	Waitlist Follow-up N=16	Effect size	Estima-te CBT-Group Effect	P	95% Conf.int Lower & Upper B.
SCL-90-R (GSI)	0.93 (SE=0.2))	0.64 (SE=0.1)	0.48 (SE=0.1)	0.96 (SE=0.2)	0.94 (SE=0.2)	0.98 (SE=0.2)	0.74	-0.40	0.03	-0.77 to -0.03
RSE	21.8 (SE=1.1)	19.3 (SE=1.1)	17.5 (SE=1.1)	22.2 (SE=1.3)	21.1 (SE=1.3)	20.4 (SE=1.5)	0.92	-2.34	0.07	-4.89 to 0.20
IES	29.1 (SE=3.8)	24.8 (SE=3.8)	16.6 (SE=3.4)	27.3 (SE=4.7)	20.1 (SE=4.7)	25 (SE=4.9)	1.14	-8.38	0.17	-20.4 to 3.64
IIP-32	41.6 (SE=4.3)	33.3 (SE=3.7)	30.8 (SE=4.3)	38.3 (SE=4.5)	38.7 (SE=4.1)	36.6 (SE=4.8)	0.78	-5.66	0.18	-14.0 to 2.71
EDI	43.7 (SE=7.3)	28.8 (SE=5.6)	25.4 (SE=4.9)	41.4 (SE=8.1)	34.1 (SE=8.4)	37.5 (SE=9.4)	1.01	-8.81	0.23	-23.4 to 5.76

Table 5.3: Primary and secondary outcomes.
Mean questionnaire scores and standard error at baseline, post-treatment and follow-up, effect-sizes (at follow-up) & estimate CBT group effects with p values & 95% Confidence intervals using a Linear (Mixed Effects) Random Intercept Model of Analysis

Figure 5.2a : Differences between group CBT and waiting list on the Global Severity Index of the Symptom Check List (SCL-90-R) at baseline, post-treatment and at 3 months follow-up.

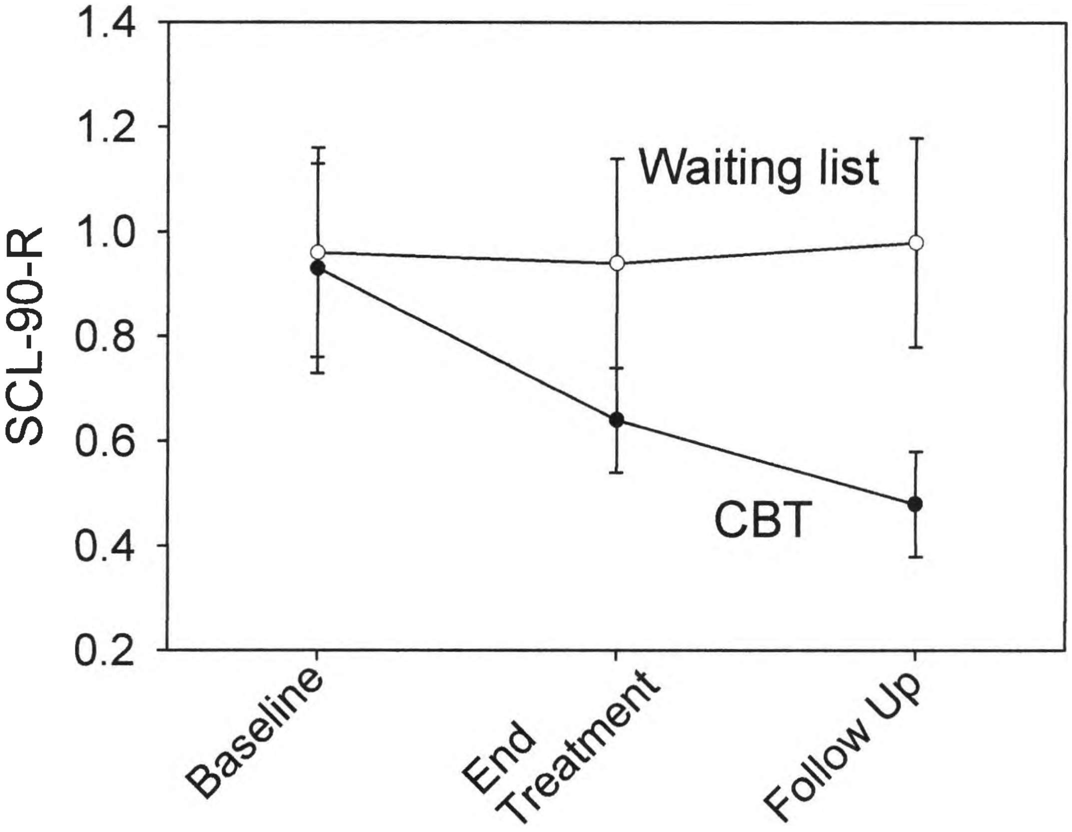

Figure 5.2 a: Differences between group CBT for MRKH (treatment) and waiting list (waitinglist) on the Symptom Check List (SCL-90-R) pre-treatment (handSCLbase), post treatment (handSCLpost) & 3 months' follow-up (handSCLfollup)

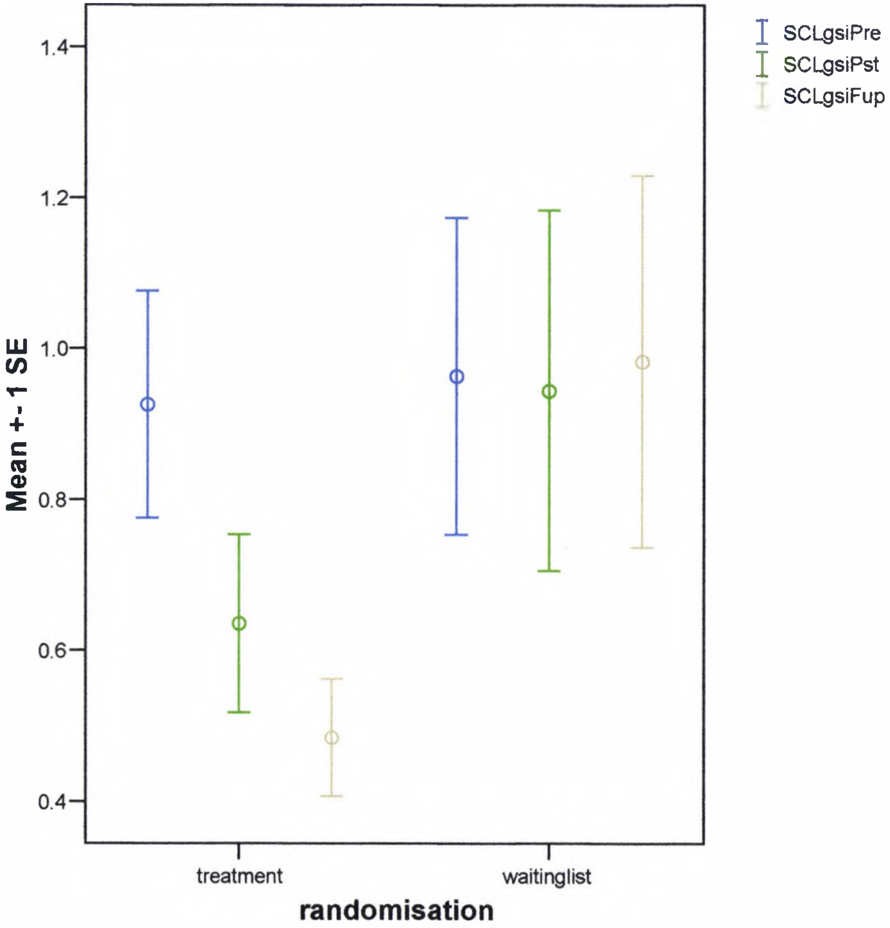

Figure 5.2 b: Differences between group CBT for MRKH and waiting list on the Rosenberg Self Esteem Scale (RSE)

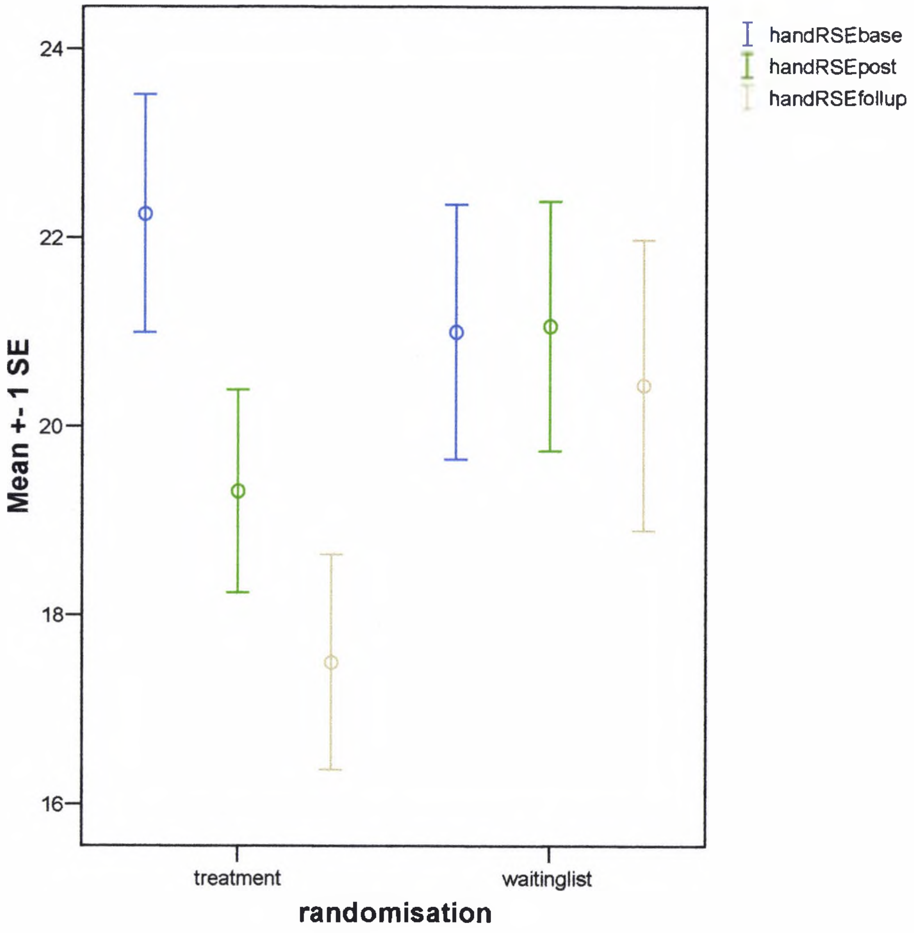

Figure 5.2 c: Differences between group CBT for MRKH and waiting list on the Impact of Event Scale (IES)

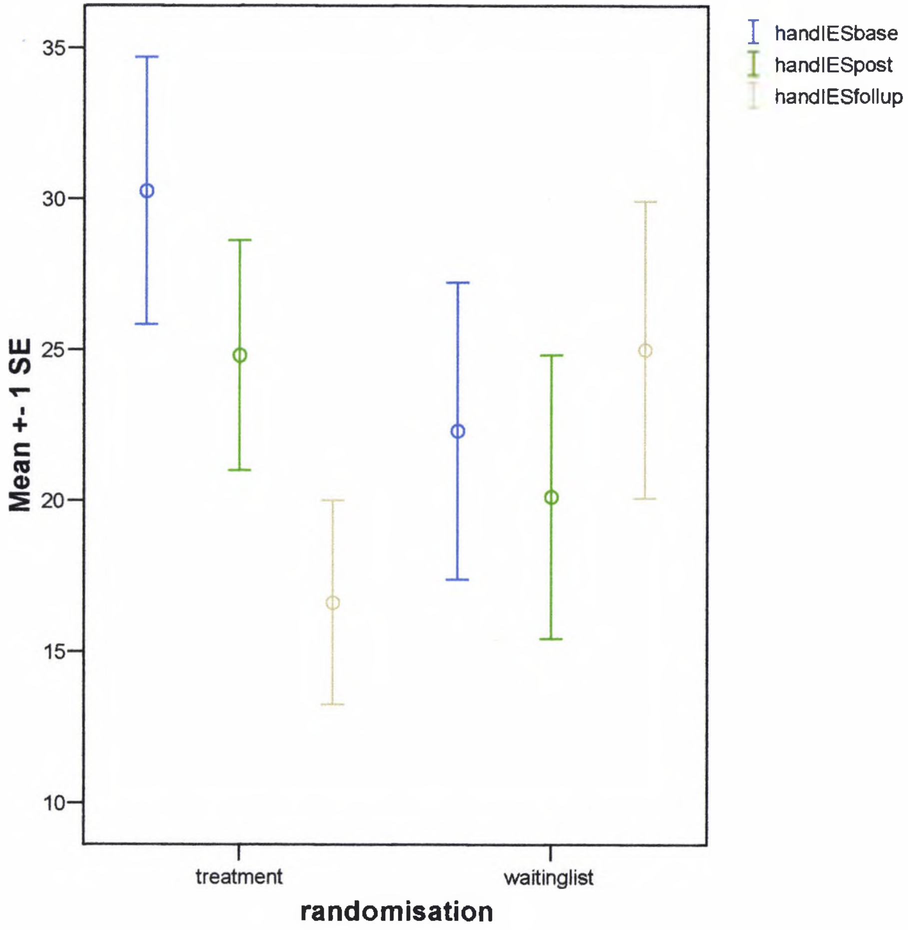

Figure 5.2 d: Differences between group CBT for MRKH and waiting list on the Inventory of Interpersonal Problems (IIP-32)

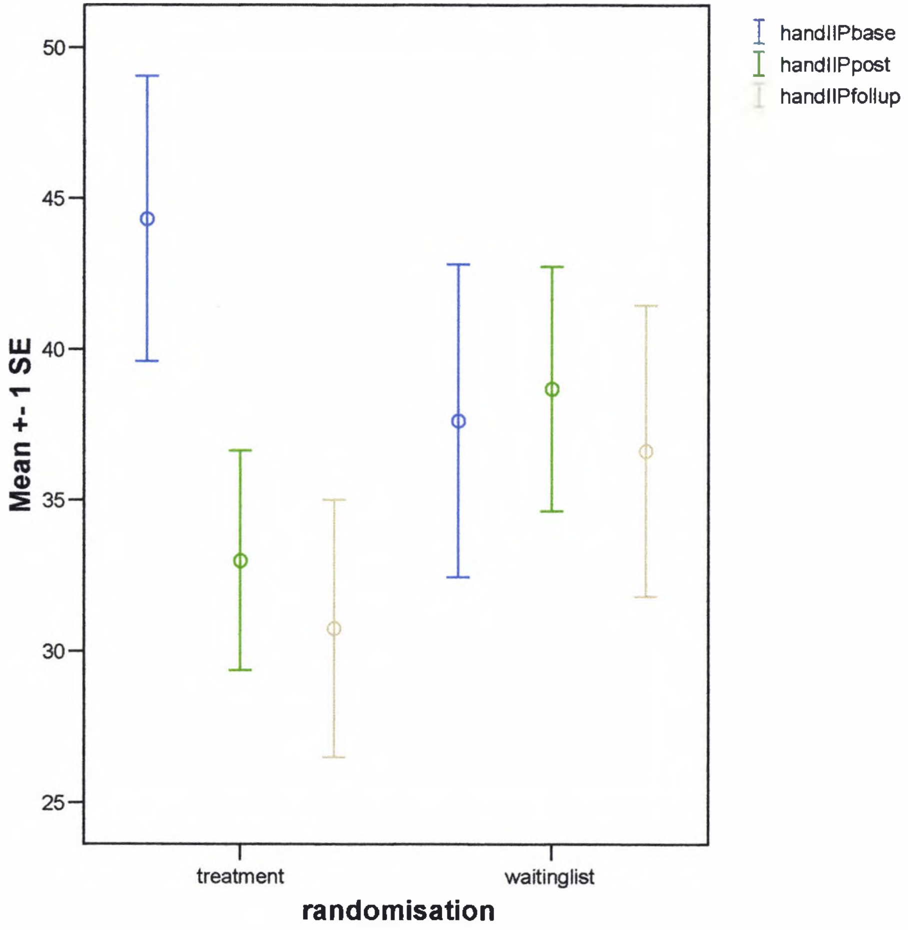

Figure 5.2 e: Differences between group CBT for MRKH and waiting list on the Eating Disorder Inventory (EDI)

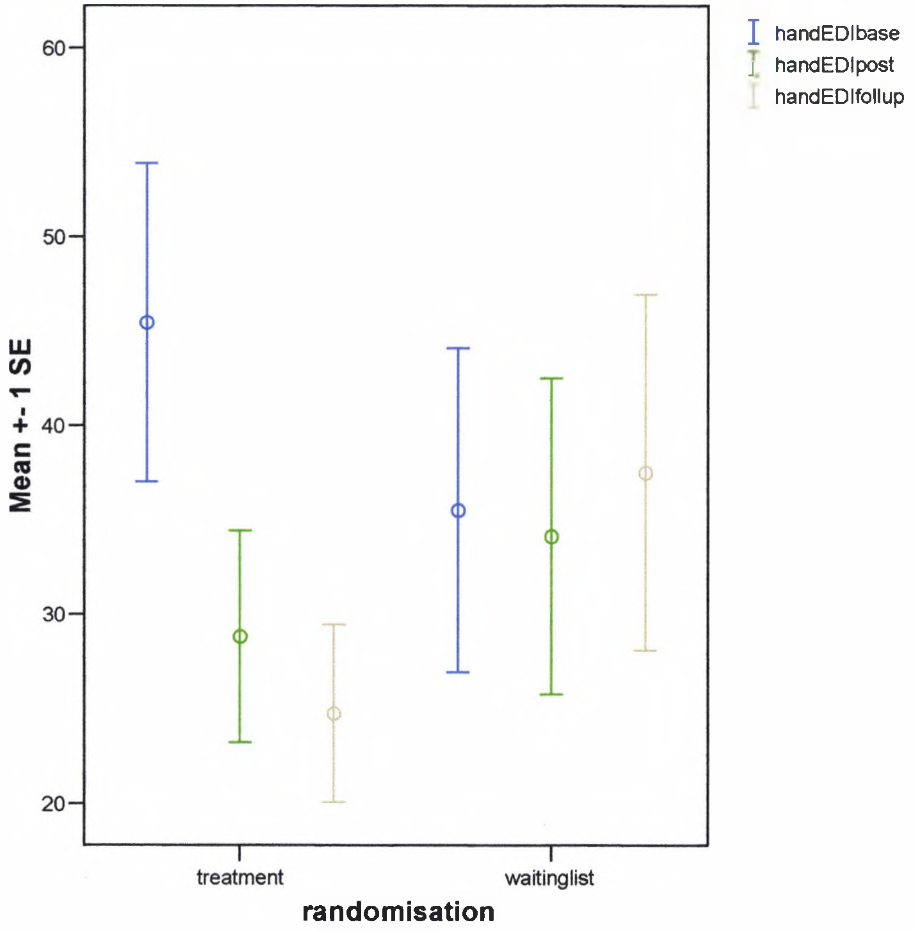

Table 5.4: Participants' quotes about their experience of therapy from their 'goodbye letters'

	Effect of Different Treatment Components, Techniques and Processes
Social Support/Sharing	(a) 'I feel liberated by discovering that others have had similar experiences and reactions to me. .... Now I can judge myself less harshly and feel less inclined to hide myself from other people, as I discovered that I am more sane and normal than I thought. ....Sharing our stories the weight of loneliness has shifted from my shoulders and mind, and I feel more positive, and supported'. (b) 'I will miss coming, but I now associate MRKH with this room of people with whom I have forged links and have shared so intimate detail,... To know that you are all out there brings me so much comfort; .... I will always have you all in my head and draw strength and knowledge from you all, knowing that you are out there maybe feeling similar things.'
Writing Tasks	"Through the writing exercises, and discussing these in therapy, I have been provided with a powerful tool that has allowed me to reorganize the somewhat muddled memory of being diagnosed with MRKH. .....a huge problem has been broken down, making it more manageable, and a smaller "monster" which plays a smaller role in my life than it previously did.......
CBT Strategies - Challenging Unhelpful Beliefs	'By getting varied perspectives, opinions have been turned on their head, making you consider other issues around it, and discover different and new dimensions. Through the process of coming to understand ones' thoughts and feelings and challenging these, the negative image of MRKH and its varied aspects have been turned round.'
	Impact of Therapy on Patients' Views of Themselves and Their MRKH
Increased Acceptance of MRKH	(a) 'MRKH does not need to be the be all and end all of my experiences, or the heavy load that will stand in the way of everything. It can be put in "its place", it need not dominate my life. ....I will live life to the full, no matter what happens. I can now bring back colour and choices in my life, reach out for my dreams and make a difference to myself and others. I ......am more accepting of MRKH ..., both in my heart and mind.' (b) 'I have allowed myself to acknowledge MRKH rather than bury it. Life has made me naturally brave, but now I am being braver by acknowledging that I can have feelings about MRKH and express these. I am learning to "mourn" the choices that I would have faced in a different way had I not had MRKH, mark these, and make choices from those available to me and my husband.'
Shedding MRKH as Identity	'I feel a great sense of relief, more free, facing a future that feels less burdened, brighter; with much shame, embarrassment and an "ugly" secret "dispersed". I now know that MRKH is not me, I am not MRKH; it is just a part of me, but I am also much more than that. .... I can now see that having the condition does not make me anything of a lesser person, I am as lovable, acceptable, and capable as the next person, and people will like me for who I am....... I can interact with people differently and say "no" when I need to, and be honest about myself to others, I no longer have anything to hide.'
Reducing the Power of MRKH	'To confront this condition has been to break its power over me. As I come to terms with the enormous significance of this realisation, it is like music to my soul. I am free to break out from the bars behind which I have been trapped for so long, now I can fly....'

Table 5.5: Participants' perspectives taken from their therapeutic writings about their experiences and therapy – 2 CASE VIGNETTES

Experience	**Vignette 1**	**Vignette 2**
Run up to diagnosis – *Therapeutic writing exercise 1*	My younger sisters had started their periods. I was not worried, I thought periods happen only to some girls and not to others. .... during the investigations I started worrying ...... that I had some disease and that I will die if I did not have any (periods)..... no one explained.....	My periods had not come, something was not right...... the GP referred us......I saw registrar after registrar who were all trying to ascertain if I was pregnant......
Diagnosis: being told you have no vagina and uterus and cannot carry a child - *Therapeutic writing exercise 1*	I was alone when the doctor told me. I was in shock, and could only think about the womb.... I told my dad, who cried. I never saw him cry...... what was worse, he did not say anything. I had no one to support me. I felt I was done and wished I had died there and then.	Following an exam under anaesthetic, I was told I had no womb and no vagina, but that he (the gynae) could fix the vagina so that I could have sex, but that I could not have babies, and that it would take a special man to be in a relationship with me. I left the room in shock............
Coping – *Therapeutic writing exercise 2*	I blocked out what the doctor had said and hoped that my womb was only underdeveloped and would grow or that womb transplants would become available as a technique. I protected myself from reality, until I went again and it all started to sink in. I had wanted to hit the doctor, tell him that he was wrong, and had no right to determine my future. I became depressed, but then I decided to become the best I could and fluctuated from working very hard to being depressed and overeating and totally losing control, and wondering what it was all for.... I avoided dad and the topic of (arranged) marriage.	I finished with my boyfriend, I could not see a way of pursuing a relationship, as in my head I kept hearing the doctors words. I stopped going out, I stopped eating, I just worked. I exercised to get a perfect body and made myself as pretty as I could, to be accepted, as I felt so rejected........ I had to proof myself and tried to be perfect in every other way, to please, give and be a saint in order to be loved again..... I no longer felt like part of my family, I burried my feelings as they did not know how to support me, it was "harder for my mother to cope, so why was I upset".
Conclusions drawn about self, others, the world, future – *Therapeutic writing exercise 3*	I am less important, an extra weight on this life and my family. Everything that has meaning has fallen to pieces, I am an in-complete woman, without any goals, a hopeless person, some-body that wastes space, an extra mitten. I am nothing I have nothing, no real value, nothing I do would count. The world has come to a dead end, there is no future, no way to go forward.....	I was barren, a freak, someone who should not have been born, a miscarriage survived. Everyone would know that I was a freak...... I was unloveable and inadequate......the plan of marrying and having babies was shattered. I could not have my rite of passage into womanhood, I was both a child and an old woman in one. I now had to walk the path of life alone........
Challenging negative/idiosyncratic conclusions drawn about the self, others, world and future, considering previous/current goals, finding meaning etc. – *Therapeutic writing exercise 3 (4)*	I am still loveable, a bloke can take me or leave me, as I can offer him and the world much, beyond childbearing. I am looking for an advantage in this, working out a future with a different meaning and have much to achieve. This (MRKH) has not changed the character of the person I am, who is caring and responsible, a real fighter and peacemaker for the good of the world. I am being tested, and through this I have become more open minded, wiser, and stronger.	I ask myself what is the worst that can happen and MRKH is not that bad in the scheme of things. It effects small parts of my life, which I could address if I so wish. I am not sick, I am not disabled, I am not stupid, or ugly, I have eyes and I can see and understand.... and look deeper.....and if others do not that is their problem. I am strong, I can cope with anything. I focus on what is important in my life...look after myself and live life day by day. I do not need to proof myself and relationships I can take or leave.
The group therapy/writings/talking/sharing – *Therapeutic writing exercise 5*	Through the care, the love, sharing our thoughts, our feelings, and making each other feel understood, the loneliness and weight shifted from my shoulders and I felt supported in my time of need. We fought against the odds and learned together that we can realise our dreams, that there is more beyond having MRKH, and that we can be happy again.	The first time that I could talk and share this terrible secret. I could do it in a safe way..... I was allowed to be upset, and no one was shocked by what I had to bring, I could be honest, and I was believed. I challenged the messages that I had picked up from my family and the doctor and which did not necessarily get shaped into the right beliefs, as it was not as simple as 'loved, not loved'. ...... Therapy has made me feel like this; I am loveable as a person.... I am good enough, you don't need a womb or children for that.....

Figure 5.3: Participants' perspectives of their experiences & therapy - Group Vignette Posters – 1

Figure 5.3: Participants' perspectives of their experiences & therapy - Group Vignette Posters – 2

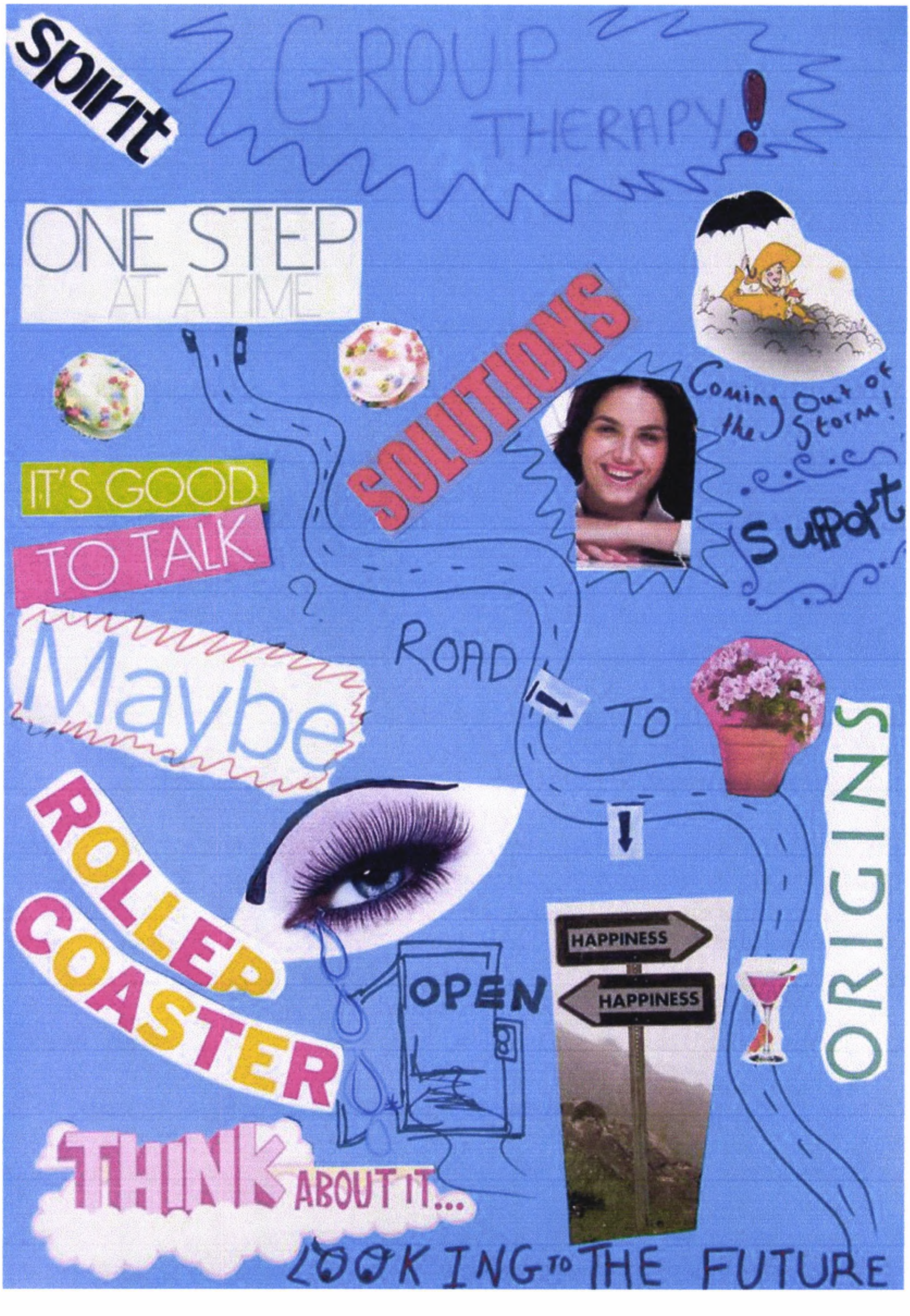

Figure 5.3: Participants' perspectives of their experiences & therapy - Group Vignette Posters – 3

Table 5.6: Participants' perspectives of their experiences & therapy – GROUP VIGNETTE TEXT that goes with posters Fig. 5.3

"What the groups have helped us to do is to (1) stand back and move away from the MRKH and see it as separate from ourselves. This enables us to see how it effects us and has effected us and to take a little more control of it. We can now more objectively analyse and understand MRKH and our journeys and (2) assimilate MRKH and accept it as part of us – not in a violent and destructive or shocking manner, in that it has been forced on us, but in a calmer way, with less conflict and desperation. In a way which makes us feel stronger in the end. These two points may seem contradictory, but in practice they are not – rather they complement and encourage each other. In saying this though, we are not saying we are all perfectly fine now and MRKH is a wonderful asset! We are saying we have gained some kind of insight and a powerful tool to help us learn to live with MRKH, without it taking control of/over us, or even influencing, or playing a part, in every aspect of our lives".

CHAPTER SIX: A CROSS-SECTIONAL COMPARISON OF STUDY PARTICIPANTS, NON-PARTICIPANTS AND COMPARISON WOMEN

6.1 INTRODUCTION:

Very little is known from research into MRKH about the psychological functioning of women with this disorder (see chapter 2) and how they compare with other women in terms of levels of psychiatric symptoms, interpersonal problems or self-esteem or indeed any other aspects of psychological functioning. A further question is whether within the group of women with MRKH those who decide not to take up the offer of psychological treatment may have better psychological functioning than those who choose to take up such treatment. In the study presented in the previous chapter only a small proportion (n=39/331; 12%) of the women on the Centre's MRKH register chose to participate and a larger group (78/331; 24%) actively decided not to participate. A related question is what are the characteristics of MRKH women who complete psychological treatment and how do they compare to those of women who drop out from treatment. In the study presented in the previous chapter a total of 7 women (18%) who started it, dropped out. It was the clinical impression of the researcher that at least some of these individuals who dropped out did so because they were not functioning well. Finally, it would be of interest to know whether following psychological treatment the psychological functioning of women with MRKH becomes similar to that of women without this disorder.

6.2. AIMS:

The aims of this chapter are:

(1) to conduct a cross-sectional comparison of the psychological characteristics of women with MRKH compared to a group of women without MRKH.

(2) to conduct a cross-sectional comparison of the psychological characteristics of women with MRKH who decided not to take up the offer of taking part in a psychological treatment trial, compared to those who did and completed or dropped out.

(3) to conduct a cross-sectional comparison of the psychological characteristics of women with MRKH who have completed psychological therapy compared to a group of women without MRKH.

6.3. Hypotheses:

Hypothesis 1: Compared to women without MRKH, those with MRKH will have significantly poorer functioning on the SCL-90-R, RSE, IIP-32 and EDI.

Hypothesis 2: There will be significant differences in SCL-90-R, IES, RSE, IIP-32 and EDI scores between women with MRKH who decided not to take part in a psychological treatment trial, those who did and completed and those who dropped out.

Hypothesis 2.a: Women who decide not to not to take up the offer of taking part in a psychological treatment trial will have less pathological scores on the SCL-90-R, IES, RSE, IIP-32 and EDI than women who either took part and completed or dropped out. Added to this completers will have less pathological scores, than drop outs have.

Hypothesis 3: At follow-up, the psychological functioning of women with MRKH who have completed psychological therapy is comparable to that of comparison women without MRKH.

6.4 Methods:

Subjects:

The MRKH subjects have been described in detail in chapter 5. Control women were recruited from a London City International Church congregation, and from the City University (London) student population. Those approached were chosen to be as similar as possible in terms of their sociodemographic characteristics to the study's participants. The women were given a brief explanation by the researcher (JHB) of the purpose of the study, and asked whether they might be interested in participating. If they indicated that they were, they were provided with an envelope containing an information sheet for the study (for a copy see appendix 6.1), a set of questionnaires (see below) and a self-addressed pre-paid envelope (to JHB). Participants were asked to complete questionnaires anonymously, i.e. without giving their name, but to indicate their age, ethnicity, occupation, relationship status, and whether they had any children on the top questionnaire. Of 42 women who were approached, 31 returned their completed questionnaires, which is a 73.8% response rate. The mean age of these women was 27.8 (SE=1.5), which is comparable to that of the study participants which was 28.2 (SE=1.4). 67.7% of the comparison subjects were of a

"White caucasian" background and 32.3% of other ethnic origins, which is comparable to the ethnic mix of the study participants which was 74.4% and 25.6% respectively (see table 5.2). 45% of comparison subjects were with a partner and 55% were without a current partner, compared to 61.5% and 38.5% respectively of the study participants. This means that study participants had a higher percentage of being in a relationship than that of the comparison group. Furthermore, 16.1% of the comparison subjects had children and 83.9% did not have children, which is comparable to that of the study participants which was 12.8% and 87.2% respectively. 19.4% of comparison women fitted into the 'high' socio-economic bracket, 38.7% into 'medium to low', 35.5% into that of 'student' and 6.4% into that of a 'housewife', which is comparable to that of the study participants which was 17.9%, 51.3%, 28.2 and 2.6% respectively. Thus overall the two groups were highly similar in terms of their socio-demographic characteristics, as planned.

Measures:

These have been described in chapter 5 and include the SCL-90-R, IES, RSE, IIP-32 and EDI. The comparison group were not given the IES, as this was not thought to be meaningful for them.

Statistical Analysis:

Two-group comparisons between MRKH women and comparison women on questionnaire measures were conducted using independent samples t-tests (2-tailed). Three group comparisons between study-completers, drop-outs and non-participants were conducted using univariate analysis of variance tests (ANOVA).

As these are only exploratory analyses, no Bonferroni corrections for multiple testing were performed.

6.5. RESULTS:

6.5.1. Comparison of MRKH women with control women

Sixty-six women with MRKH (combining both study participants and non-participants) who had returned useable questionnaires, where included in this analysis, and were compared with 31 comparison women without MRKH on the varied measures, using independent samples t-tests. The results are displayed in table 6.1. There was a trend for women with MRKH to have higher SCL-90-R scores than comparison women (p = 0.133). Moreover, women with MRKH had significantly higher RSE (i.e. lower self-esteem) and EDI scores than comparison women. There was no difference between groups on the IIP-32.

An additional descriptive analysis of the subscale scores of the SCL-90-R and EDI is presented in section 6.5.5. below to explore where the differences between women with MRKH and comparison women lie.

6.5.2. Comparison of study non-participants, completers and non-completers

Scores of non-participants, completers and non-completers on the varied measures were compared using One-way ANOVAs. No significant between group differences were found on any of the measures, as depicted in table 6.2.

6.5.3. Comparison of MRKH women after psychological treatment with control women

Follow-up questionnaire scores of women with MRKH who had completed the group CBT treatment were compared with scores of the comparison women without MRKH using independent samples t-tests. Results are shown in table 6.3. Of note, after completing group CBT, women with MRKH had somewhat lower mean SCL-90-R scores than the comparison women (although this is not statistically significant) and were indistinguishable from comparison women on self-esteem, interpersonal relating and on the EDI.

6.5.4. SCL-90-R Subscales in Women with MRKH and comparison groups

As shown in section 6.5.1 above, there was a trend for women with MRKH to be more symptomatic on the SCL-90-R global severity score than comparison women. A further exploratory analysis (descriptive data only) was therefore conducted comparing these two groups on the subscales of the SCL-90-R, to identify whether there were any particular subscales on which they differed (table 6.4). Sub-scale scores were also examined for study non-participants, completers and drop-outs. Moreover, to put these scores into a broader context they can also be contrasted with SCL-90-R population norms for “non-patients”, “psychiatric outpatients” and “psychiatric inpatients” (see table 6.6).

Eye-balling the data in table 6.4 suggests that in contrast to comparison women, MRKH women have somewhat higher scores on their global severity index (GSI) and on all subscales, and therefore are overall somewhat more impaired than the comparison group. Contrasting this with relevant population norms for both the SCL-90-R GSI and subscale scores, the scores of MRKH women lie between the norms for 'non-patients' and 'psychiatric outpatients'. Interestingly the 31 comparison women without MRKH also had higher scores on the GSI than the "non-patient" population norms[1].

Considering the SCL-90-R subscales scores of 'non-participants', treatment 'completers' and 'drop-outs' (see table 6.5) it appears that compared to non-participants, drop-outs have particularly high scores on 'interpersonal sensitivity and psychoticism with completers being in-between. Comparing these scores with population norms (table 6.6), it can be noted that "drop outs/non-completers" in the

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[1] This may suggest that on the one hand the women without MRKH do not seem to appear as representative of the general population as hoped. I.e. they did not quite match the samples on which the measure was standardised and from which these norms were derived in terms of normative levels of psychological well-being; since women without MRKH seemed to be experiencing higher levels of distress than the "non-patient" population norms with which they were expected to compare. On the other hand the study and comparison sample were thought to be well matched on socio-demographic characteristics, see section 6.4, page 194, and one was thought to be able to function as normative for the other in a cross-sectional comparison of women with and without the condition. However, it is possible that the comparison women were "super matched" in terms of the sociodemographics of e.g. working and studying, of not having children (the reason possibly being their singleness: they featured a somewhat lower percentage of being in relationships compared to women with MRKH, and were drawn from the London City populus). Whereas, the sample on which the measure was standardised was that of a stratified random sample from a diversely comprised county in one of the larger Eastern American states, possibly featuring large socio-demographic and situational variation, though descriptive demography was not complete in this cohort. This difficulty of representativeness and matching can be linked to the difficulties outlined in footnote 2 overleaf, to which can be added the need for the consideration of (i) the kind of populations on which these norms are based, (ii) the sizes of the samples employed to derive these norms from (which in this case are impressive: Norm A - 1002 psychiatric outpatients; Norm B - 974 non-patients; Norm C - 423 psychiatric outpatients, and are gender specific Derogatis, 1992, see table 6.6), vis a vis (iii) the size of the comparison sample used (which is not as impressive) and (iv) how all of this both effects what are considered "normal ranges" on this measure/the varied measures used in this study, and the interpretation of findings and evaluation of treatment outcome etc.

trial have higher scores than psychiatric outpatients on 'interpersonal sensitivity' and 'psychoticism/interpersonal alienation'.

6.5.5. Subscales on the EDI

As shown in section 6.5.1, women with MRKH had significantly higher EDI total scores than comparison women. It was therefore decided to explore this further by looking at the subscales of the EDI to discern where any differences lay between the two groups. Table 6.7 shows the EDI subscale scores for women with MRKH and the comparison women. In contrast to comparison women, MRKH women appear to have higher scores on the "interoceptive awareness" and "ineffectiveness" subscales.

Comparing the EDI sum and subscale scores of MRKH women, as outlined in table 6.7 with their population norms taken from a non-clinical sample (Wicks, Siegert & Walkey, 2004) (see Table 6.8), it can be noted that MRKH women have a slightly higher overall sum score on the EDI than their population norms, and that they have higher scores than the population norms on the subscales of both 'interoceptive awareness'; 'ineffectiveness'; 'interpersonal distrust'; and 'maturity fears'.

It is interesting to note that the comparison women in the present study have lower EDI sum scores than the non-clinical population controls[2].

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[2] This highlights the difficulties in deciding which norms to choose, and the need for culture specific or national standardisations of assessment instruments as outlined by Kordy, Percevic & Martinovich (2001). However, within the multicultural population that inhabits the UK this is not an easy task, hence the creation of a small control group within the present study. Note that the sample size in Wicks, Siegert & Walkey (2004) study was n=260 women, see table 6.8.

6.6. DISCUSSION

The key findings of this small cross-sectional study are as follows:

(a) Women with MRKH differed from comparison women of similar age and ethnicity in terms of their overall SCL-90-R, RSE and EDI scores. Thus hypothesis one was partially confirmed. The lack of difference between MRKH and comparison women on the IIP-32 was somewhat unexpected, but may reflect the fact that this instrument measures relatively broad aspects of interpersonal relationship patterns.

On the SCL-90-R the scores of MRKH women lie somewhere between population norms for non-patient and psychiatric out-patient scores, suggesting overall mild impairment on this scale and its subscales. On the EDI subscales, MRKH women had higher scores on 'interoceptive awareness'; 'interpersonal distrust'; and 'ineffectiveness' in contrast to the comparison group. Similarly, in comparison to the population norms, MRKH women appeared to have higher scores on these scales as well as that of the 'maturity fears' subscale.

Taken together these findings build up a picture of subtle but definite impairments in MRKH women in the area of self-esteem, interpersonal effectiveness and distrust, together with fears of being a mature woman. This fits in well with some of the findings from the systematic review of the literature on MRKH (Chapter 2), as well as what clinical experience working with these women suggests, aspects of which were described and included in the theory and model of therapy (Chapter 4).

(b) The second hypothesis of clear differences between non-participants, completers and drop-outs in relation to their overall questionnaire scores was not confirmed. However, an examination of the subscale scores suggests that drop-outs have particularly high 'interpersonal sensitivity' and 'psychoticism/interpersonal alienation' scores compared to the other MRKH groups and compared to population norms. This may be an important pointer towards their reasons for dropping out. These women may simply have found the idea of participating in a group treatment too threatening, even though they originally agreed to it. This would suggest that in future more time should be taken preparing potential participants for group treatment or direct those with high baseline 'interpersonal sensitivity' or 'psychoticism/ interpersonal alienation' scores in the direction of individual therapy.

c) The third hypothesis that CBT completers at follow-up would have similar scores to comparison women was supported. In fact, the mean follow-up scores of MRKH women who had completed CBT were as low or even lower, than the comparison women on all the measures. This underscores the value of the model and therapy developed in reducing the distress experienced by women with MRKH following diagnosis, whilst improving their psychological wellbeing, self-esteem and interpersonal functioning.

The limitations of this cross-sectional study are as follows. First, the sample size is small, in particular when it comes to looking at sub-groups (such as the group of non-completers). This suggests that in some instances a failure to find differences between groups may have been due to lack of power. Second, study non-participants and participants were combined to form an overall MRKH sample. It is not clear how representative this sample was of women with MRKH in general, as only 66 (20%) of 331 women on the Centre's register provided questionnaire data. Third, the number of comparisons is large and it is therefore likely that some differences were found by chance. Having said that, the differences between groups taken together, build up a coherent picture. Fourth, the scores of the comparison women were used twice, once to compare with MRKH women who have not had psychological treatment and then to contrast them against the follow-up scores of treatment completers. This is clearly a very 'rough and ready' analysis and ideally comparison women should have been given the same questionnaires twice at the same time interval as the MRKH women. However, due to time-constraints this was not possible.

This study also has some strengths. The study and comparison sample were well matched on sociodemographic characteristics and the response rate of the comparison group was high. Perhaps the main strength of this study is that it adds to the still very limited knowledge of psychological functioning in women with MRKH.

Table 6.1. Cross-sectional comparison of women with MRKH and comparison women on questionnaire measures

Variable	Women with MRKH N=66	Comparison women N=31	t	P
SCL-90-R (GSI)	0.90 (SE=0.1)	0.67 (SE=0.1)	1.52	0.133
RSE	22.8 (SE=0.7)	19.3 (SE=0.9)	2.77	0.007
IIP-32	38.8 (SE=2.4)	34.5 (SE=3.0)	1.04	0.299
EDI	40.4 (SE=4.2)	26.8 (SE=3.7)	2.41	0.018

Table 6.2: Comparison of clinical features for study non-participants, completers, and drop-outs.

Variable	Non-participants N=27	Study Completers N=32	Study Drop-outs N=7	F	p
SCL-90-R (GSI)	0.83 (SE=0.2)	0.95 (SE=0.1)	0.96 (SE=0.2)	0.20	0.82
RSE	23.9 (SE=1.3)	21.6 (SE=0.9)	23.7 (SE=2.4)	1.05	0.36
IES	32.0 (SE=3.7)	26.3 (SE=3.3)	36.9 (SE=5.9)	1.25	0.29
IIP-32	37.1 (SE=3.8)	41.0 (SE=3.5)	34.9 (SE=6.0)	0.49	0.62
EDI	37.2 (SE=6.8)	40.5 (SE=6.0)	52.0 (SE=12.9)	0.48	0.62

Table 6.3: Comparison between MRKH women who had completed the study treatment (at follow-up) with control women on questionnaire measures.

Variable	CBT Follow-up N=16	Control Women N=31	F	p
SCL-90-R	0.48 (SE=0.1)	0.67 (SE=0.1)	-1.41	0.17
RSE	17.5 (SE=1.1)	19.3 (SE=0.9)	0.03	0.26
IIP-32	30.8 (SE=4.3)	34.5 (SE=3.0)	0.07	0.45
EDI	25.4 (SE=4.9)	26.8 (SE=3.7)	0.00	0.94

Table 6.4: SCL-90-R sub-scale scores in women with MRKH and comparison women without MRKH.

SCl-90 Subscore	MRKH women N=66	Comparison women without MRKH N=31
GSI	0.90 (SE=0.1)	0.67 (SE=0.1)
Somatisation	0.74 (SE=0.1)	0.59 (SE=0.1)
Obsessive Compulsive	1.09 (SE=0.1)	0.86 (SE=0.1)
Interpersonal Sensitivity	1.13 (SE=0.1)	0.95 (SE=0.2)
Depression	1.27 (SE=0.1)	0.92 (SE=0.1)
Anxiety	0.78 (SE=0.1)	0.53 (SE=0.1)
Hostility	0.68 (SE=0.1)	0.52 (SE=0.1)
Phobic Anxiety	0.52 (SE=0.1)	0.23 (SE=0.1)
Paranoia	0.80 (SE=0.1)	0.68 (SE=0.2)
Psychoticism	0.73 (SE=0.1)	0.46 (SE=0.1)

Table 6.5: SCL-90-R sub-scale scores in women with MRKH who were study non-participants, completers, or treatment drop-outs

SCl-90 Subscore	Non-participants (N=27)	Treatment Completers (N=32)	Drop-Outs (N=7)
GSI	0.83 (SE=0.2)	0.95 (SE=0.1)	0.96 (SE=0.2)
Somatisation	0.68 (SE=0.2)	0.78 (SE=0.1)	0.74 (SE=0.2)
Obsessive Compulsive	0.97 (SE=0.2)	1.18 (SE=0.2)	1.14 (SE=0.3)
Interpersonal Sensitivity	0.90 (SE=0.2)	1.23 (SE=0.2)	1.57 (SE=0.4)
Depression	1.23 (SE=0.2)	1.26 (SE=0.2)	1.45 (SE=0.4)
Anxiety	0.73 (SE=0.2)	0.86 (SE=0.1)	0.61 (SE=0.3)
Hostility	0.72 (SE=0.2)	0.63 (SE=0.1)	0.76 (SE=0.4)
Phobic Anxiety	0.66 (SE=0.2)	0.48 (SE=0.1)	0.14 (SE=0.1)
Paranoia	0.57 (SE=0.1)	0.97 (SE=0.2)	0.90 (SE=0.3)
Psychoticism	0.60 (SE=0.1)	0.77 (SE=0.1)	1.07 (SE=0.4)

Table 6.6: **SCL-90-R norms for A. Psychiatric Outpatients, B. Non-patients and C. Psychiatric Inpatients,**

Taken from Derogatis (1992)

Norms A – psychiatric outpatients (n=1002)

	males		**females**		**total**	
	mean	**SD**	**mean**	**SD**	**mean**	**SD**
Somatization	.70	.67	.99	.78	.87	.75
Obsessive-Compulsive	1.41	.89	1.51	.91	1.47	.91
Interpersonal Sensitivity	1.36	.90	1.44	.88	1.41	.89
Depression	1.59	.92	1.94	.93	1.79	.94
Anxiety	1.30	.83	1.59	.90	1.47	.88
Hostility	1.00	.89	1.17	.95	1.10	.93
Phobic Anxiety	.65	.74	.81	.84	.74	.90
Paranoid Ideation	1.07	.90	1.21	.94	1.16	.92
Psychoticism	.90	.65	.98	.74	.94	.70
Global Severity Index	1.14	.64	1.35	.69	1.26	.68
PSDI	2.04	.58	2.22	.56	2.14	.58
PST	47.64	19.22	52.03	18.61	50.17	18.98

Norms B – nonpatients (n=974)

	males		**females**		**total**	
	mean	**SD**	**mean**	**SD**	**mean**	**SD**
Somatization	.29	.33	.43	.47	.36	.42
Obsessive-Compulsive	.34	.39	.44	.49	.39	.45
Interpersonal Sensitivity	.25	.31	.35	.43	.29	.39
Depression	.28	.31	.46	.52	.36	.44

Anxiety	.22	.27	.37	.43	.30	.37
Hostility	.29	.37	.33	.42	.30	.40
Phobic Anxiety	.08	.19	.19	.38	.13	.31
Paranoid Ideation	.34	.40	.34	.46	.34	.44
Psychoticism	.13	.22	.15	.25	.14	.25
Global Severity Index	.25	.24	.36	.35	.31	.31
PSDI	1.31	.37	1.37	.39	1.32	.42
PST	16.97	13.85	22.00	16.21	19.29	15.48

Norms C – psychiatric inpatients (n=423)

	males		**females**		**total**	
	mean	**SD**	**mean**	**SD**	**mean**	**SD**
Somatization	.82	.78	1.10	.85	.99	.84
Obsessive-Compulsive	1.22	.96	1.57	.99	1.45	1.00
Interpersonal Sensitivity	1.03	.87	1.48	.98	1.32	.97
Depression	1.41	1.02	1.92	1.05	1.74	1.08
Anxiety	1.22	.95	1.64	1.07	1.48	1.05
Hostility	.73	.76	1.07	1.03	.94	.95
Phobic Anxiety	.71	.88	1.09	1.09	.96	1.03
Paranoid Ideation	1.08	.84	1.36	1.04	1.26	.98
Psychoticism	.91	.78	1.21	.86	1.11	.85
Global Severity Index	1.06	.74	1.44	.83	1.30	.82
PSDI	1.99	.72	2.23	.72	2.15	.73
PST	43.90	22.95	53.44	21.50	50.03	22.40

Table 6.7: EDI sub-scale scores in women with MRKH and comparison women without MRKH.

EDI Subscore	MRKH women N=66	Comparison women without MRKH N=31
Sum	40.4 (SE=4.2)	26.8 (SE=3.7)
Drive for thinness	3.5 (SE=0.7)	4.2 (SE=0.8)
Interoceptive awareness	4.7 (SE=0.7)	1.8 (SE=0.5)
Perfectionism	4.6 (SE=0.5)	4.2 (SE=0.7)
Interpersonal distrust	4.0 (SE=0.6)	2.3 (SE=0.5)
Ineffectiveness	6.7 (SE=1.0)	2.5 (SE=0.7)
Body dissatisfaction	10.7 (SE=1.0)	8.2 (SE=1.4)
Maturity fears	4.5 (SE=0.6)	3.2 (SE=0.6)
Bulimia	1.6 (SE=0.4)	0.5 (SE=0.2)

Table 6.8: EDI norms, summary statistics of the subscales, and of the total Eating Disorder Inventory - raw scores, Taken from Wicks, Siegert & Walkey, 2004

	Norms Female University Students New Zealand (n=260)	
	Mean	**SD**
Sumscore	35.19	25.74
Drive for Thinness	4.77	5.74
Interoceptive Awareness	2.99	3.95
Perfectionism	5.14	4.18
Interpersonal Distrust	2.51	3.18
Ineffective	3.30	4.49
Body Dissatisfaction	11.42	8.00
Maturity Fears	2.86	3.58
Bulimia	2.20	3.49

CHAPTER SEVEN: DISCUSSION

Introduction:

In this chapter I will first provide a summary of the key findings and will then go on to look at some of the research, clinical and service implications from the body of work presented here.

7.1 Summary and key findings:

7.1.1. Introduction:

The Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH) is a congenital abnormality of the female genital tract, manifesting in a non-formation of the vagina and the uterus, with normal ovaries. It is a common cause of primary amenorrhoea, is typically diagnosed in mid-adolescence, and is just one example of a gynaecological condition that effects young women. Little is known about the psychological impact and management of this condition. The Medical Research Council's Framework for Complex Interventions was followed and a cognitive-behavioural model and group treatment of the impact of MRKH on these women developed, based on a systematic review of the literature on the psychological aspects of the disorder and clinical experience working with this client group. The aim of the present study was to carry out a preliminary test of the efficacy of this intervention compared to waiting-list control. In parallel with this a cross-sectional comparison of women with MRKH with women without the condition was performed to discern any differences between these groups in terms of levels of psychiatric symptoms, interpersonal problems, self-esteem, or other aspect of psychological functioning (at pre-treatment and follow up).

7.1.2. Method/Techniques:

39 women with MRKH were randomized to a group cognitive-behavioural intervention (N=19) or to waiting-list (N=20). Outcomes were assessed at post treatment (7 weeks) and 3 months follow-up. The main outcome measure was the Symptom Check-list (SCL-90-R) assessing psychiatric symptoms. Other outcomes were impact of diagnosis, self-esteem, interpersonal functioning and eating disorder-related variables. The cross-sectional study compared 31 women without MRKH, and 66 women with MRKH (39 women who participated in the RCT and 27 women who did not want to take part in the RCT but had provided questionnaire measures).

7.1.3. Results/Outcome:

RCT participants who were allocated to the cognitive-behavioural group intervention had reduced psychological symptoms on the SCL-90-R and improved self-esteem and interpersonal functioning at end of treatment and at follow-up, whereas those on the waiting list remained unchanged. In the cross-sectional comparison, women with MRKH had significantly lower self-esteem and higher EDI scores compared to women without MRKH. However, following treatment the questionnaire scores of MRKH women became indistinguishable from those of comparison women without MRKH

7.1.4. Conclusions/Discussion:

This study shows that a specific psychological intervention can ameliorate the psychological impact of MRKH. This model of treatment may also be applicable to women with other congenital or acquired gynaecological conditions impacting on their sense of self and femininity.

7.2 Strengths and limitations of the work:

The strengths of the work presented here are that (A) it followed the MRC's framework for developing complex interventions, in devising a cognitive-behavioural model and group treatment of the core negative impact of MRKH on these women and the factors that keep it in place. The model and treatment developed and trialed were based not only on the researcher's clinical experience of working with this client group, but on a systematic review of the literature on the psychological aspects of the disorder, a narrative review of what is known about psychosexual differentiation, and drew on cognitive schema and trauma theory, in an iterative process. (B) Furthermore, it is the first (albeit small and preliminary) randomised controlled trial investigating such a treatment in women with MRKH, the results of which are encouraging in that the intervention led to lasting and large improvements in psychiatric symptoms, traumatic impact of diagnosis, self-esteem, interpersonal relationships and eating disorder related symptoms. (C) Finally, the model and psychological treatment for MRKH developed and trialed is novel, and may go on to serve as an exemplar for the development of interventions in other areas of gynaecological medicine, and has potential for being adapted for use in conditions such as CAIS, POF, early onset endometrial cancer and others, all of which may have a psychological impact not dissimilar to MRKH, as discussed in section 5.15.

Limitations of the study include, that i) the model is still rather speculative. In an ideal world the study might have benefited from more preparatory work such as first testing out components of the model before going to intervention mode. However, due to time constraints of the thesis this was not possible (see more below). Furthermore, ii) the sample size of the study was small, but as noted in section 5.15, the likelihood that a larger scale study will ever be mounted, is rather slim.

7.3 Implications for future research in this area:

7.3.1. Further work on elucidating the model:

The CBT model of the core impact of MRKH developed here is still largely speculative, with mainly indirect or anecdotal evidence supporting its different components. Whilst some support for the model comes from the RCT presented here, additional evidence is needed to consolidate the model. One promising strategy might be to use patients' therapeutic writings (and perhaps also session transcripts) for exploring further, in a qualitative analysis, the key components of the model and how they relate to each other. Due to time constraints this was not done here, however in what follows some ideas for future work in this area are provided. For example, early writing assignments over the course of therapy asked people to describe what happened when they were diagnosed and to reflect on the impact this had on their view of themselves, others, the world and their future. This might yield information on what is typically remembered about the event of being diagnosed and the appraisals and coping strategies that ensued. In relation to being diagnosed it might yield some information on what is remembered and in how much detail. In relation to subsequent appraisals a qualitative content analysis of these versus the negative/idiosynchratic appraisals related to "events" of MRKH suggested in the model (see chapter 4) might confirm, add to or substract from the 'categories of appraisal' presented in chapter 4 and identify key recurring themes. Likewise, participants' actual maladaptive strategies connected to these appraisals could be looked at versus those suggested in table 4.1 by looking at therapeutic writing exercise 2. This process of triangulation; of looking at the patient within-therapy data to see how and whether their experience confirms the model developed from clinical experience and the literature, and using different methods to draw conclusions, can be a very helpful strategy in elucidating the model.

In a similar way qualitative analysis of therapy transcripts (in particular the final sessions) and participants' goodbye letters may be useful in trying to 'map' the changes in participants' perspectives through the process of therapy and discern what the changes in their appraisals are, i.e. what the 'changes in their life story', are; how they rework their MRKH schema, at an individual and group level and to consider varied theories around these processes. For example, the joint story that these women ‘weave’ may seem to be one of an individual/group process from “chaos” towards “part-restitution” and “quest” as described by Frank (1995), or that it entails a process of moving from a fragmented, disorganized, incomplete story to a honest and coherent story, as suggested by Pennebaker (1997). Alternatively, it may involve a process of deconstruction, to a reconstructed and developed narrative that is more ‘freeing’ (Nicholson, 1995). Alternatively, as suggested by Kubler-Ross’ (1969) it may involve that a person moves from ‘denial/working through to completion/assimilation’ (denial/anger/bargaining/depression/”acceptance”) of losses in her life, as in an adaptation to other bad news.

This information might also yield some answers to the question of what constitutes ‘good’ adaptation to MRKH, as a ‘total/full acceptance/assimilation’ of MRKH might not be an altogether appropriate, or realistic end-goal in this. Some of the losses incurred may never be fully acceptable to these women. This point was underscored by the group vignette (posters, but particularly the text) in chapter 5, (Figure 5:3 1-3 & table 5.6). This outline of a typical group experience of therapy (particularly the text in table 5.6), narrates the process of acceptance of MRKH and its associated losses as part of this experience and eloquently captures what may be a more appropriate goal of therapy for these women.

7.3.2. Therapeutic writings as predictors of therapy outcome

The therapeutic writings of these women could also be used as predictors of therapy outcome. As described in chapter 4, Pennebaker and colleagues have developed text-analytic methods for studying therapeutic writings and predicting health outcomes on other measures. Such text-analysis has focused on change over time in ratio of emotion and cognitive words used, change in perspective over time (use of personal pronouns) and level of intensity of negative emotions expressed. Unfortunately such analyses, because it involves transcribing texts, was beyond the scope of the present thesis.

7.3.3. Measurement issues:

One of the central ideas of the model proposed here is that MRKH is maintained by idiosyncratic negative appraisals of MRKH related events and that these over time become incorporated into schema-level beliefs. If this is correct there should be a way of demonstrating that with successful therapy these beliefs lessen. A broad range of tried and tested outcome measures was used in the present study and the rationale for their use was explained in chapter 5. None of these measures tap into the core issues of MRKH, MRKH-related beliefs and how these women's views of themselves changed over the course of treatment. It had been considered at the start of the study whether to include a generic measure of schematic beliefs such as the Young Schema Questionnaire (Young & Klosko, 1990). However this did not seem to catch the flavour of what was happening for these women, moreover the questionnaire was felt to be rather too long. Thus future research might focus on designing a questionnaire measure which taps into MRKH specific beliefs.

7.4 Altering or adding to the treatment programme

7.4.1. Improving uptake of the intervention and reducing drop-out:

Given the low take up rate of the RCT (12% of those approached), questions arise around the appeal and acceptability of the intervention and this has been noted in chapter 5 as one of the limitations to the study. In relation to this, the issue of women with MRKH's lack of familiarity and fear of psychological therapy in general was raised as a barrier for participating in the treatment study. Furthermore, treatment 'non-completer' had higher scores on the subscales on the SCL-90-R of 'interpersonal sensitivity' & 'interpersonal alienation', suggesting that they might have found a group intervention particularly problematic. The low treatment uptake rate might best be addressed by some motivational work around the 'pros' and 'cons' of therapy as a preparation for group therapy and hearing or reading about the experiences of others who had gone through the treatment

During such a preparatory stage it might also be possible to identify women with high levels of 'interpersonal sensitivity' and direct them towards one-to-one therapy. There is also a broader point to be considered here. These women's fear and misconceptions of therapy are understandable and highlight the need for ongoing education and information about what psychological treatment involves, how it might work and what are common misconceptions about therapy. This might help correct the belief that one has to be ‘mad’ or ‘weak’ to engage in these interventions, and instill the idea that working through the issues in varied ways is actually a very healthy strategy, “away from MRKH taking control of you”.

Such information and education might also include the idea that given the challenges of MRKH at different stages of a woman’s life coming to therapy is not a ‘single shot’ but that different challenges and different stages might require different interventions, such as having one to one therapy, attending support group meetings, having couple therapy, or doing group therapy, all of which may complement each other .

7.4.2. Addressing the effects of IVF surrogacy

As outlined earlier one of the most difficult aspects of MRKH for these women is their infertility. Whilst the existing treatment focuses on this to some extent, it might be useful to add a further session to the existing programme, discussing IVF surrogacy treatment and exploring and preparing for the difficulties that a woman may encounter if she chooses to go for this. Alternatively this could be provided as an add-on intervention at a couple level. The procedures that are involved in IVF surrogacy are likely to serve for these women as a strong reminder of earlier medical investigations. They thus have the potential for re-enforcing the negative beliefs that these women already may have developed in relation to their MRKH and may re-traumatise them and potentially alienate them further from their bodies. Moreover, the medicalisation[2], of what otherwise is a private, intimate, and beautiful process (i.e. having a baby) may be experienced as yet another major intrusion of privacy. Thus it may be useful to discuss with the woman and her husband[3] what the differences and similarities are between IVF surrogacy and earlier MRKH related interventions, and discuss ways of dealing with difficulties encountered as a result of IVF surrogacy and how to negotiate the procedure.

7.4.3. Early Intervention

As already suggested in chapter 5 a more targeted early intervention for adolescents who have recently been diagnosed, could be easily developed, adapted from the programme, in its existing form. The aim of such an intervention would be to prevent the development of some of the more schema-level maladaptive beliefs.

7.4.4. Involving family members in treatment

The treatment approach described here involves only the woman with MRKH. However, there is some suggestion from the literature on MRKH and - my own clinical experience would certainly back this up - that parents (and other family members) are deeply affected by the diagnosis of MRKH. Parents may blame themselves for their daughter's MRKH, they may feel ashamed and find it hard to seek support for themselves and they may have a sense of loss for their own future in terms of their loss of the idea of ever having grandchildren. Moreover, the way

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[2] and the introduction of health professionals (i.e. fertility specialists, embryologists, sonographers, nurses, lab. technicians) and yet another person into the relationship (i.e. the carrier mother)

[3] Current legislation dictates that the woman with MRKH is married in order for her and her partner to be eligible for IVF Surrogacy

parents and other family members respond to the diagnosis of MRKH may lead to the development and maintenance of the negative appraisals that young women typically develop in these situations. Therefore, it could be argued that parents do need as much help to process MRKH and related events to effectively support their daughter in trying to adapt to MRKH. In my own place of work at the Centre at Queen Charlotte's a twice yearly support group takes place to which both the women with MRKH, their partners, families and friends are invited. An added suggestion would be to run specific parent therapeutic groups providing parents with relevant information on MRKH and its treatment and teaching them skills on how best to support their daughter both practically e.g. during dilator treatment and emotionally. Similar parents' skills workshops have been developed in other areas, for example for parents of people with anorexia nervosa (Whitney, Murray, Gavan, Todd, Whitaker & Treasure (2005).

7.5 Further evaluation and dissemination of the psychological intervention for MRKH:

The work presented here was informed by the MRC framework for complex interventions and included a theory phase, a model development phase and an exploratory trial phase. The MRC framework describes two further steps: a definitive randomised controlled trial phase and a long-term implementation or dissemination phase.

I have already discussed in chapter 5 the difficulties with conducting a definitive RCT of the group intervention described here. These difficulties focus mainly on practical and logistical considerations. One way of making the group CBT intervention for MRKH more widely available would be to translate the group treatment into a web-based treatment package with therapist-guided internet chat groups. This would widen access to treatment and allow women living in remote areas to participate. This way of working has been used in other conditions/settings where face-to-face therapy is impractical with good results (Golkaramnay, Wangemann, Dogs, Dogs & Kordy, 2003). Web-based treatment may also have the added benefit of lowering the threshold of accessing psychological care for those women who find it very hard to look at the "awful" secret that they feel they are hiding, provided it is done in a guided and safe way.

Having a web-based version of the treatment might then make it possible to conduct a more definitive RCT across including participants not just from different centres, but also different countries.

Clinically, web-based treatment could also function as an adjunct to face-to-face therapy, with a mix of one-to-one sessions and email contact, and eventually group therapy, when enough numbers of clients have been accumulated to form a group.

The material provided in this thesis and in the treatment manual associated with it, could be also used to generate more traditional printed service users resource materials. The topics discussed in the therapy programme and materials used, could be put together into a self-help manual, to which medical information on the condition could be added and with accompanying excerpts of therapeutic writings used to illustrate or highlight specific points. This would be the first such book in this field, something service users, and women with MRKH in general, have asked for, and would be likely to find helpful.

7.6 Implications for clinical practice and service improvements:

7.6.1. The role of gynaecologists and other health professionals in women's adaptation or adjustment to MRKH:

My own clinical experience and the systematic review of the literature in chapter 2 suggested that women's adaptation or adjustment to MRKH is profoundly influenced by health professionals' behaviour during clinical encounters, especially during the early stages of diagnosis and treatment. Thus, for example if the woman feels treated 'as a specimen', and technical and medical aspects of the condition and treatment are emphasised, she may conclude that she is a freak, not a proper person. Furthermore, if she is told about the absence of her womb and vagina and that she cannot have children in a detached and clinical manner with no acknowledgement of what this might mean for her, she may conclude that she is not allowed to have any feelings or emotional response to it, since to the consultant/medical staff this does not seem to see it as 'a big deal'. Sadly, amongst the participants of the trial there were several who in their within-therapy writings commented on unhelpful medical encounters and how these had lasting negative effects.

Whilst ‘bad news cannot be made into good news’, perhaps the most important aspects of good specialist care for women with MRKH are for her to be treated throughout as an individual with empathy, compassion and respect for her autonomy and for medical /gynaecological and psychological care/treatment to be integrated and to inform each other. Such treatment and care not only has the potential for reducing distress but is also less likely to cause iatrogenic negative appraisals.

With this in mind the present study may also make a contribution to educating gynaecologists, radiographers, clinical nurse specialists and other health professionals likely to come into contact with women with MRKH and help inform their clinical practice.

7.7 Some concluding remarks from a personal perspective as a Counselling Psychologist:

The patient group under review clearly are a distressed and traumatised group and the existing evidence base in the area is poor. It therefore was my intent and heart-felt duty, whilst having the privilege and opportunity of working with these women at the National Centre, and being the only Counselling Psychologist doing this work in the UK at the time, to bridge an important gap in our knowledge, by coming to an understanding and conceptualisation of the condition in therapeutic terms and develop and demonstrate the efficacy of an intervention for this group in an iterative process. I did not intend to let the possibility slip of being at the frontier of developments in this area in a very small way, whilst also engaging in useful CPD in the shape of doing a top-up DPsych (post-chartered Counselling Psychology). I wanted to develop a fully defined intervention to an appropriate alternative using a protocol that was theoretically defensible, reproducible, and adequately controlled in a study with appropriate statistical power. In addition I sought to generate cross-sectional data on the psychological functioning in women with MRKH compared to women who did not have this condition. I wanted to share the findings from these studies with Health Professionals, and particularly Counselling Psychologists, working in this field or associated fields (the former worldwide, the latter worldwide and nationally) via publications and conference presentations at appropriate fora (such as the BABCP meeting Warwick July 2006 and the AACBT Sydney October 2006 at which I will be presenting). This would ensure, that these professionals would obtain the understanding, framework, and tools that they would need/were looking for to work with this and similar client groups in their own clinical settings and adapt it according to their situation and needs and further built on it. I trust the work commenced is serving this purpose, and will hopefully go on to continue to be developed further, in time to come. These women are certainly deserving of this, and it will provide practitioners with both a great challenge, and eventually, just like me, with a great reward.

CHAPTER EIGHT: REFERENCES

ACSF investigators (1992). Aids and Sexual Behaviour in France. *Nature, 360,* 407-409.

Aittomaki, K., & Eroila, H., & Kajanoja, P.A. (2001). A Population-based Study of the Incidence of Mullerian Aplasia in Finland. *Fertility & Sterility, 76,* 624-625.

APA (2005). The American Journal of Psychiatry – Information for Authors – Patient Perspectives. URL *http://www.ajp.psychiatryonline.org/misc/ifora.shtml*

Baker, P., & Gallant, M.J. (1984). Self-esteem: Measurement Strategies and Problems. *Humboldt Journal of Social Relations, 12* (1), 36-48.

Bandura, A. (1977). *Social Learning Theory.* New Jersey: Prentice Hall.

Barkham, M., & Hardy, G.E., & Startup, M. (1996). The IIP-32: a Short Version of the Inventory of Interpersonal Problems. *British Journal of Clinical Psychology, 35,* 21-35

Baruch, G., & Barnett, R., & Rivers, C. (1983). *Life Prints: New Patterns of Love and Work for Today's Women.* New York: New American Library.

Beck, A.T. (1976). *Cognitive Therapy and the Emotional Disorders.* New York: International Universities Press.

Beck, J.S. (1996). Cognitive Therapy of Personality Disorders. In Salkovskis P.M. (ed) *Frontiers of Cognitive Therapy.* New York: The Guilford Press.

Bem, S.L. (1981). Gender Schema Theory: a Cognitive Account of Sex Typing. *Psychological Review, 88,* 354-364.

Beski, S., & Gorgy, A., & Venkat, G., Craft, I.L., & Edmonds, K. (2000). Gestational Surrogacy: a Feasible Option for Patients with Rokitansky Syndrome. *Human Reproduction, 15* (11), 2326-2328.

Bigler, R.S., & Jones, L.C., & Lobliner, D.B. (1997). Social Categorisation & the Formation of Intergroup Attitudes in Children. *Child Development, 68,* 530-543.

Blascovich, J., & Tomaka, J. (1991). Measures of Self-esteem. In J.P. Robinson, P.R. Shaver and L.S. Wrightsman (Eds) *Measures of Personality and Social Psychological Attitudes. Vol. 1.* San Diego, CA: Academic Press.

Boersma-Heller, J.G. (2001). *Towards a Representation of Participants' Experience of Attenuated Cognitive-behavioural Therapy for Bulimia Nervosa using a Self-help Manual.* Unpublished MSc Counselling Psychology Dissertation. London: City University.

Bonaparte, M. (1953). *Female Sexuality.* New York: International University Press.

Brophy, C.J., Norvell, N.K., & Kiluk, D.J. (1988). An Examination of the Factor Structure and Convergent and Discriminant Validity of the SCL-90-R in an Outpatient Clinic Population. *Journal of Personality Assessment, 52* (2), 334-340.

Brooks-Gunn, J., & Reiter, E.D. (1990). The Role of Pubertal Processes in Early Adult Transition. In S. Feldman and G. Elliott (Eds) *At the Threshold: the Developing Adolescent.* Cambridge MA: Harvard University Press.

Bryan, A.L., & Nigro, J.A., & Counseller, V.S. (1949). One Hundred Cases of Congenital Absence of the Vagina. *Surgery, Gynaecology & Obstetrics, 88,* 79-86.

Buchman, M. (1989). *The Script of Life in Modern Society: Entry into Adulthood in a Changing World.* Chicago: University Press.

Clark, D.M. (1986). A Cognitive Approach to Panic Behaviour. *Research & Therapy, 24,* 461-470.

Clark, D.M. (1997). Panic Disorder and Social Phobia. In D.M. Clark and C.G. Fairburn (Eds) *Science and Practice of Cognitive Behavioural Therapy.* Oxford: Oxford University Press.

Corcoran, K., & Fischer, J. (1994). *Measures for Clinical Practice – A Sourcebook* (3rd ed., vol. 2, Adults) New York: The Free Press.

Cohen, J. (1988). *Statistical Power Analysis for the Behavioural Sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates

Coles, R., & Stokes, F. (1985). *Sex and the American Teenager.* New York: Harper & Row.

Consort Group (2001). Revised Recommendations for Improving the Quality of Reports of Parallel Group Randomised Trials. *JAMA, 285,* 1987-1991.

Counseller, V.S. (1948). Congenital Absence of the Vagina. *Journal of the American Medical Association, 136,* 861-866.

Croak, A.J., Gebhart, J.B., Klingele, C.J., & Lee, R.A. (2003). Therapeutic Strategies for Vaginal Mullerian Agenesis. *The Journal of Reproductive Medicine, 48* (6), 395-401.

David, A., Carmil, D., Bar-David, E., & Serr, M. (1975). Congenital Absence of the Vagina – Clinical and Psychological Aspects. *Obstetrics & Gynecology, 46* (4), 407-409.

Derogatis, L.R., Lipman, R.S., & Covi, L. (1973). SCL-90: an Outpatient Psychiatric Rating Scale: Preliminary Report. *Psychopharmacological Bulletin, 9,* 13-27.

Derogatis, L.R. (1992). *SCL-90-R Administration, Scoring & Procedures Manual – II for the R(evised) Version.* Towson MD: Clinical Psychometric Research.

Dubas, J.S., Graber, J.A., & Petersen, A.C. (1991). A Longitudinal Investigation of Adolescent's Changing Perceptions of Pubertal Timing. *Developmental Psychology, 27,* 580-586.

Dupuytren (1817/1927). In S. Judian The Baldwin Operation for the Formation of an Artifical Vagina: Report of Six Cases. *Surgery, Gynaecology & Obstetrics, 44,* 530-539.

Edmonds, D.K. (2000). Congenital Malformations of the Genital Tract. *Obstetrics and Gynecology Clinics of North America, 27* (1), 49-62.

Edmonds, D.K. (2003). Congenital Malformations of the Genital Tract and their Management. Best Practice and Research in Clinical *Obstetrics & Gynaecology, 17 (1),* 1-18.

Ehlers, A., & Clark, D.M. (2000). *A Cognitive Model of Post-traumatic Stress Disorder. Behaviour Research & Therapy, 38,* 319-345.

Elders, G.H. (1980). Adolescence in Historical Perspective. In J. Adelson (ed) *Handbook of Adolescent Psychology.* New York: Wiley.

Everitt, B.S., & Pickles, A. (2000). *Statistical Aspects of Design & Analysis of Clinical Trials.* London: ICP.

Fagot, B.I., & Leinbach, M.D. (1989). The Young Child's Gender Schema: Environmental Input, Internal Organisation. *Child Development, 60,* 663-672.

Fagot, B.I., & Leinbach, M.D. (1993). Gender-role Development in Young Children: from Discrimination to Labelling. *Developmental Review, 13,* 205-224.

Fairbairn, W.R.D. (1952). Features in the Analysis of a Patient with a Physical Genital Abnormality *In Psycho-analytic Studies of Personality.* London: Tavistock Publications 197-222.

Fairburn, C.G. (1985). Cognitive-behavioural Treatment for Bulimia. In D.M. Garner & P.E. Garfinkel *Handbook of Psychotherapy for Anorexia Nervosa and Bulimia Nervosa.* New York: Guilford Press.

Fallowfield, L., & Jenkins, V. (2004). Communicating Sad, Bad, and Difficult News in Medicine. *Lancet, 363,* 312-319.

Folch, M., Pigem, I., & Konje, J.C. (2000). Mullerian Agenesis: Etiology, Diagnosis, and Management. *Obstetrical and Gynecological Survey, 55* (10), 644-649.

Frank, R.T. (1938). The Formation of an Artificial Vagina without Operation. *American Journal of Obstetrics & Gynecology, 35,* 1053.

Frank, A.W. (1995). *The Wounded Storyteller.* Chicago: The University of Chicago Press.

Freud, S. (1932/3). *New Introductory Lectures on Psycho-analysis.* New York: W.W. Norton.

Garner, D.M., Olmstead, M.P., & Polivy, J. (1983). Development and Validation of a Multi-dimensional Eating Disorder Inventory for Anorexia & Bulimia Nervosa. *International Journal of Eating Disorders, 2,* 15-34.

Garner, D.M., & Garfinkel, P.E. (1997). *Handbook of Treatment for Eating Disorders.* London: Guildford Press.

Ghirardini, G., & Popp, L.W. (1995). The Mayer-von Rokitansky-Küster-Hauser Syndrome (Uterus Bipartitus Solidus Rudimentarius cum Vagina Solida): the Development of Gynecology through the History of a Name. *Clin. Exp. Obst. Gyn, 22* (1), 86-91.

Gilbert, P. (2001). Evolutionary Approaches to Psychopathology: the Role of Natural Defences. *Australian and New Zealand Journal of Psychiatry, 35,* 17-27.

Glaser, B.G., & Strauss, A. (1967). *The Discovery of Grounded Theory – Strategies for Qualitative Research.* Chicago: Aldine.

Goldfarb, J.M., Austin, C., & Peskin, B. (2000). Fifteen Years of Experience of Working with In-vitro Fertilisation, Surrogate Gestational Pregnancy Programme. *Human Reproduction, 15,* 1075-1078.

Golkaramnay, V., Wangemann, T., Dogs, J., Dogs, P., & Kordy, H. (2003). New Bridges for Gaps in Psychotherapeutic Service Provision by the Internet: Hopes, Challenges and a Solution. *Psychotherapy Psychosomatic Medicine Psychology, 53,* 399-405.

Goy, R.W., & McEwen, B.S. (1990). *Sexual Differentiation of the Brain.* Cambridge: MIT Press.

Green, R. (1974). *Sexual Identity Conflict in Children & Adults.* New York: Basic Books.

Greenacre, P. (1950). Sexual Problems of Early Female Sexual Development. *Psycho-analytic Study of the Child, 5,* 122-138.

Greenacre, P. (1958). Early Physical Determinants in the Development of the Sense of Identity. *Journal of the American Psycho-analytic Assocciation, 6,* 612-627.

Greenberger, D., & Padesky, C.A. (1995). *Mind over Mood: Change How you Feel by Changing the Way you Think.* New York: Guilford Press.

Haffner, D.W. (1995). *Facing the Facts: Sexual Health for Adolescents - National*

Commission on Adolescent Sexual Health. USA: Sexuality Information & Eduction Council of the United States (SIECUS).

Hall, G.S. (1904). *Adolescence: its Psychology and its Relations to Physiology, Anthropology, Sociology, Sex, Crime, Religion & Education (Vols 1-2).* New York: Appleton-Century-Crofts.

Hauser, G.A., & Schreiner, W.E. (1961). Das Mayer-Rokitansky-Küster-Syndrom, Uterus Bipartitus Solidus Rudimentarius cum Vagina Solida. *Schweizerische Medizinische Wochenschrift, 12,* 381-384.

Hecker, B.R., & McGuire, L.S. (1977). Psychosocial Function in Women Treated for Vaginal Agenesis. *American Journal of Obstetrics & Gynecology, 129* (5), 543-547.

Hendrix, C.C., Jurich, A.P. & Schumm, W.R. (1994). Validation of the Impact of Event Scale on 2 Samples of American Vietnam Veterans. *Psychological Reports, 75,* 321-322.

Hines, M., Ahmed, S.F., & Hughes, I.A. (2003). Psychological Outcomes and Gender-related Development in Complete Androgen Insensitivity Syndrome. *Archives of Sexual Behaviour 32* (2), 93-101.

Holt, R.E., & Slade, P. (2003). Living with an Incomplete Vagina and Womb: an Interpretative Phenomenological Analysis of the Experience of Vaginal Agenesis. *Psychology, Health & Medicine, 8* (1), 19-23.

Horowitz, M., Wilner, A., & Alvarez, W. (1979). Impact of Events Scale: A Measure of Subjective Stress. *Psychosomatic Medicine, 41,* 209-218.

Horowitz, M.J. (1986). *Stress Response Syndromes.* Northvale NJ: Aronson.

Janoff-Bulman, R. (1992). *Shattered Assumptions: Towards a New Psychology of Trauma.* New York: Free Press.

Jensen, V.K., & Reiter, S.L. (1999). Psychosocial Aspects of Congenital Female Tract Anomalies. In G. Gidwana & T. Falcone (Eds) *Congenital Malformations of the Female Gential Tract: Diagnosis and Management.* Philadelpia: Lippincott Wiliams & Wilkins.

Kagan, J. (1970). The Determinants of Attention in the Infant. *American Scientist, 58,* 298-306.

Kaplan, E.H. (1968). Congenital Absence of the Vagina – Psychiatric Aspects of Diagnosis and Management. *New York State Journal of Medicine, 14,* 1937-1941.

Kaplan, E.H. (1970). Congenital Absence of the Vagina. *Psychoanalytic Quarterly, 39,* 52-70.

Kennedy, B.L., Morris, R.L., Pedley, L.L., & Schwab, J.J. (2001). The Ability of the Symptom Checklist SCL-90 to Differentiate Various Anxiety and Depressive Disorders. *Psychiatric Quarterly, 72, 3,* 2001.

Kestenberg, J.G. (1956a). Vicissitudes of Female Sexuality. *Journal of the American Psycho-analytic Assocociation, 4,* 453-476.

Kesterberg, J.S. (1956b). On the Development of Maternal Feelings in Early Childhood. *Psycho-analytic Study of the Child, 11,* 257-291.

Kiger, J.A., & Murphy, S.A. (1987). A Reliability Assessment of the Symptom Checklist-90-R. Suitability for Postdisaster Bereaved and Non-loss Study Samples. *West. J. Nurs. Res., 9* (4), 572-588.

Kipke, M.D. (1999). *Adolescent Development and the Biology of Puberty.* Washington:

National Academy Press.

Kline, P. (1981). *Fact & Fantasy in Freudian Theory.* London: Methuen.

Kordy, H., Percevic, R., & Martinovich, Z. (2001). Norms, Normality, and Clinical Significant Change: Implications for the Evaluation of Treatment Outcomes for Eating Disorders. *International Journal of Eating Disorders, 30* (2), 176-186.

Kübler-Ross, E. (1970). *On Death & Dying.* London: Tavistock

Kulka, R.A., Schlenger, W.E., Fairbank, J.A., Jordan, B.U., Hough, R.L., Marmar C.R., & Weiss, D.S. (1990). *Trauma and the Vietnam War Generation: Report of Findings from the National Vietnam Veterans Readjustment Study.* New York: Brunner Mazel.

Küster, H.Z. (1910). Uterus Bipartitus Solidus Rudimentarius Cum Vagina Solida. *Z. Geburtshilfe Gynaekol., 67,* 692-718.

Landau, S., & Everitt, B.S. (2004). *A Handbook of Statistical Analysis using SPSS.* London: Chapman & Hall/CRC.

Lange, A. (1994). Writing Assignments with Families Managing Legacies of Extreme Traumas. *Journal of Family Therapy, 18* (4), *373-388.*

Langer, M., Grünberger, W., & Ringer, M. (1990). Vaginal Agenesis and Congenital Adrenal Hyperplasia – Psychological Sequelae of Diagnosis & Neovagina Formation. *Acta Obstet. Gynecol. Scand., 69* (4), 343-349.

Liao, L.M. (2003). Learning to Assist Women Born with Atypical Genitalia: A Journey Through Ignorance, Taboo & Dilemmas. *Journal of Reproductive and Infant Psychology, 21 (3),* 229-238.

Mallinckrodt, C.H., Scott Clark, W., Carroll, R.J, & Molenberghs, G. (2003). Assessing Response Profiles for Longitudinal Clinical Trial Data with Subject Dropout under Regulatory Considerations - Technical Report 0221. URL: *http://www.stats.ucl.ac.bc/IAP.*

Mamdani, M., Sykora, K., Li, P., Normand, S-L. T., Streiner, D.L., Austin, P.C., Rochon, P.A., & Anderson, G.M. (2005). Readers Guide to Critical Appraisal of Cohort Studies: 2. Addressing Potential for Confounding. *British Medical Journal, 330,* 960-962.

Martin, C.L., Ruble, D.N., & Szkrybalo, J. (2004). Recognising the Centrality of Gender Identity & Stereotype Knowledge in Gender Development and Moving toward a Theoretical Integration: Reply to Bandura & Bussey (2004). *Psychological Bulletin, 130* (5), 702-710.

Martinez, S., Stillerman, L., & Waldo, M. (2005). Reliability and Validity of the SCL-90-R With Hispanic College Students. *Behavioural Sciences, 27,* 254-264.

Masica, D.N., Money, J., & Ehrhardt, A.A. (1971). Fetal Feminisation and Female Identity in the Testicular Feminising Syndrome of Androgen Insensitivity. *Archives of Sexual Behaviour 1* (2), 131-142.

Masters, W.H., & Johnson, V.E. (1961). The Artificial Vagina: Anatomic, Physiological, Psychosexual Function. *West. Jnl. Surg. Gyn. Obs., 59,* 192-212.

Mayer, C.A.J. (1829). Uber Verdoppelungen des Uterus und Ihre Arten, nebst Bemerkungen Uber Hasenscharte und Wolfsrachen. *J. Chir. Augenheilkunde, 13,* 525-564.

McGinn, L.K., & Young, J.E. (1996). Schema-Focused Therapy. In Salkovskis P.M. (ed) *Frontiers of Cognitive Therapy.* New York: The Guilford Press.

Meinert, C.L. (1986). *Clinical Trials – Design, Conduct & Analysis.* New York: Oxford University Press.

Mitchell, J. (1982). *Feminine Sexuality.* Macmillan Academy and Professional Ltd.

Möbus, V., Sachweh, K., Knapstein, P.C., & Kreienberg, R. (1993). Women after Surgically Corrected Vaginal Aplasia: a Follow-up of Psychosexual Rehabilitation. *Geburtshilfe Frauenheilkunde, 53* (2), 125-131.

Mohr, D.C., Beutler, L.E., Engle, D., Shoham-Salomon, V., Bergan, J., Kaszniak, A.W., & Yost, E.B. (1990). Identification of Patients at Risk for Non-response and Negative Outcome in Psychotherapy. *Journal of Consulting & Clinical Psychology, 58,* 622-628.

Money, J., Hampson, J.G., & Hampson, J.L. (1957). Imprinting and the Establishment of Gender Role. *Arch. Neurol. Psychiatry, 77,* 333-336.

Moorey, S. (1996). Cognitive Therapy in Adverse Life Circumstances. In Salkovskis P.M. (ed) *Frontiers of Cognitive Therapy.* New York: Guilford Press.

MRC (2002). A Framework for Development & Evaluation of RCT's for Complex Interventions to Improve Health. England: MRC Website; URL *http://www.mrc.ac.uk/pdf-mrc_cpr.pdf.*

Muran, J.C., Segal, Z.V., Wallner A., Samstag, L., & Crawford, C.E. (1994). Patient Pre-treatment, Interpersonal Problems and Therapeutic Alliance in Short-term Cognitive Therapy. *Journal of Consulting and Clinical Psychology, 62,* 185-190.

Nadarajah, S., Quek, J., Rose, G.L., & Edmonds, D.K. (2005). Sexual Function in Women Treated with Dilators for Vaginal Agenesis. *Journal of Pediatrics & Adolescent Gynecology, 18,* 39-42.

Newman, E., Kaloupek, D.G., & Keane, T. (1996). Assessment of Post-traumatic Stress Disorder in Clinical and Research Settings. In B.A. van der Kolk, A.C. McFaerlane & L. Weisaeth *Traumatic Stress: the Effects of Overwhelming Experience on Mind and Body.* New York: Guilford Press.

Nicholson, S. (1995). The Narrative Dance – A Practice Map of White's Therapy. *The Australian & New Zealand Journal of Family Therapy, 16* (1), 23-28.

Niederland, W.G. (1965). Narcissistic Ego Impairment in Patients with Early Physical Malformations. *Psycho-analytic Study of the Child, 20,* 518-534.

Normand, S-L.T., Sykora, K., Li P., Mamdani, M., Rochon, P.A., & Anderson, G.M. (2005). Readers' Guide to Critical Appraisal of Cohort Studies: 3. Analytic Strategies to Reduce Confounding. *British Medical Journal, 330,* 1021-1023.

NSCAG (2003/4 & 2004/5). Reports to NSCAG of the Psychological Services Provided Over the Period March 2003-April 2004 & March 2004-April 2005 at The National Centre for Adolescent and Adult Women with Congenital Abnormalities of the Genital Tract. London: Queen Charlotte's & Chelsea Hospital.

Obeidallah, D.A., Brennan, R.T., Brooks-Gunn, J., Kindlon, D., & Earls, F. (1999). *Socio-economic Status, Race & Girl's Pubertal Maturation: Results from PHDCN.* Chicago: N.I.J.

Padeksy, C.A. (1994). Schema Change Processes in Cognitive Therapy. *Clinical Psychology & Psychotherapy, 1* (5), 267-278.

Pennebaker, J.W. (1997). *Opening up: the Healing Power of Expressing Emotions.* New York: Guilford Press.

Pennebaker, J.W. (2004). *Writing to Heal: a Journal for Recovering from Trauma &*

Emotional Upheaval. Oakland CA: New Herbinger Publications.

Petersen, A.C. (1988). Adolescent Development. *American Review of Psychology, 39,* 583-607.

Persons, J.B. (1989). *Cognitive Therapy in Practice: a Case Formulation Approach.* New York, NY, USA: W.W. Norton and Co. Inc.

Petrozza, J.C., Gray, M.R., Davis, A.J., & Reindollar, R.H. (1997). Congenital Absence of the Uterus and Vagina is not Commonly Transmitted as a Dominant Genetic Trait: Outcomes of Surrogate Pregnancies. *Fertility & Sterility, 67,* 387-389.

Piaget, J. (1952). *The Origins of Intelligence in Children.* London: Routledge & Kegan Paul.

Pocock, S.J. (1983). *Clinical Trials – A Practical Approach.* Chichester: John Wiley & Sons.

Poland, M.L., & Evans, T.N. (1985). Psychological Aspects of Vaginal Agenesis. *Journal of Reproductive Medicine, 30* (4), 340-344.

Rachman, S. (1980). Emotional Processing. *Behaviour Research & Therapy, 18,* 51-60.

Rennie, D., & Brewer, L. (1987). A Grounded Theory of Thesis Blocking. *Teaching of Psychology, 14,* 10-16.

Robson, S., & Oliver, G.D. (2000). Management of Vaginal Agenesis: Review of 10 Years Practice in a Tertiary Referral Centre. *Aust. NZ. J. Obstet. & Gynaecology, 40 (4),* 430-433.

Rochon, P., Gurwitz, J.H., Sykora, K., Mamdani, M., Streiner, D.L., Garfinkel, S., Normand, S-L.T., & Anderson, G.M. (2005). Readers' Guide to Critical Appraisal of Cohort Studies: 1. Role & Design. *British Medical Journal, 330,* 895-897.

Rock, J.A., Reeves, L.A., Retto, H., Baramki, T.A., Zacur, H.A., & Jones, H.W. (1983). Success Following Vaginal Creation for Mullerian Agenesis. *Fertility & Sterility, 39* (6), 809-813.

Rokitansky, C. (1838). Uber die Sogenannten Verdoppelungen des Uterus. *Med. Jahrb. Ost. Staat., 26,* 39-77.

Rosenberg, M. (1965). *Rosenberg Self Esteem Scale (RSE), Society and Adolescent Self-image.* Princeton NJ: Princeton University Press.

Rothbaum, B., & Foa, E.B. (1996). Cognitive-behavioural Therapy for Post-traumatic Stress Disorder. In B.A. van der Kolk, A.C. McFaerlane & L. Weisaeth (Eds) *Traumatic Stress: the Effects of Overwhelming Experience on Mind and Body.* New York: Guilford Press.

Sabbath, J., Morris, T.A., Ludwig, A.O., Menzer-Benaron, D., & Sturgis, S.H. (1962). Congenital Anomalies. In S.H. Sturgis (Ed) *The Gynaecological Patient – a Psycho-endocrine Study.* New York: Grune & Stratton.

Salkovskis, P.M. (1996). *Frontiers of Cognitive Therapy.* New York: Guilford Press.

Sandler, J., Dare, C., & Holder, A. (1970). Basic Psycho-analytic Concepts: IX Working Through. *British Journal of Psychiatry, 117,* 617-621.

Sargis, H.T., Wylie, B., Thomay, W.S., & Kalani, H. (1960). Construction of a Functional Vagina, a New Surgical Approach in Congenital Absence of the Vagina. *American Journal of Obstetrics & Gynecology,* 67-72.

Scales, P.A. (1991). *Portrait of Young Adolescents in the 1990's: Implications for Healthy Growth and Development.* North Carolina: Center for Early Adolescence, University of North Carolina at Chapel Hill.

Schalet, A. (2004). Must We Fear Adolescent Sexuality. Medscape General Medicine, 6 (4); URL *http://www.medscape.com/viewarticle/494933_print (1of 22).*

Schmidt, U., Evans, K., Tiller, J., & Treasure, J. (1995). Puberty, Sexual Milestones and Childhood Sexual Abuse: How are they Related in Eating Disorder Patients? *Psychological Medicine, 25,* 413-417.

Schmidt, U., & Treasure, J. (1998). *Workbook: Motivational Enhancement Therapy.* Unpublished manuscript. London: OEDU, Maudsley Hospital.

Schmitz, N., Hartkamp, N., Kruse, J., Franke, G.H., Reister, G. & Tress, W. (2000). The Symptom Check-List-90-R (SCL-90-R): a German Validation Study. *Qual. Life Res., 9* (2), 185-193.

Schmitz, N., Kruse, J., Heckrath, C., Alberti, L., & Tress, W. (1999). Diagnosing Mental Disorders in Primary Care: The General Health Questionnaire (GHQ) and the Symptom Check List (SCL-90-R) as Screening Instruments. *Soc. Psychiatry Psychiatr. Epidemiol., 34* (7), 360-366.

Schoutrop, M., Lange, A., Duurland, C., Bermond, B., Sporry, A., de Goederen, A. (1997). The Effect of Structured Writing Assignments on Reprocessing Traumatic Events: an Uncontrolled Trial. *Journal of Clinical Psychology and Psychotherapy, 4* (3), 179-185.

Schwarzwald, J., Solomon, Z., Weisenberg, M., & Mikulincer, M. (1987). Validation of the Impact of Events Scale for Psychological Sequelae of Combat. *Journal of Consulting & Clinical Psychology, 55,* 251-256.

See, L. (2005). *Snowflower and the Secret Fan.* London: Bloomsbury.

Silver, R.C., & Wortman, C.B. (2001). The Myths of Coping with Loss Revisited. In Stroebe M.S. & Hanson R.O. & Stroebe W. & Schut H. (eds) *Consequences, Coping and Care.* Washington DC: APA.

Sloan, I.H., Rozensky, R.H., & Kaplan, L. (1994). A Shooting Incident in an Elementary School: Effect of Workers Stress on Public Safety, Mental Health, and Medical Personnel. *Journal of Traumatic Stress, 7,* 565-574.

Slijper, F.M.E., Frets, P.G., Boehmer, A.L., Drop, S.L., & Niermeijer, M.F. (2000). Androgen Insensitivity Syndrome (AIS): Emotional Reactions of Parents and Adults to Clinical Diagnosis of AIS and its Confirmation by Androgen Receptor Gene Mutation Analysis. *Hormone Research, 53,* 9-15.

Smolka, H. (1962). The Indication for Construction of an Artificial Vagina in Vaginal Aplasia, from a Psychological and Socialogical Viewpoint. *Geburts. und Frauenheilkunde. 22,* 1187-1190.

Stattin, H., & Magnusson, D. (1990). *Pubertal Maturation in Female Development.* Hillsdale NY: Lawrence Erlbaum Associates.

Sternbach, R. (1987). *Mastering Pain.* London: Arlington Books.

Stoller, R.J. (1964). The Hermaphrodite Identity of Hermaphrodites. *J. Nerv. Ment. Dis. 139,* 453-457.

Strubbe, E.H., Cremer, C.W., & Willemsen, W.N. (1994). The Mayer-Rokitansky-Kuster-Hauser Syndrome, without and with Associated Features: Two Separate Entities? *Clinical Dysmorphology, 3,* 192-199.

Sundin, E.C., & Horowitz, M.J. (2002). Impact of Event Scale: Psychometric Properties. *The British Journal of Psychiatry, 180,*205-209.

Tanner, J.M. (1989). Foetus *into Man: Physical Growth from Conception to Maturity*

(2^{nd} Edition). Ware: Castlemead Publications.

Teasedale, J.D., & Barnard, P.J. (1993). *Affect, Cognition & Change: Re-modelling Depressive Thought.* Hove: Lawrence Erlbaum Associates.

Teasdale, J.D. (1997). The Relationship Between Cognition and Emotion: The Mind-in-place in Mood Disorders. In D.M. Clark & C.G. Fairburn (Eds) Science and Practice of Cognitive Therapy. Oxford: Oxford Medical Publications.

Turunen, A. (1952). Congenital Absence of the Vagina. *Annales Chirurgiae et Gynaecologiae Fenniae, 46,* 125-142.

Vecchietti, G., & Ardillo, L. (1970). *La Sindrome di Rokitanksy-Kuster-Hauser, Fisiopatologia Clinica Dell'aplasie Vaginale con Corni Uterini Rudimentali.* Roma: Soc. Ed. Universo.

Weeks, J. (1986). *Sexuality.* Chichester: Ellis Harwood & Tavistock.

Weiss, D.S., & Marmar, C.R. (1997). The Impact of Event Scale-Revised. In J.P. Wilson & T.M. Keane (Eds.) *Assessing Psychological Trauma and PTSD p399-411.* New York; Guilford Press.

Weijenborg, Ph.Th.M., van Dijk, J.G., & van Hall, E.V. (1986). The Mullerian Agenesis Syndrome: I am It. In L. Dennerstein & I. Fraser (Eds) *Hormones and Behaviour.* Amsterdam: Exerpta Medica.

Weijenborg, P.T.M., & ter Kuile, M.M. (2000). The Effect of a Group Programme on Women with the Mayer-Rokitansky-Kuster-Hauser Syndrome. *British Journal of Obstetrics and Gynaecology, 107,* 365-368.

Whitney, J., Murray, J., Gavan, K., Todd, G., Whitaker, W., & Treasure, J. (2005). Experience of Caring for Someone with Anorexia Nervosa: Qualitative Study. *British Journal of Psychiatry, 187,* 444-449.

Wicks, L., Siegert, R.J., & Walkey, F.H. (2004). A Confirmation of the Eight Factor Structure of the Eating Disorders Inventory in a Non-clinical Sample, with New Zealand Norms. *New Zealand Journal of Psychology, 33* (1), 3-7.

Williams, R.M., Hodgkinson, P., Joseph, S., & Yule, W. (1995). Attitudes to Emotion, Crisis Support & Distress 30 Months after the Capsize of a Passenger Ferry Disaster. *Crisis Intervention, 1,* 209-214.

Young, J. E., & Klosko, J.S. (1996). *Reinventing Your Life.* New York: Penguin Books.

Zilberg, N.J., Weiss, D.S., & Horowitz, M.J. (1982). Impact of Events Scale: a Cross-validation Study and some Empirical Evidence Supporting a Conceptual Model of Stress Response Syndromes. *Journal of Consulting and Clinical Psychology, 50,* 407-414.

SECTION C

CRITICAL
LITERATURE REVIEW

CHAPTER NINE: COGNITIVE-BEHAVIOURAL THEORY IN ANOREXIA NERVOSA AS APPLIED IN/TO THERAPY: A REVIEW[1] - *Loss of a sense of self into an anorexic identity & female thinness in adolescence & beyond*

9.1. Background to this Paper:

Anorexia nervosa (AN) has been known in the Western and non-Western world throughout the ages, however, became more specifically medicalised in the later half of the 19th century with the publication of the accounts of the physician Gull (1874) & Laseque (1873). Anorexia is considered to form a quintessentially women's disorder, as only 4% of those suffering from AN are male. It typically effects young women (of all social classes) within a few years of their menarche (median age onset 17) and represents the third most common condition in adolescence (Lucas, Beard & O'Fallon, 1991). The mean incidence of anorexia in the general population, estimated from 12 cumulative studies, is 19 per 100,000 a year in females and 2 per 100,000 a year in males (Pawluck & Gorey, 1998). Van Hoeken, Lucas & Hoek (1998) reviewing the prevalence of Anorexia in Western women, estimate it to range from 0.1-1%. Although earlier research suggested that AN might recently have increased in frequency, this is no longer thought to be the case (Fombonne, 1995; Turnbul, Ward, Treasure, Jick & Derby, 1996). Psychologically and socially AN can bring about wide ranging problems both for the person affected and their family, friends, teachers and colleagues (Schmidt, Tiller & Morgan, 1995). The medical consequences of starvation and progressive weight loss can

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[1] This review was written during my Post-MSc Counselling Psychology training in September 2002, and was slightly modified for inclusion in this portfolio. However, it was not updated in terms of including more current contributions to the field that may have been published between September 2002 and now (May 2006), due to time constraints.

be severe, including leucopenia, arrhytmias, prolonged QT intervals, endocrine abnormalities and osteoporosis, to name a few. AN is arguably the most lethal of psychiatric illnesses, as the all cause standardised mortality rate of Anorexia is three times higher than that of other psychiatric illnesses. As many as 15-18% of anorexic patients eventually succumb to (the medical complications of) starvation or suicide (Harri & Barraclough, 1998; Sullivan, 1995).

The existence of AN, as a severe mental and potentially fatal illness, has generated the need for the development of a theoretical model explaining the disorder, whilst in the main providing a rationale for the design of a framework of care. Kaplan (2002) in a review of the existing literature on the psychological treatment of AN, suggests that over the last 30 years, little progress has been made in developing new, effective treatments for the disorder. He states that the appropriate treatment for AN is still the subject of much debate. This is unlike its sister condition Bulimia Nervosa (BN), for which a clear model of Cognitive-behavioural theory and treatment has been developed (Fairburn, 1997). Cognitive-behavioural theory, in its most general sense, includes principles of learning (Wolpe, 1958) (i.e. behavioural theory), and the general idea that ones' emotions are influenced by ones' thought and that emotional disorders result from particular interpretations of events (Beck, 1985 & 1976) (i.e. cognitive theory). In its more specific sense, it aims to explain the development and maintenance of the most important cognitive and behavioural aspects of a disorder. To in doing so, provide (a) a model of the development and maintenance of the disorder (with a possible overlap between both maintenance and development); (b) devise a set of treatment procedures that focus on the core pathology of the disorder, and reversing its maintaining factors; and (c) provide an application to treatment that follows from the theory/model proposed, or propose a Cognitive-behavioural-therapy of the disorder (Clark, 1997). Fairburn's (1997) specific premise for BN was that these women judge self-worth largely, or even exclusively in terms of shape and weight[2]

Kaplan (2002) in his review of the existing literature on the psychological treatment of AN, furthermore, notes that the early theoretical contributions to the field of AN were primarily developed on the basis of clinical observations and anecdotal reports. He also states that few Randomised Controlled Trials (RCTs) in support of these theories, as applied to therapy, have been conducted in the more than 125 years that have passed since the first recorded clinical description by Gull (1874) & Laseque (1873) of AN, and that these have only yielded equivocal results (Kaplan, 2002). Though, Cooper (1997) in a review of cognitive theories of AN as they are usually applied to treatment, states that more recently, empirical evidence has been collected to test the different aspects/components of these theories.

9.2 Rationale for and Aims of this Paper:

Considering the existence of (a) AN as a severe mental and potential fatal illness, the need for a theoretical model explaining the disorder and a framework of care, as well as (b) Kaplan's (2002) negative review of the area, (c) Fairburn's (1997) Cognitive-

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[2] Which lead to characteristic extreme & rigid dieting, characterised by rigid rules, which could be easily violated, due to dichotomous ways of thinking, the physiological, and psychological effects of dietary restraint. This leads to episodes of subjective overeating, making the patient feel better in the short-term, but in the long-term leading to a renewed effort to curb food, reinforcing further concerns about shape and weight. Here "ameliorating" the effect of a binge, through vomiting (as an easy way to get rid of food and "all the calories consumed this way"), only reinforces further binge-eating. Therapy, therefore, focuses on the effects of food restriction and vomiting, and the cognitions underlying these etc.

behavioural explanation of, and treatment for, its sister condition BN, and (d) Cooper's (1997) observations; it was felt that it would be helpful to conduct a systematic review of the literature with the aim to answer the following questions:

A. What are the actual early contributions of cognitive-behavioural theories of AN to the understanding of the development and maintenance of the most important cognitive and behavioural aspects of AN, - its core pathology.

B. Following from these models, what is their suggested framework for focusing on the core pathology and reversing its maintaining factors/i.e. their application to treatment; the Cognitive-behavioural-therapy that follows from the theory/model proposed.[3]

C. What are the more recent theoretical (Cognitive-behavioural) contributions to the field of AN.

D. What is the empirical evidence that has been collected to test treatment based on a Cognitive-behavioural model, possibly in the form of any RCTs that have been conducted. - Evaluation of models I.

E. What is the more recently gathered evidence regarding the different aspects of the cognitive theories of AN developed. – Evaluation of models II.

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[3] Question A & B are taken together in point 3, as it seemed logical, to ensure flow, and for ease of reading. However, A & B are separately posed above, as they form separate, yet related questions.

F. What are the limitations of the existing models outlined, gaps in knowledge, research & clinical implications. – Evaluation of models III.

G. What conclusions can be drawn.

In addressing the above outlined questions, this chapter aims to clarify what the Cognitive-behavioural theories of AN as applied to therapy are, their varied emphasis, the relevant research. To create some order in what can be a bewildering and baffling amount of data, whilst aiding understanding and evidence based clinical practice of counselling psychologists working with sufferers of AN in a range of community, primary care, and acute settings.

With the above questions in mind, PubMed (Science Direct/Medline) & PsycINFO searches were conducted, with hand searches of the reference section of all articles, books and chapters retrieved by computer and hand search. The following search terms were used: Anorexia (and) Nervosa, and cognitive and/or behavioural, and theory or treatment; Anorexia Nervosa, and recent, and theoretical, and contributions; empirical, and evidence, and for, and cognitive-behavioural, and treatment, and for, and Anorexia Nervosa; evidence, and for, and aspects, and of, and cognitive-theory, and Anorexia Nervosa.

All titles, abstracts and the full articles were evaluated by J.G. Heller for potential relevance. Some information is from the English translation of a work originally published in Russian (Marilov, Crisp & Ben-Tovim, 2000) that J.G. Heller had translated by a friend who is both fluent in English and Russian. Other foreign articles were excluded (i.e. articles written in Polish, Chinese, Spanish etc.).

Sources were included if they discussed issues pertaining to the above points, however, were excluded if they discussed theory & therapy other than proposing a cognitive-behavioural model, such as psychodynamic or family therapy approaches, or engaged in a discussion of cultural aspects of AN or neuropsychological aspects etc. 152 sources were found, 63 of these were judged to include material relevant to the review, providing possibly answers to the questions posed above.

The following emerges from these sources, to the questions posed.

9.3 What are (a) the Actual Early Contributions of Cognitive-behavioural Theories of AN to the Understanding of the Development and Maintenance of the most Important Cognitive and Behavioural Aspects of AN, - its Core Pathology. And (b) what is their Suggested Framework for Focusing on the Core Pathology and Reversing its Maintaining Factors.

Looking at the work of the authors: Bliss & Branch (1960); Crisp (1965); Farguharson & Hyland (1966); Dally (1969); Rowland (1970); Theander (1970); Bruch (1973, 1977, 1978); Galdston (1974); Carper & David (1977); Hausermann, Lavin (1977); Garner & Garfinkel (1978 & 1980); Garfinkel, Moldofski, Garner, Stancer & Coscina (1978); Beck & Emery, (1979); and Hollon & Beck (1979), - provides answers to some aspects of this question. But, more particularly, firstly, Garner & Bemis (1982/85), secondly, Bemis (Vitousek) & Hollen (1990) (including Garner, Vitousek & Pike 1997; Vitousek, Watson & Wilson 1998), and, thirdly, Slade (1982), (including Slade & Duker, 1988), provide a more complete answer to this question. These authors have become known for the theories that they proposed of AN and the treatment/therapy that they suggest that flows from this. These are described in section 9.3.1, 9.3.2 & 9.3.3 in detail, as follows.

9.3.1 Garner & Bemis (1982/85):

The role of cognitions in AN has been implicitly recognised for a long time. Clinical observations by Bliss & Branch (1960), Bruch (1973, 1977, 1978), and Galdston (1974) frequently mentioned the unusual beliefs expressed by AN patients, their disturbance of the way that they experienced their body shape and weight, expressed in a relentless pursuit of thinness, and phobic dread of becoming fat and a denial of the serious implications of continual weight loss. The presence of these features are indeed required to make a diagnosis of AN, alongside a refusal to maintain at least 85% of normal body weight and amenorrhea in post-menarchal girls and women (DSM-V - APA, 1994). The observations reported, highlighted the possible importance of maladaptive thinking in the development of AN. This implicit recognition of the role of cognitive variables was turned into a formal CBT model of AN by Garner & Bemis in a seminal paper in 1982. The theory proposed, took as its fundamental premise the patient's central belief that "they must become thin". Having reviewed the varied etiological theories of AN previously developed, they accounted for the proximal sources of this belief to lay in a series of events or experiences that converged and led to this conclusion on the part of the Anorexic patient.

Garner & Bemis (1982) state that the literature suggests that the potential AN patient is typically introverted, sensitive and isolated, trying to live up to the expectations of others, by the time they reach adolescence (Bliss & Branch, 1960; Bruch, 1973, 1978; Crisp, 1965; Dally, 1969: Farguharson & Hyland, 1966; Rowland, 1970; Theander, 1970). In the interval immediately preceding the onset of anorexic symptoms, such individuals may become withdrawn, feel helpless and perhaps depressed, experiencing a loss of control (Bruch, 1978; Casper & Davis, 1977). This episode may be precipitated by an external stressor such as an interpersonal conflict or a change of living situation, or by a developmental crisis triggered by the emergence of secondary sexual characteristics and menarche. In the midst of this period of dysphoria and social isolation, those who will become anorexic arrive at the idea that losing weight will somehow alleviate their distress. In a culture that has made slenderness the chief attribute of female beauty, young women who are plagued by self-doubts may conclude that the elusive answer to their perceived deficiencies rests with the attainment of a figure that would be envied by all (Bliss & Branch, 1960; Dally, 1969; Garner & Garfinkel, 1978, 1980). Struggling with a pervasive sense of inadequacy and impotence, they are delighted by the discovery that their figures and appetites are among the few things over which they can exercise control, and they derive a great feeling of power from their self-restraint (Bruch, 1973, 1978; Casper & Davis, 1977). Garner & Bemis (1982) propose that alongside this positive self-reinforcement, which contributes to the maintenance of the anorexic behaviour from the start, many patients receive environmental support for their behaviour in the initial stages of dieting. However, once the idea that thinness is of paramount importance has been firmly established, external reinforcement becomes less significant as the complex of anorexic beliefs and behaviours may become functionally autonomous. As a corollary anxiety about eating becomes more prominent, it develops into a phobic orientation towards food and weight gain. This further strengthens the anorexic system through the negative reinforcement of avoiding feared situations. Gradually, the patient's preoccupation with issues related to eating and weight excludes other considerations and decreases responsiveness to external stimuli. Whilst the effect of habit as well as starvation, which includes poor concentration/concrete thinking, rigidity, social withdrawal, anxiety, depression and emotional lability, aggravates this problem further (Bemis, 1978; Bruch, 1973; Casper & Davis, 1977; Dally, 1969: Garner & Garfinkel, 1980). Eventually, the system seems to shrink to a single variable, providing its own potent reinforcement. While the baseline is unhappiness, weight loss is the one pleasure that gives relief. Patients have no wish to forego this single gratification and they are incapable of seeing beyond it. Garner & Bemis (1982) assert that the desire of the anorexic patient to retain the focal symptom and even to experience the unpleasant thoughts and emotions to help to maintain it, differentiates anorexia nervosa from the depressive, phobic, and anxiety disorders to which it is often compared.

Garner & Bemis (1982/1985) postulate that the main psychopathological disturbance in these patients are their cognitive distortions, their overvalued ideas about weight, shape & eating. It is assumed that much of the other clinical features can be understood as secondary to, and maintained by such disturbed attitudes (i.e. extreme dietary restraint, resultant weight loss, frequent weighing, preoccupation with food, eating, shape and weight, as well as the compensatory behaviours of self-induced vomiting, laxative abuse – binge/purge sub-type, and excessive exercise – non-purging sub-type), giving rise to cognitive processing biases, and low weight. Behind this, serious deficits in the self are hidden, as expressed in the patient's definition of herself/judging of self-worth in terms of shape and weight. With weight loss becoming the yardstick of self-evaluation and the patient's self-esteem being determined by success in the pursuit of thinness.

Garner & Bemis (1982/85) assert that the above issues need to be addressed in treatment, based on the cognitive-behavioural methods formulated by Beck and his co-workers for depression, phobic and anxiety disorders (Hausermann & Lavin, 1977; Beck & Emery, 1979). Whilst adapting it to take account of the ego-syntonic nature of the illness, and core pathology of the disorder, whilst reversing its maintaining factors. Firstly, they noted that its ego-syntonic nature needs to be addressed, since patients do not regard their disorder as an affliction but as an accomplishment. Their behaviour (starving) and its effects (weight loss, increased thinness) are entirely consonant with their goals (the pursuit of thinness, the avoidance of weight gain and fatness) with the result that they see little need to change and when they do present they often do so reluctantly. This is in stark contrast with the depressed or anxious patient who rarely needs to be convinced that it is desirable to change. Standard cognitive therapy is not equipped to deal with the problem of developing motivation in reluctant clients. However, it is a crucial aspect of the treatment of anorexia nervosa, as it forms a maintaining factor of the illness, alongside the core cognitive psychopathology and the effects of starvation. Therefore, Garner & Bemis (1982) advocate several specific strategies that are compatible with the cognitive model. They state that building a warm and supportive relationship is a pre-requisite in working with anorexic clients. They assert that the therapist should not attempt to challenge, refute, or deride the patient's erroneous assumptions, but accept the patient's beliefs as currently genuine for her. They propose that without disparaging the patient's opinions, it is possible to encourage her to re-examine the practical implications of her belief in thinness and ask her questions which may elicit some misgivings about the consequences of the anorexic creed. Perusing what activities she would have engaged in, had she not developed the disorder, what it is that has motivated her in her endeavours to starve herself etc. To, in doing so develop dissonance between symptoms and patient's beliefs, assumptions, behaviours by examining the internal (in)consistency of these, instead of their validity, utility or wisdom, and summarize and clarifying dilemmas in order to cultivate motivation for change (Vitousek, Watson & Wilson, 1998). In this a particular emphasis is placed on the likely contributions of starvation perse, by educating the patient on the nature of the illness and its risks and course. Linked to this, a discussion about weight stabilization is engaged in, in order to procure at least a modicum of cooperation on setting a target weight (i.e. ideally 90% of the average height-for-weight figure – especially in case of the severely malnourished patient). However, weight gain is not presented as an end in itself but rather as an important initial step in therapy. Behavioural strategies to modify weight control measures are attempted, such as replacing dysfunctional eating patterns with normal eating habits by means of reintroducing avoided foods; practicing eating with friends, relatives; shopping/cooking activities; and develop coping skills to resist binging and purging behaviours. Garner & Bemis (1982) assert that while many of Beck's behavioural strategies help patients overcome their fears, these techniques may be less effective in promoting change, since the object of avoidance in AN is the self at a higher weight, and the anorexic behaviour is maintained by both positive and negative reinforcement. The treatment of anorexia nervosa therefore requires a looking at both the elements of a "fear of fat" and a "desire for thinness". The essence of cognitive work involves teaching patients to elicit their cognitions and examine the validity of their beliefs on a moment-to-moment basis (Hollon & Beck, 1979) by means of operationalising these beliefs and expectations, and evaluating these. Re-examining actual aspects of living, using concrete small events or episodes by means of using the "what if" technique, "decentring", and looking for alternative explanations. In order to both illustrate and reveal certain false assumptions or illogical deductions (systematic distortions) in the processing of events. Additional prospective hypothesis testing, by devising informative experiments and cognitively rehearsing the proposed manipulation can be useful in further de-catastrophising the imagined consequences of feared events. Going "deeper" and searching for general principles that underlie and organize specific irrational thoughts may be engaged in, by means of looking for themes and modifying these basic assumptions, by pointing at exceptions and contradictory information etc. (Garner & Bemis, 1982/85). To in doing this address the core pathology of AN and reverse its maintaining mechanisms.

In relation to the patient's body image disturbance, Garner & Bemis (1982) say that it could be argued that the refractory "self-perception" of anorexic patients do not represent a true perceptual disturbance, but are rather products of the same strong cognitions that support anorexic behaviour patterns. They suggest that rather than deny or challenge the patient's experience by self-confrontation in a mirror etc, the patient be encouraged to reattribute her perception of herself as fat to her illness rather than to the stimulus properties of her own body. She is to use a contrary internal statement that overrides or checks the perception of herself as fat. This may take the form of a counter-argument that says “I am like a colour-blind person trying to coordinate her own wardrobe and need to rely on objective data of someone I can trust to determine my actual size” (Garfinkel, Moldofsky, Garner, Stancer & Coscina, 1978).

9.3.2 Bemis Vitousek & Hollen (1990):

Garner & Bemis’ (1982/85) paper describes what is still the leading cognitive-behavioural account of AN. This has since been elaborated by Vitousek (previously Bemis) and colleagues in a series of articles that have further focused on the role of information processing (Bemis Vitousek & Hollen, 1990), motivation (Vitousek, Watson & Wilson, 1998) etc. The former paper conceptualises AN in terms of schema theory, extending the importance of information processing in AN beyond processes driven by assumptions to processes driven by schemas (organised cognitive structures) and core beliefs. The latter, also becomes the focus of modification in therapy. Bemis Vitousek & Hollen (1990) mapped low self-worth/perfectionism, attitudes to eating/weight/shape and an evaluation of the self in terms of weight and shape onto a disturbance at the level of self-schemata (long-standing negative self-evaluations), weight-related schemata (beliefs about weight & shape) and weight-related self-schemata (self=weight). They proposed that patients develop rigidly organised cognitive structures of their world so that their view of themselves are bound with beliefs about weight, eating and appearance that influence perception, thought, affect and behaviour (Garner, Vitousek & Pike, 1997). I.e. self-worth becomes largely and exclusively judged/valued in terms of weight and shape. These weight-related self-schemata represent the core psychopathology of AN and accounts for its persistence by determining selective attention & memory, as does the tenacity of core beliefs, positive and negative reinforcement effects and the starvation syndrome (which Garner & Bemis, 1982/85 previously attributed the stability of pathological behaviour to). In addition they function to simplify, organise & stabilize the individual's experience of herself and the environment. Providing a concise, inclusive set of rules from which appropriate attitudes and behaviour can be deducted. These hold the promise of control since responsibility for key events is located in the self rather than in the environment, which can provide a great sense of relief. This may be particularly important in patients with AN whose experience of themselves may seem formless and chaotic. Beneath the cognitive clutter of the eating disorder, the superficial notions about eating and weight that fill these patients conscious awareness, this more basic theme, this deeper connotation, can often be discerned (Bemis Vitousek & Hollen, 1990)[4].

9.3.3 Slade (1982):

This basic theme was also eluded to by Slade in a paper published in the same year as the original paper by Garner & Bemis (1982), when he suggested that AN represents a secondary adaptation to a more general set of psychological problems that patients are experiencing (Slade, 1982). He argued that the pursuit of complete control over eating arises in patients in (a) the context of "*general life dissatisfaction*", resulting from a number of developmental/environmental factors (e.g. adolescent conflict such as establishing independence; or interpersonal problems such as social anxiety; or frequent stress and failure experiences such as exams/personal relationships), and (b) "*general*

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[4] All of the above outlined aspects are addressed in therapy, as per previous suggestions by Garner & Bemis (1982/85).

dissatisfaction with self" (low self-esteem & perfectionist tendencies).[5] Linked with this are (c) "*specific psychosocial stimuli*", such as discriminative stimuli for dieting behaviour, e.g. comments from peers/significant others concerning bodily shape and weight, or current Western aesthetic preferences for thinness in women. Slade's (1982) central proposal was therefore that the setting conditions of general life dissatisfaction in the light of low self-esteem and perfectionist tendencies amounted to a perceived sense of little or no sense of self and personal control over events in the world. Slade (1982) asserted that consequently individuals with AN responded to a "need to control absolutely some aspect of their life situation to attain some sense of self and total success in at least one area", by exerting pathological control over their eating behaviour. The latter being the perfect candidate for this, as in the final analysis, it is independent of the behaviour of other people. When every other action is fraught with the possibility of failure, where the rule is one must be an outright winner or one has absolutely failed, where failure and personal inadequacy are not allowed, where the demand is that the individual must be independent and strong, then a food control self comes into its own. These acts of control are straightforward and uncomplicated. They give a sense of supreme autonomy for they are independent of anyone else. Success is measurable, and immediate and belongs unequivocally to the person who has achieved it. Where personhood is food control, then personal fulfillment can be obtained from moment to controlling moment. Certainty of self can be gained in the here and now, here is evidence of doing something "absolutely right", of achieving socially approved ideals. So this food-control self is morally superior, a tangible way of realising perfectionist aims.

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[5] Which according to Duker & Slade (1988) have their source in the values of the "Protestant" or "Work" Ethic.

Having once become control dependent the person's self concept becomes anchored in this (Duker & Slade, 1988).

The above hypothesised antecedent events/variables explaining the development of AN, were incorporated into a (cognitive) behavioural framework, specifying the antecedent elements, including setting conditions and discriminative stimuli. These determine the initial occurrence of the behaviour and also its consequences, including the nature of the reinforcing stimuli, reinforcement history and reinforcement schedules. The latter go on to determine its maintenance, exacerbation and change over time. The proposed lead to a sophisticated behavioural and functional analysis of AN in which the need for control was central (de Silva, 1995). Positive reinforcement in this analysis is not simply seen as a consequence of dieting per se but rather as a function of successful behaviour in the context of perceived failure in all other areas of functioning. Thus it is suggested that successful dieting in other setting conditions would not normally produce the same positive reinforcement effects. Without the major setting conditions, or given success in other areas, dieting behaviour would not receive powerful reinforcement and would not lead on to AN. The AN patients dieting is negatively reinforced, in this analysis through avoidance of the fear of weight gain and alteration of body image, of the social disapproval that comes with weight gain/over-weightness, and avoidance of the problems. I.e. the singe minded preoccupation with food, eating, weight and body size enables the anorexic to avoid direct confrontation with the stressors that preceded the onset of the disorder and any other difficult problems, which forced the major motivation of the anorexic behaviour in the first place (adolescent conflict, interpersonal problems, and stress and failure experiences).

Considering the above, the root task of therapy therefore, is to foster the patient's sense of selfhood away from starvation, i.e. to establish some major sources of positive self-satisfaction/reinforcement other than dieting. Or, to put the opposite case, Slade (1982) suggested that intervention approaches which were focused solely on producing weight gain were unlikely to be effective in the long term. It follows from the former, that apart from keeping the patient alive and in reasonable physical health, treatment should be aimed at encouraging the development of alternative goals: interests, enthusiasm and successful behaviours. A whole new repertoire of behaviours to replace the singe one of anorexic behaviour, i.e. the establishment of independence from and within the family, academic and vocational training, social and leisure interests etc. The more varied the range of activities and interests the greater the probability that the patient would obtain strong positive satisfaction/reinforcement and a sense of self-esteem and mastery in at least one of them. The more the focus is on the relative importance of thinness as a life goal relative to other goals (rather than attempting to modify individual dysfunctional cognitions) the less important the former may become (Duker & Slade, 1998). Thus the anorexic system is dismantled and replaced with more rewarding ways of life. Another therapeutic implication proposed by Slade (1982), concerns the resolution of the antecedent events leading to the development of anorexia in the first place. Each of the areas of adolescent conflict, interpersonal problems and stress/failure experiences needs to be explored and worked with.

The content of 9.3.1, 9.3.2 & 9.3.3 can be summarised, outlining the core psychopathology and maintaining mechanisms identified, and application of the model to treatment/therapy, as represented in table 9.1, overleaf.

Having considered the early contributions of Cognitive-behavioural theories of AN to the understanding of the development and maintenance of the most important cognitive and behavioural aspects of AN, its core pathology, and following from these models what their suggested framework for focusing on the core pathology and reversing maintaining factors are, more recent theoretical (Cognitive-behavioural) contributions need to be addressed, which is done in the following section, through the following question.

9.4 What are the More Recent Theoretical (Cognitive-behavioural) Contributions to the Field of AN:

Wolff & Serpell (1998); Fairburn, Shafran & Cooper (1999); Shafran, Cooper & Fairburn (2002); and Fairburn, Cooper & Shafran (in Press)[6] can be considered to have provided the more recent theoretical contributions to the field of AN. Their theories are described in section 9.4.1, 9.4.2, 9.4.3, & 9.4.4 respectively, noting both theory and its application to treatment, as follows:

9.4.1 Wolff & Serpell (1998):

Wolff & Serpell (1998)[7], modified Garner & Bemis' (1982/85) cognitive behavioural account of AN whilst retaining its central premise that extreme concerns about shape and

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[6] This paper was still in Press in 09/2002 when this review was first written. However, it was subsequently published in 2003

[7] Of the "Maudsley Group", at the Maudsley Hospital Eating Disorder Unit in London, one of the Centres of Excellence in the Field of Eating Disorders.

weight are the core features of the disorder (i.e. a linking of weight/shape schemata -body image-, with self-esteem schemata).[8] They elaborated on the idea that patients develop schemata that mesh a view of self with culturally derived beliefs of the desirability of thinness in women. Noting that in such a context, self becomes linked to being thin and the beliefs of having worth, being special, good and in control. Where the absence of thinness and not being able to control ones' weight, becomes loaded with beliefs about being fat, worthless, bad, and powerless. They note that these could be seen as an interacting cognitive subsystem operating (Teasedale & Barnard, 1993; Teasedale, 1997). In other words; here cognitive schemata are interlinked, and it is not the culturally derived belief about thinness in women that causes distress per se, but the intimacy of its link to self-worth/esteem. This includes ones' specialness/goodness, to others, one's power in society & perceived control over ones' predicament, via the intermediary of the body experience.

Wolff & Serpell (1998) note the relevance of <u>pro-anorexia beliefs</u> in the maintenance of the disorder, such as "If I did not have Anorexia my whole world would fall apart, and <u>metacognitions</u> (Teasedale, 1985), i.e. thoughts about these thoughts; such as "I would then not be able to cope", which go on to impact ambivalence to treatment. They also note the presence of <u>Positive Automatic Thoughts</u> (PATs: such as; "I look more attractive", "I am in control", "I'll be more popular"), linked to body-image self schema in the maintenance of the condition. Furthermore, they outline the effects of <u>+/- reinforcement</u> (+ attention from family; being special; - avoidance of food), dichotomous thinking etc, but particularly safety behaviours, in relation to this. As well as the effects

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[8] Which Bemis Vitousek & Hollen (1990) also alluded to in their extension of the same.

of starvation & rumination. They suggest that starvation driven rumination about food, as well as hunger, dampen emotions. That they inhibit the “mental space” for processing of emotionally charged information. Thus the patient not only experiences cognitive dysfunction, but also an emotional dysregulation. They, finally, refer to any interpersonal elements that effect the maintenance of the disorder, that may need consideration, when patients fail to respond to therapy.

Following from this, therapy involves an assessment of the patient’s main concerns; how the illness effects her, how it developed and the treatment options open to her, with a feedback letter from the therapist to the patient, to foster a shared understanding of what is happening and aid the therapeutic alliance. To, in this start looking at the ‘pros’ and ‘cons’ of change, the pro-anorexia meta-cognitions, the ‘good’ Anorexia provides, but also its ‘costs’. To from this, find activities or ways of being which can begin to replace the Anorexia, by fulfilling some of its functions. To start (challenging &) answering both negative and positive automatic thoughts, and conducting behavioural experiments. Addressing individual negative schema, defining these and plotting the positive dimension of it, placing oneself on it, and then others. Furthermore, a loosening of the connection between linked schema, without directly confronting body image issues. Linked schema can be represented on two dimensions, such as being liked/disliked, being fat/thin, and the patient can plot herself and others on this, possibly being surprised to find a looser connection between the two, than previously thought. The patient may be asked to present how much being thin makes her a special person and to represent that on a pie-chart. The remaining segments represent other factors, and the patient is asked to brainstorm on these and put them into the second pie chart one by one, with a third chart noting what makes other people special. And, finally, to look at any interpersonal element that features in the maintenance of the disorder (Wolff & Serpell, 1998).

9.4.2 Fairburn, Shafran & Cooper (1999):

Fairburn, Shafran & Cooper (1999) synthesised Garner & Bemis (1982) and Slade's (1982) ideas into a single organised framework, by integrating the core features of both accounts, i.e. issues of self control and concerns about shape & weight.

In this account of AN, that is exclusively concerned with the processes that maintain the disorder, it is argued that the central feature is an extreme need for self-control, arising from a general sense of ineffectiveness and perfectionism in the context of low self-esteem. The need for self-control becomes primarily focused on eating, and is reinforced through three main feedback mechanisms, since 1. dietary restriction directly enhances a person's sense of being in control and thereby their self-worth, as highlighted by Slade (1982). 2. This is further exaggerated by the narrowing of interests etc. that accompanies starvation. 3. Extreme concerns about shape and weight encourage dietary restriction, as control over eating, shape and weight are being used as major indices of both self-control in general and self-worth, in the context of a contemporary Western society which places a socio-cultural value on thinness (Garner & Bemis, 1982/85).

By successfully controlling their eating, these individuals are controlling all that is important in their lives. In this way they are also avoiding having to face other difficulties, such as family problems, forming relationships and issues of sex. Successful control in the context of perceived failure and the resulting increase in sense in self-worth, makes dietary restriction highly rewarding and resistant to change. In the longer-term it results in some people beginning to determine themselves in terms of anorexia nervosa. Linking their identity and the disorder, this contributes further to the disorders' ego-syntonic character.

Fairburn, Shafran & Cooper (1999) assert that seeing issues relating to self-control as being at the heart of AN, provides a simple organising principle which accounts for many features of the disorder, including its resistance to change and ego-syntonicity, as Slade's (1982) account did. However, this is then linked to the concerns about shape and weight that Garner & Bemis (1982/85) highlighted, but without placing emphasis on other etiological and maintaining factors. Overvaluation of weight and shape as an important maintaining factor in this theory is also acknowledged to be associated with information processing biases as Bemis Vitousek & Hollen (1990) suggested, but is seen as largely operating through issues of self-control. Added to this they suggest that shape and weight may not be an essential feature of AN, and a control based theory provides an alternative account of the disorder when found in the absence of concerns about shape and weight with only two of the maintaining mechanisms operating (Lee, Ho & Hsu, 1993).

The implications of the above theory for the treatment of AN is that interventions must not only tackle concerns about shape and weight, the disturbed eating itself and associated weight control behaviour, body checking and low body weight. It must also have as its principal focus a successful addressing of the use of dietary restriction to achieve a sense of self control and self-worth, and the patient's need for self control in general. Thus a redirection and moderation of self control is needed, through helping patients derive satisfaction and a sense of achievement from other activities, as Slade (1982) suggested and using cognitive restructuring procedures, as advocated by Garner & Bemis (1982/85) & Bemis Vitousek & Hollen (1990). An integration of work on self-control needs to take place with other aspects of treatment (i.e. weight restoration etc.). Fairburn, Shafran & Cooper (1999) hope that the above model offers a simple and more focused treatment than Garner & Bemis' (1982/85), and Slade's (1982) approaches.

9.4.3 Shafran, Cooper & Fairburn (2002):

Shafran, Cooper & Fairburn (2002) in a paper on cognitive-behavioural analysis of clinical perfectionism, attest that AN may, in some cases, be conceptualized as a direct expression of perfectionism. They state that descriptions of AN patients invariably highlight their perfectionist tendencies and perfectionism has been suggested to play an important role in the maintenance of AN (Slade, 1982). People with perfectionism determinedly pursue their standards despite adverse consequences. This is the case with AN, where patients stubbornly pursue standards of control over eating, weight or shape, despite adverse consequences. Failure to meet standards results in self-criticism and maintains negative self-evaluation. These perfectionist tendencies may persist after weight restoration.

Therapy involves, broadening the patient's schema for self-evaluation, as per previous suggestions. I.e. behavioural experiments to test competing hypotheses, addressing patient's personal standards and self-criticism in general, helping them to identify and change rules that embody dichotomous thinking, paying attention to cognitive biases that maintain perfectionism, providing information about the nature of selective attention, keeping positive data-logs, increasing engagement in pleasurable activities etc. (Shafran, Cooper & Fairburn, 2002).

9.4.4 Fairburn, Cooper & Shafran (in Press):

The most recent theoretical contribution to the field has come from Fairburn, Cooper & Shafran in an article that is still in press[9]. It is concerned with the psychopathological processes that account for the persistence of not only AN, but the full range of severe eating disorders (Bulimia-Nervosa – BN, Binge Eating Disorder - BED & Eating Disorders Not Otherwise Specified – EDNOS). They suggest in a first line of argument that the core mechanism maintaining eating disorders, as suggested by cognitive-behavioural theory (i.e. a central cognitive disturbance characterised by the over-evaluation of eating, weight, shape and their control, with most of the other clinical features being understood as stemming directly from this core psychopathology) be extended in its focus to embrace four additional maintaining mechanisms. These mechanisms interact in some patients with the core eating disorder maintaining mechanism and when this occurs it is an obstacle to change. The additional maintaining processes concern the influence of (1) clinical perfectionism (Shafran, Cooper & Fairburn, 2002), (2) pervasive low-self esteem, (3) difficulty coping with intense mood states (anxiety, anger, depression), and (4) interpersonal difficulties. It is of interest that issues relating to self control are not seen as being as at the heart of AN, providing the simple organising principle that accounted for many features of the disorder, that they

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[9] Was still in press at the time of writing this review, see previous footnotes written to this effect

suggested in their (1999) theory of the maintenance of AN. The maintaining mechanism of low self-esteem (Garner & Bemis, 1982/85 etc.) and clinical perfectionism, as stated in their previous (2002) account, is included, whilst components regarding mood and interpersonal difficulties, not previously referred to, are added, drawn possibly from other accounts of AN such as Wolff & Serpell's (1998) theory, and family therapy perspectives of the same (Eisler, Dare, Russell, Szmukler, leGrange & Dodge, 1997). The second line of argument in Fairburn, Cooper & Safran's latest paper (though less relevant here) is that the shared, distinctive clinical features of eating disorders tend to be maintained by similar psychopathological procedures. I.e. they suggest that common mechanisms are involved in the persistence of AN, BN, BED & EDNOS and that thus a new transdiagnostic theory of the maintenance of the full range of eating disorders can be proposed. However, the formulation of AN needs to be modified to include the starvation syndrome as a main process maintaining the disorder (Fairburn, Cooper & Shafran, in Press).

The implications for treatment are that its content is dictated by the particular psychopathological features present and the processes that appear to be maintaining them, using procedures as previously suggested (Fairburn, Shafran & Cooper, 1999; Shafran, Cooper & Fairburn, 2002).

The above theories and its application to treatment as outlined in section 9.4.1, 9.4.2, 9.4.3 & 9.4.4 can be summarised and diagrammatically represented, as seen in table 9.2 overleaf. This table, encapsulates table 9.1, i.e. the summaries of section 9.3.1, 9.3.2 &

9.3.3, to ensure a full overview of the CBT theories developed of AN, and their application to the treatment of AN, so far.

Having addressed question A & B, question C can be posed and answered as follows:

9.5. Evaluation of Models I: What is the Empirical Evidence that has been Collected to Test Treatment based on a Cognitive-behavioural model, possibly in the form of any RCTs that have been conducted:

Two Reviews of the literature of clinical evidence for the treatment & theory of AN, including small RCTs can be found. These are by Kaplan (2002) & Treasure & Schmidt (2001).

It can be stated that in so far as treatments based on a cognitive model are effective, they provide a source of evidence for the relevance of CBT in treating AN and indirect evidence of the existence and importance of a cognitive disturbance as a key feature in the psychopathology of AN.

Kaplan (2002) in examining outpatient randomised controlled treatment trials, suggests that these studies have had difficulty demonstrating specificity of effectiveness for the therapies used. This, in part, relates to the small number of participants entered into these studies, which limits the power to distinguish between different treatments. For example Channon, de Silva, Hemsley & Perkins (1989) randomised adult outpatients with AN to 3 treatments: (i) CBT (according to Garner & Bemis 1982/85), (ii) behaviour therapy (BT: graded hierarchies of feared foods and exposure to these), and (iii) control treatment (non-specific support and medical monitoring). However, there were only 8 subjects randomised to each of the treatment cells, making the interpretation of outcome differences between the different treatments somewhat problematic. In fact, no significant differences were found on any of the significant outcome measures between the 3 groups. Channon, de Silva, Hemsley & Perkins (1989) acknowledged that the BT and CBT employed in the trial assumed that individuals wanted to make certain changes in their eating behaviour and/or attitudes, without first perusing the 'pros' and 'cons' of change with them. This, they asserted, was somewhat inappropriate, since AN patients fail to perceive the central symptoms of thinness to be aversive and view it as a higher value which justifies suffering the accompanying symptoms. Furthermore, Garner & Bemis (1982/1985); Vitousek, Watson & Wilson (1998); and Wolff & Serpell (1998), particularly, emphasised that motivational work be part of CBT for AN. Channon, de Silva, Hemsley & Perkins (1989) did note that, regardless of motivation to change, the number of sessions attended by patients between CBT and BT differed, which seemed to make the former appear more acceptable to participants than the latter.

Treasure & Schmidt (2001) in a review of the clinical evidence for treatment in anorexia nervosa, found eight small RCTs, none of which reported an overall significant difference between therapies. Though one RCT found a significant improvement for CBT versus baseline (Serfaty, 1999). This RCT suggested that CBT was considered to be more acceptable than dietary counselling to participants, which was reflected in the studies 100% failure to take up/withdrawal rate with dietary counselling. However, they noted with Kaplan (2002) above, that RCTs were small and were unlikely to have been sufficiently powered to detect a clinically important difference between treatments if they existed. Treasure & Schmidt (2001) stated that (a) the amount of therapeutic input varied considerably between and within RCTs, (b) the way therapy was conducted lacked sufficient detail to allow replication, (c) there was variation in methods of recruitment, (d) there was variation in outcome measures used, (e) there was variation in reporting of key results, and finally (f) there was variation in description of participants' characteristics and selection, such as onset of illness, duration of illness and previous attempts at treatment.

In summary, it can be gleaned from the above, that treatment outcome data neither seem to support nor refute the proposed models.

Cooper (1997) in a review, states the importance of more recent empirical evidence that has been collated to test the different aspects/components of cognitive theories for AN, which is outlined in the following section.

9.6 Evaluation of Models II: What is the more Recently Gathered Empirical Evidence that Tests the Different Components of the Cognitive-behavioural Theories of AN Developed:

26 authors have reported on the varied components of the cognitive-behavioural theories of AN developed that have been empirically tested, which are: 1. Dysfunctional attitudes towards weight, eating and body size (twelve authors), 2. Weight-related self-schemata & differential processing of information (eight authors), 3. Control (one author), and 4.

Diffuse anxiety in stressful situations: resolving the "insoluble" (five authors). The detail of this can be outlined as follows:

9.6.1. Dysfunctional attitudes towards weight, eating and body size:

The CBT model of AN proposed by Garner & Bemis, (1982/85) stresses the role of dysfunctional attitudes towards weight, eating and body size in AN patients in the (proximal) development and maintenance of the disorder. Garner & Bemis (1982) state that the most striking finding in their own follow-up contact with former patients was the persistence of dysfunctional beliefs about weight, eating & body size, even after weight gain, which together with other clinical reports led them to develop the CBT model of AN in the first place.

Some support is provided for this by a study by Channon & de Silva (1985) which found that eating attitudes and preferred weights upon discharge from hospital were correlated significantly with follow-up weight status in AN patients. This let them to conclude that treatment methods designed specifically to address cognitive processes as well as eating behaviour were of particular interest in the treatment of AN.

Further support for this is provided by studies in which attitudes towards food have been measured. Patients with eating disorders have been shown to have many negative cognitions associated with food they believe to be high in fat or calories (Sunday, Einhorn, Halmi, 1992). Drewnowski, Pierce & Halmi (1988) found that patients with eating disorders, especially anorexics, report an aversion towards high fat foods. Results from taste studies suggested that anorexics also display a fat aversion to dairy solutions with high levels of fat and to varying solutions of fat when no sugar is added, as compared to controls, and that this did not change when patients increased in weight to normal body weight (Sunday & Halmi, 1990).

Indirect evidence of AN patients’ dysfunctional attitudes towards weight, eating and body size, comes from a large body of research on “’body image distortion“’. Numerous researchers have documented the tendency of anorexic patients to overestimate the size of their bodies (Garner & Garfinkel, 1981; Collins, Beumont, Touyz, Krass, Thompson & Philips, 1987; Freeman, Thomas, Solyom & Koopman, 1985), whereas others have found a lack of differences with normal controls (Smeets & Panhuysen, 1995; Probst, Vandereycken, Van Coppenolle, Pieters, 1998). However, studies have been conducted using various body size estimation techniques. Recent findings point to the greater significance of emotional and attitudinal factors of body image over the purely perceptual aspects of body size estimations. I.e. Fernandez-Aranda, Dahme & Meermann (1999) in a study of body image in eating disorders and an analysis of its relevance, concluded that there is no evidence for a serious impairment of body size perception (estimation) in eating disorder patients. But rather for a disturbance in the emotional aspects of body image, as expressed in negative body attitudes. This was further supported by a study carried out by Smeets, Ingleby, Hoek & Panhuysen (1999), who found that AN participants had more negative feelings and cognitions towards their bodies than the control group (normal & thin people) and stressed the importance of the influence of cognitions and emotions in body "image". Probst, Vandereyken, Van Coppenolle & Pieters (1998) suggest that the latter be renamed body "experience" since it includes affective, cognitive and physical components and the notion of body "image" overemphasises the idea of visual perception of the body and distortions in these. It is of interest to note that Garner & Bemis in 1982 already argued that the refractory self perceptions of anorexic patients did not seem to represent a true perceptual disturbance but were rather products of the same powerful cognitions that supported the anorexic behaviour pattern.

Considering the above Garner & Bemis' (1982) "blind person" analogy might not be appropriate in addressing the issues of disturbed body experience, as "blindness" refers to something perceptual. It could be suggested that cognitive restructuring (letting go of the old body schema and creating a new one) through the writing of (i) a body history (Freeman, 2002), (ii) looking at outer and inner qualities, (iii) raising awareness of how inner bad feelings are being projected onto the outer body (i.e. how feelings of badness are translated into feelings of fatness, and how the connection between how the patient's view of herself as a person -as bad, and how she visualises her body -as fat, needs to be broken), (iv) engaging in guided imagery exercises (Kearney-Cooke & Striegel-Moore, 1997), and, finally, (v) re-parenting herself to accept herself for who she is, and grow to care and love her own body.

9.6.2 Weight-related self-schemata & differential processing of information:

In addition to the emphasis on dysfunctional attitudes towards weight, eating & body size, Bemis Vitousek & Hollen (1990) argued that negative self-schemata & weight related schemata, which combine into weight-related self-schemata, are at the core of AN. In relation to these "negative self-schemata" proposed, researchers report that AN patients are more likely than normal controls to possess negative self-image, characterising themselves as ineffective and dissatisfied (Garner & Garfinkel, 1981; Slade & Dewey, 1986). Cooper & Fairburn (1992) collected self-statements from patients with eating disorders, dieters and non-dieting controls, whilst they performed three behavioural tests (looking at themselves in a full length mirror, weighing themselves and eating chocolate). They found that patients with eating disorders had more negative self-statements about eating, weight and shape during the task than normal controls, while dieters occupied an intermediate position. In patients with AN, negative thoughts about eating distinguished them most from dieters, while BN patient's concern with weight and appearance distinguished them the most from these two groups. Within group comparisons indicated that the pattern of concerns in the normal controls and dieters was similar to that found in patients with BN and was different from that found in AN. This suggested that there could be an extension of concern found in the general population in BN (i.e. the valence of thoughts relevant to concerns with food/eating, weight and shape best distinguishes the patients form normal controls), while in AN concerns and preoccupation may be qualitatively different. The latter could refer to the existence of “weight related schemata“, which cause the meaning of weight etc. to be more elaborated, idiosyncratic and emotionally charged for AN patients than for others describing to a normative disturbed view about weight, i.e. slimness is “self control, is virtue, is beauty, mastery, and competence” (Bemis Vitousek & Hollen, 1990).

Bemis Vitousek & Hollon (1990) suggest that negative self-schemata and weight related schemata, which combine into weight-related self-schemata, may exert “automatic effects on the patient's processing of information“. Evidence from cognitive psychology suggests that the existence of schema in a given domain tends to produce systematic errors in the processing of information relevant to that domain through mechanisms such as overuse of schema, selective attention & memory (Turk & Salovey, 1985).

There is now limited but clear data which shows that there is a differential processing of information which has relevance to food and eating patterns in AN. Using the Stroop (Stroop, 1935) colour naming paradigm, Channon (1988) found indicators of "selective attention" in AN patients. Anorexics proved slower than controls in colour-naming words, but were particularly slow when food-related words were presented. Similar results were obtained by Ben-Tovim, Walker, Fok & Yap (1988) who asserted that AN & BN participants were significantly slower in naming the colour of the ink in which food-related words were printed than in identifying the ink colour of neutral words in responding to the former stimuli. In addition BN participants manifested a delayed response to weight related words, with anorexics showing a trend in the same direction.

Cooper (1997) asserts that, alongside selective attention, an "interpretative bias" (i.e. confirmatory bias etc.) also serves as an indicator of differential processing. Such biases distort data so that individuals obtain information that reinforces their concerns, especially when in high arousal states. Cooper (1997) in a study of bias in interpretation of ambiguous scenarios in eating disorders found, that patients with AN & BN when presented with case scenarios that had a negative outcome, would respond spontaneously to open ended questions with a weight and shape interpretation. In the forced-choice format, they selected the weight and shape interpretation in preference to interpretations not connected to shape and weight. Cooper (1997) states that in patients with eating disorders, weight and shape interpretations may be spontaneous and readily available.

They may insert material related to eating & weight into a variety of objectively irrelevant contexts and abstract such material out of situations that contain minimal or equivocal cues. Thus patients project their concerns about eating, shape and weight into a wide range of situations (Cooper, 1997; Bemis Vitousek & Hollen, 1990).

9.6.3 Control:

Both Slade (1982) & Fairburn, Shafran & Cooper's (1999) theoretical models of AN have made the case for the role of perceived control in the onset and maintenance of AN. A study by Dalgleish, Tchanturia, Serpell, Hems, de Silva & Treasure (2001) investigated the above by assessing perceptions of control over events in the world in groups of patients with AN, BN and healthy controls. Results indicated that on the one hand the two eating disorder groups perceived themselves as having less personal control over events in the world, relative to healthy controls, even if depression levels were co-varied out. Furthermore, the eating disorder groups also exhibited a depressive attributional style (they made more internal, global, and stable attributions for negative events in the world). On the other hand, for specific negative events that had actually occurred, they made a depressive attributional analysis that involved attributing the cause of those bad events to aspects of themselves. Based on this data the authors of this paper concluded that it could be tentatively argued that this reduced sense of agency represents a process central to the core eating disorder pathology, as discussed by Slade (1982), Fairburn, Shafran & Cooper (1999), whereas the depressive attributional style could be seen as a function of associated depressed mood (Dalgleish, Tchanturia, Serpell, Hems, de Silva & Treasure (2001).

9.6.4 Diffuse anxiety in stressful situations: resolving the "insoluble":

There is much evidence for the antecedent factors and triggering events assumed by Slade (1982). The idea that the pursuit of complete control over eating arises in patients in the context of "general life dissatisfaction" resulting from anxiety and stress experiences etc. (Slade, 1982), or that the anorexic patient experiences an episode of dysphoria precipitated by an external stressor such as family difficulties, examinations (Beumont, George, Smart, 1976), which makes her arrive at the idea that losing weight will somehow alleviate her distress (due to sociocultural influences moulding the form of the illness & determining the content of the patients preoccupations), as suggested by Garner & Bemis (1982) has been supported by a number of studies. Marilov, Crisp & Ben-Tovim (2000) found that AN sufferers express diffuse anxiety in stressful situations and they appear to retreat into illness as a means of resolving the "insoluble". This relates to what Cooper (1997) earlier suggested when she stated that patients faced with ambiguous scenarios give it a shape & weight interpretation. I.e. in a time of overwhelmedness and diffuse anxiety, core beliefs about ones' own inadequacy surface and cognitive distortions go unchallenged. This links to the suggestion that AN is functional underneath the superficial notions of weight and shape in that it serves to simplify, organise and stabilise the individuals experience of herself and the environment, providing a concise and inclusive set of rules from which appropriate attitudes & behaviour can be deducted and a blind panic avoided, as asserted by Bemis Vitousek & Hollen (1999). Finally, many anorexics (especially of the restrictive sub-type) show perfectionistic or obsessional tendencies (Dally & Gomez, 1979; Strober, 1980; Marilov, Crisp & Ben-Tovim, 2000).

Section 9.6.1, 9.6.2, 9.6.3 & 9.6.4 can be summarised as follows, see table 9.3 overleaf.

In summary, experimental data have been provided to support the leading Cognitive-behavioural model of AN, particularly Garner & Bemis' (1985) & Vitousek & Hollen's (1990).

9.7. Evaluation of Models III: What are the Limitations of Existing Models, Gaps in Current Knowledge of AN, Research & Clinical Implications:

Garner & Bemis (1982) highlighted the general prominence of denial and resistance in the phenomenology of AN, which was further addressed in a paper by Vitousek, Watson & Wilson, (1998). Ambivalence and resistance to change was identified as a primary symptom of AN, as well as a maintaining mechanism that needed to be addressed to come to any behavioural change (Kaplan, 2002). This idea was felt to need further development by the Maudsley Group. This was done by Schmidt & Treasure (1998), who specifically, developed a workbook on motivational work with eating disorder patients that could be integrated into therapy. This book joins together the ideas of Garner & Bemis (1982/85) & Vitousek & Hollen (1990) & Wolff and Serpell (1998)[10], regarding this and closed the gap that any of them left vis a vis this. The book provides a comprehensive tool to help therapist and patient switch the balance of the 'pros' & 'cons' of change. The use of motivational interviewing techniques has become part of all treatment at the Maudsley Unit engaged in, i.e. with any of the eating disorders presenting.

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[10] Also from the Maudsley Group

Garner & Bemis (1982/85) not only advocated the prominence of denial and resistance in the phenomenology of AN, but also underlined the importance of the starvation state in perpetuating the disorder and the absolute need to engage in nutritional rehabilitation. Almost all models stress the importance of this, though it is not specifically outlined in Shafran, Cooper & Fairburn's (2002) model, and Slade (1982) refers to it in an indirect way.

As to the short-comings of their model, Garner & Bemis (1982) themselves asserted that their model entails a remote version of the pathenogenesis of AN, which presents only a subset of the manifold causes of and motivation for the disorder. They say that they do not suggest that cognitive distortions are the sole causal factors in anorexia nervosa and, therefore, should be the sole focus of intervention. They do not advocate a single etiological model that is sufficient to account for every instance of the disorder. They do hypothesise that treatment will rarely be successful unless patient's cognitions about weight and appearance are modified.

However, Garner & Bemis (1982/85) furthermore suggest, together with Fairburn, Cooper & Shafran (In Press) that the above noted cognitive shifts are not always sufficient. They note that an analysis of maintaining variables might indicate the need for an interpersonal focus due to e.g. enmeshment or faulty communication within the family system. Therefore, it follows, that family work may be a valuable addition to the treatment programme, especially in case of the younger patient (Rosman, Minuchin, Baker & Liebman, 1977; Dare & Eisler, 1987; Eisler, Dare, Russell, Szmukler, leGrange, Dodge, 1997) and some involvement may be of value as well in adults with AN (Dare, Eisler, Russell, Treasure, Dodge, 2001). It could be said that Cognitive schemas do not develop in isolation, but rather reflect repetitive family interactional patterns. Therefore, looking at the meaning of symptoms (which are adaptive yet dysfunctional), requires opposing and altering the meaning through challenging it and shifting interactional patterns (Garner, Vitousek & Pike, 1997).

Particularly during the later stages of therapy, problems less directly related to the presenting symptoms are likely to become prominent. The emergence of additional difficulties need not be considered symptom substitution, but may indicate the reappearance of a more ordinary and manageable set of problems that may have preceded the development of AN (Garner & Bemis, 1982).

Garner, Vitousek & Pike (1997) add to this that relapse prevention and preparing for termination is what any piece of work requires, with a summary of the fundamentals of progress made, whilst looking at areas of continued vulnerability, and developing a plan for dealing with these (Garner, Vitousek & Pike, 1997).

Slade (1982), assessing his own writings, suggests that while none of the individual elements of his behavioural and functional analysis of AN is original, the balance of emphasis does seem to differ from Garner & Bemis (1982); in particular, the assignment of special emphasis on the notion of context-dependent reinforcements. He goes on to say that this notion is both speculative and central to the model as outlined. Another speculative aspect of the model is the notion that the major setting conditions (general life dissatisfaction, low self-esteem/perfectionist tendencies) generate in combination a "need to control some aspect of the life situation and or attain certain success in some area".

Fairburn, Shafran & Cooper (1999) synthesised both Garner & Bemis' (1982/85) cognitive distortions and Slade's (1982) issues of control as the core maintaining mechanism of the disorder, which was further extended by Fairburn & Cooper & Shafran (In Press), including a focus on other maintaining mechanisms as appropriate. However, the problem with the latter theory is that it may be of particular relevance in sharpening conceptualisation and treatment of BN which has had a narrow focus, but may not necessarily add to the already existing conceptualisations of AN, described above, their own 1999 & 2002 paper included, which have both broad and narrow foci. Furthermore, Fairburn, Cooper & Shafran's latest writings (In Press) tend to confuse what they have previously stated to be the core psychopathology and maintenance of AN (& treatment proposed), which can be elicited from the overall overview of cognitive-behavioural theories of AN developed, the core psychopathology and maintaining mechanisms identified, its therapy etc. as outlined in table 9.2.

Overall, vis a vis the empirical evidence that has been collected to test treatment based on a Cognitive-behavioural model, possibly in the form of any RCTs that have been conducted, it appears that it has proven difficult to carry out large scale comparative studies, since AN is less prevalent than its sister condition BN, of which RCTs evaluating treatment effectiveness exist (Wilson & Fairburn, 1998). The number of specialist treatment Centres providing potential participants into these studies is relatively small, with patterns of referral (regional/national) varying. The illness is life threatening in nature, patients suffer from profound complications and some require hospitalisation and years of outpatient treatment, which complicates study designs. Considering the profound complications of AN, a placebo group and a waiting list control group as controls to fully investigate the specific effects of the experimental treatments under investigation, is not thought to be feasible in this population. The placebo group and waiting list control condition could then only be limited to patients who were not seriously emaciated and would restrict studies to treatment of only mildly ill cases. Finally, treatment has a high drop-out and attrition rate due to the ego-sytonic nature of the illness, i.e. patients are difficult to engage (Bowers, 2001; Channon, de Silva, Hemsley & Perkins, 1989; Kaplan, 2002; Schmidt, 1997). Overall it can be stated that the outcome data, neither support nor refute any of the proposed Cognitive-behavioural models of AN.

Possibly, qualitative research of patients' experiences of therapy and what they perceive to attribute to processes of change, i.e. what they think the effective ingredients of therapy are, might help to confirm existing theories and provide pointers for quantitative follow-up.[11]

However, the fact that there is little evidence from RCTs that refute or support any of the proposed models, should not be interpreted as if these treatments are of no value clinically. It is not appropriate to dismiss models & treatments because of the general

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[11] As I undertook with patients with Bulimia Nervosa. This study and its findings are described & discussed in my unpublished MSc Counselling Psychology thesis (Boersma-Heller, 2001).

paucity of clinical trials directing treatment efforts. It can be argued that evidence from RCTs are not required to embark on treatment, as the natural history of starvation is known and effective treatment of starvation is also known. What factors have to be considered in terms of acute medical risk management (i.e. re-feeding etc.) have been extensively documented (Treasure, 2002). Alongside this, the use of detailed clinical expertise and theories developed, guided by the body of research in support of its components, is what currently informs treatment, while further studies are under way (de Silva, 1995). In this the patient's values such as acceptability of treatment, and personal requirements need to be taken into account, such as CBT vs dietary counselling (Serfaty, 1999), active therapy vs outpatient therapy (Dare, Eisler, Russell, Treasure & Dodge, 2001; Treasure & Ward, 1997) and outpatient vs inpatient treatment, in those individuals who do not warrant hospital admission for life saving reasons or because of lack of progress in outpatient treatment (Crisp, Norton & Gowers, 1991).

Cooper & Cooper (1988) state that CBT models of AN have impressive face validity, and from the above discussion, it appears that several pieces of evidence, that test different components of the cognitive theory developed of AN (such as possible dysfunctional attitudes to weight, eating & body size; weight related self-schemata & differential processing of information; control; and diffuse anxiety in stressful situations) lend support to this type of formulation.

Notwithstanding this, all the theories proposed are particularly weak with regard to explaining the aetiology of the disorder in question. CBT models focus by their very nature on proximal causes and maintenance variables, though Slade (1982) with his sophisticated behavioural and functional analysis and Fairburn, Cooper & Shafran (In Press) in their latest transdiagnostic model and previous 1999 theory (Fairburn, Shafran & Cooper, 1999) provide a versatile attempt at taking issues further. Therefore, the models described have a useful role in the domain to which they are limited. That is accounting how the proximal factors lead to certain behaviours and how the latter are maintained and strengthened, generating effective strategies for treatment.

Taken all of this into account, it needs mentioning that CBT requires a tailoring to the patient's individual needs, as noted above. In every case it is important to see how what is hypothesised to make up the core psychopathology and its maintaining mechanisms in the theories discussed, rings true in the case under review. Focusing on the particular mechanisms that seem relevant, and translating this into the specific treatment interventions discussed. This is roughly in line with Fairburn, Cooper & Shafran's latest thinking (In Press).

In summary, CBT for AN generally focuses on how engaging in starving oneself works and does not work in resolving the patient's issues. It addresses how the behaviour came about and how to trade it in and trade up, so that whatever the purposes behind the disorder, these can be accomplished in a healthy and better way (Bowers, 2001). CBT can, on the one hand, look at the relative importance of thinness as a life goal relative to other goals and/or, on the other hand concentrate at attempting to modify individual dysfunctional cognitions, engaging in schema work etc. (Slade, 1982; Fairburn, Shafran & Cooper, 1999; Garner & Bemis 1982/85; Bemis Vitousek & Hollon, 1990; Wolff &

Serpell, 1998). Looking at issues both from and indirect and direct angle, whilst the varied maintaining mechanisms are addressed as appropriate (Shafran, Cooper & Fairburn, 2002; Fairburn, Cooper & Shafran, In Press).

9.8 What Conclusions can be Drawn:

The area of AN is challenging both in terms of study and subsequently in terms of treatment, and vice versa, in an ongoing cycle. Attempting to come to an understanding of AN feels somewhat analogous to studying Freud (1905) as an academic pursuit and trying to come to an overall understanding of his continually changing, rather dense theory of psychosexual development, now zooming in then zooming out, now emphasising this then emphasising that, then going back all over again. Such a process reflects the complexity of the topic studied, which is yet so well and yet so little understood.

The cognitive-behavioural theory of AN keeps developing and there is an ongoing debate as to its detail. Kaplan (2002), in a review of the area, as referred to in section 9.1, concluded that little progress has been made in the last few decades. However, this review, as Garfinkel (2002) also stated, shows that the past two-and-a-half to three decades have seen dramatic changes in the approach to eating disorders. This has included a marked improvement in the recognition and understanding of the disorder, which have been transmitted to the benefit of patients, resulting in a subsequent reduction of mortality of AN (Fichter & Quadfleigh, 1999). The past two-and-a-half to three decades has seen the development of Garner & Bemis' (1982/850 cognitive-behavioural theory of AN (which was further elaborated by Vitousek & Hollen, 1990, including schema work); Slades' (1982) sophisticated behavioural and functional analysis of AN; the merging of Garner & Bemis (1982/85) theory with Slade's (1982) in a model proposed by Fairburn, Shafran & Cooper (1999); whilst this was extended to include other maintaining mechanisms, existing alongside the core, which needed addressing as appropriate (Fairburn, Cooper & Shafran, In Press). Attempts at RCTs have been made and extensive research on the various components of a cognitive-behavioural theory of AN has been carried out, as discussed in this review, whilst more research is under way. It is acknowledged, however, that there remain significant difficulties in treating people with AN, since the illness is complex and its nature unyielding. Many challenges lay still ahead in terms of further research and treatment efforts in the coming years to decrease the impact of AN on the individual, family, friends, teachers and colleagues, and guide clinician's practice. From the above there are no pretensions that the case for CBT for AN has been proven, however, there is enough data that is sufficiently encouraging to warrant further examination.

In closing off, it is noted that in coming to a further understanding of what and how the AN patient thinks, how themes in thinking featured have arisen in life and through what means they are perpetuated, it is important to not try and over-simplify what is happening by using purist mono-theories and therapies, in the clinicians own desire to conceptualise what is happening. To clinically engage in an excessive focus on weight gain that neglect detection and treatment of associated psychological features and comorbidity is inappropriate, as is treatment that exclusively focuses on psychological intervention and one maintaining mechanism over the other (Schmidt, 1997). AN is a serious psychiatric disorder with substantial morbidity. The principle of parsimony, so exalted by scientists, cannot be applied to this choice of domain, because minimalism would be achieved at considerable cost. It could be argued that if the clinician seeks to simplify matters in order to make sense, s/he could be said to mirror the anorexic patient's attempt to try and simplify her world. I.e. the therapist could be found to be engaging in "anorexic" ways of thinking herself (Bemis Vitousek & Hollen, 1990). Therefore, the counselling psychologist's clinical practice needs to be guided by theory and research in evidence of it, but a flexible, thoughtful, tailored, comprehensive approach is called for in working with this most challenging client group in the range of community, primary care and acute settings, that s/he works in, considering all of the points as outlined above.

Table 9.1: Cognitive-behavioural theories of AN – Core Psychopathology, Maintaining mechanism & (application to) treatment of AN Page 1

	Core Psychopathology of AN	**Maintaining mechanisms**	**(Application to) Treatment of AN**
Garner & Bemis 1982/85	Patient's cognitive distortions: their over-valued ideas about shape, weight & eating. (Much of the other clinical features can be understood as secondary & maintained by such disturbed attitudes).	1. Positive & 2. negative reinforcement. (+ delight in discovery of control of appetite & figure, great feeling of power from self-restraint & environmental support in initial stages, - avoiding feared situations – fear of fat. 3. Disturbed attitudes; tenacity core beliefs, self-worth defined by shape/weight, giving rise to cognitive processing biases. 4. Habit, & effects of starvation.	Warm & supportive relationship, not challenge/refute/deride patient's erroneous assumptions, accept patient's belief as currently genuine for her: Re-examine practical implications of these, develop dissonance between symptoms & beliefs/assumptions/behaviours, educate on nature of illness, risks & course; cultivating motivation for change, discussing weight stabilisation as an initial step, and behavioural strategies to replace dysfunctional eating patterns with normal eating habits, introducing avoided foods etc. Elicit cognitions (fear of fat and desire for thinness), operationalise, re-examine; using "what if" technique, "decentring", engaging in prospective hypothesis testing, by devising informative experiments, cognitively rehearsing proposed manipulations etc. Going deeper, looking at general principles that underlie, organize specific thoughts, looking at themes and modifying these basic assumptions. Engage in body-image work, using "colour-blind person" analogy
Bemis Vitousek & Hollen (1990)	Weight-related self-schemata. (patient has rigid cognitive structuring of world so that the patient's view of herself are bound with beliefs about weight, eating & appearance, ie. self worth becomes largely & exclusively judged in terms of weight & shape).	(Schema determined) selective attention, memory, ie. faulty information processing. Tenacity core beliefs. Positive & negative reinforcement. Starvation state. Functionality.	As above. Patient's schemas & core beliefs, fusion of self-value with weight/shape, (self=weight) becomes focus for modification in therapy, as above. Understanding of that & how weight-related self-schemata simplify, organise and stabilise patient's experience of self & the environment, providing a concise, inclusive set of rules from which appropriate attitudes and behaviour can be deducted, holding the promise of control, ensuring form and order: meaning of AN.

Table 9.1: Cognitive-behavioural theories of AN – Core Psychopathology, Maintaining mechanism & (application to) treatment of AN Page 2

	Core Psychopathology of AN	Maintaining mechanisms	(Application to) Treatment of AN
Slade (1982)	Extreme need for control (in the context of general life dissatisfaction & dissatisf. with self - low self-esteem & perfectionist tendencies- and specific psycho-social stimuli).	Positive & negative reinforcement. (+ = sense satisfaction dieting, plus successful behaviour in context of perceived failure in other areas of functioning) & (-- = 1. avoidance of fear of weight gain & alteration of body-image 2. social disapproval that comes with weight gain/ overweightness, and avoidance of the problem). Stressors/conflict/problems that preceded onset of AN. Functionality (need for control). Anchoring of person's self-concept in control.	Foster sense of selfhood, away from starvation, ie. establish some major sources of positive self-reinforcement/satisfaction other than dieting. Encourage development of alternative goals: interests, enthusiasm and successful behaviours. A repertoire of behaviours to replace the single one of anorexic behaviour, ie. the establishment of independence from and within the family, academic and vocational training, social and leisure interests. Focus on relative importance of thinness as a life goal relative to other goals (rather than attempting to modify individual dysfunctional cognitions); dismantle anorexic system and replace with more rewarding ways of life. Resolve the antecedent events leading to development of anorexia in first place, addressing each of the areas of adolescent conflict, interpersonal problems and stress/failure experiences. Have functional analysis in mind of AN in all of this, and don't focus solely on weight gain.

Table 9.2: Cognitive-behavioural theories of AN – Core Psychopathology, Maintaining mechanism & (application to) treatment of AN Page 1

	Core Psychopathology of AN	Maintaining mechanisms	(Application to) Treatment of AN
Garner & Bemis 1982/85	Patient's cognitive distortions: their over-valued ideas about shape, weight & eating. (Much of the other clinical features can be understood as secondary & maintained by such disturbed attitudes).	1. Positive & 2. negative reinforcement. (+ delight in discovery of control of appetite & figure, great feeling of power from self-restraint & environmental support in initial stages, - avoiding feared situations – fear of fat. 3. Disturbed attitudes; tenacity core beliefs, self-worth defined by shape/weight, giving rise to cognitive processing biases. 4. Habit, & effects of starvation.	Warm & supportive relationship, not challenge/refute/deride patient's erroneous assumptions, accept patient's belief as currently genuine for her: Re-examine practical implications of these, develop dissonance between symptoms & beliefs/assumptions/behaviours, educate on nature of illness, risks & course; cultivating motivation for change, discussing weight stabilisation as an initial step, and behavioural strategies to replace dysfunctional eating patterns with normal eating habits, introducing avoided foods etc. Elicit cognitions (fear of fat and desire for thinness), operationalise, re-examine; using "what if" technique, "decentring", engaging in prospective hypothesis testing, by devising informative experiments, cognitively rehearsing proposed manipulations etc. Going deeper, looking at general principles that underlie, organize specific thoughts, looking at themes and modifying these basic assumptions. Engage in body-image work, using "colour-blind person" analogy
Bemis Vitousek & Hollen (1990)	Weight-related self-schemata. (patient has rigid cognitive structuring of world so that the patient's view of herself are bound with beliefs about weight, eating & appearance, ie. self worth becomes largely & exclusively judged in terms of weight & shape).	(Schema determined) selective attention, memory, ie. faulty information processing. Tenacity core beliefs. Positive & negative reinforcement. Starvation state. Functionality.	As above. Patient's schemas & core beliefs, fusion of self-value with weight/shape, (self=weight) becomes focus for modification in therapy, as above. Understanding of that & how weight-related self-schemata simplify, organise and stabilise patient's experience of self & the environment, providing a concise, inclusive set of rules from which appropriate attitudes and behaviour can be deducted, holding the promise of control, ensuring form and order: meaning of AN.

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	Core Psychopathology of AN	**Maintaining mechanisms**	**(Application to) Treatment of AN**
Slade (1982)	Extreme need for control (in the context of general life dissatisfaction & dissatisf. with self - low self-esteem & perfectionist tendencies- and specific psychosocial stimuli).	Positive & negative reinforcement. (+ = sense satisfaction dieting, plus successful behaviour in context of perceived failure in other areas of functionning) & (-- = 1. avoidance of fear of weight gain & alteration of body-image 2. social disapproval that comes with weight gain/ overweightness, and avoidance of the problem) Stressors/conflict/problems that preceded onset of AN. Functionality (need for control). Anchoring of person's self-concept in control.	Foster sense of selfhood, away from starvation, ie. establish some major sources of positive self-reinforcement/satisfaction other than dieting. Encourage development of alternative goals: interests, enthusiasm and successful behaviours. A repertoire of behaviours to replace the single one of anorexic behaviour, ie. the establishment of independence from and within the family, academic and vocational training, social and leisure interests. Focus on relative importance of thinness as a life goal relative to other goals (rather than attempting to modify individual dysfunctional cognitions); dismantle anorexic system and replace with more rewarding ways of life. Resolve the antecedent events leading to development of anorexia in first place, addressing each of the areas of adolescent conflict, interpersonal problems and stress/failure experiences. Have functional analysis in mind of AN in all of this, and don't focus solely on weight gain.
Wolff & Serpell (1998)	Weight/shape schemata overlap with self-esteem schemata. interacting subsystem	Pro-anorexia beliefs, Positive Automatic Thoughst, +/- re-inforecement, starve-. tion & rumination, Interpersonal elements	Assess patients concerns; effect illness, development & outline treatment options, foster shared understanding. Look pros/cons change, pro-anorexia meta-cognitions, good Anorexia & costs, Find activities, ways being that replace Anorexia, by fulfilling some of its functions. Answer - & + automatic thoughts by conducting behavioural experiments. Address individual – schema, define, plot. Represent linked schema, plot & pie chart how much being thin makes patient a special person, with a second noting the other factors, and a third noting what

Table 9.2: Cognitive-behavioural theories of AN – Core Psychopathology, Maintaining mechanism & (application to) treatment of AN Page 3

	Core Psychopathology of AN	Maintaining mechanisms	(Application to) Treatment of AN
Wolff & Serpell (1998) continued			makes others special. Look at interpersonal elements when resistant to change.
Fairburn, Shafran & Cooper (1999)	Extreme need for <u>self-control</u> (arising from general sense of ineffectiveness & perfectionism in context of low self-esteem).	1. Dietary restriction directly enhances person's sense of control & self-worth. 2. Starvation state -(narrowing interest). 3. Extreme concerns about shape & weight encourage dietary restriction, since control over eating/ shape/weight are being used as major indices of both control in general & self-worth in contemporary society. Issue of self-control provides account, when found in absence of concerns about weight & shape.	Treatment must not only tackle concerns about shape & weight, the disturbed eating itself and associated weight control, behaviour, body checking and low body weight. It must have as its principal focus a successful addressing of the use of dietary restrictions to achieve a sense of self control and self-worth, as well as the patient's need for self control in general. A redirection and moderation of self control is needed through helping patients derive satisfaction and a sense of achievement from other activities, as per Slade (1982) & Garner & Bemis (1982/85) & Bemis Vitousek & Hollen (1990) above. An integration of work on self-control needs to take place with other aspects of treatment (ie. weight restoration etc.).
Shafran, Cooper & Fairburn (2002)	Dysfunctional schema for evaluating self: <u>AN as an expression of perfectionism</u>	(+ & - Reinforcement). Biased evaluation of pursuits/achievement, of personally demanding standards.	Broaden patient's self-schema for self-evaluation, as per previous suggestions. Ie. behavioural experiments to test competing hypotheses, addressing patient's personal standards and self-criticism in general, helping them to identify and change rules that embody dichotomous thinking,

	Core Psychopathology of AN	**Maintaining mechanisms**	**(Application to) Treatment of AN**
Shafran, Cooper & Fairburn (2002) continued			paying attention to cognitive biases that maintain perfectionism, providing information about the nature of selective attention, keeping positive data-logs, increasing engagement in pleasurable activities etc.
Fairburn, Cooper & Shafran (In Press)	Cognitive distortions: overvalued ideas shape, weight, eating and their control. (Definiton of self in terms of weight and shape).	1. Perfectionism. 2. Low self-esteem. 3. Difficulty coping with intense mood states. 4. Interpersonal difficulties. Main Starvation state/syndrome	The content of treatment is dictated by the particular psychopathological features present and the processes that appear to be maintaining them, using procedures as suggested by the same authors in their 1999 & 2002 publications.

Table 9.3: Summary of recently gathered evidence regarding the different aspects of the cognitive theories of AN developed **page 1**

A. Dysfunctional attitudes towards weight, eating and body size:

0. Clinical reports of
    - dysfunctional beliefs about eating, body size (Garner & Bemis, 1982), even after weight gain in follow-up
    - eating attitudes & preferred weight (Channon & de Silva, 1985), discharge vs follow-up correlated
1. Measured attitudes towards food
    - Negative cognitions associated with food that patients with eating disorders belief to be high in fat or calories (Sunday, Einhorn, Halmi, 1992) & patients with eating disorders, especially Anorexics, report an aversion towards high fat foods (Drewnowski, Pierce & Halmi, 1988)
    - Taste studies suggest Anorexics display a fat aversion compared to controls (Sunday & Halmi, 1990), which did not change when patients increased in weight to normal body weight
2. Body size estimations of "body image distortions"
    - Numerous researchers have documented the tendency of anorexic patients to overestimate the size of their bodies (Garner & Garfinkel, 1981; Collins, Beumont, Touyz, Krass, Thompson & Philips, 1987; Freeman, Thomas, Solyom & Koopman, 1985), whereas others have found a lack of differences with normal controls (Smeets & Panhuysen, 1995; Probst, Vandereycken, Van Coppenolle, Pieters, 1998).
    - Recent findings point to the greater significance of emotional and attitudinal factors of body image over the purely perceptual aspects of body size estimations. Fernandez-Aranda, Dahme & Meermann (1999) concluded that there is no evidence for a serious impairment of body size perception (estimation) in eating disorder patients, but rather for a disturbance in the emotional aspects of body image, as expressed in negative body attitudes.
    - Smeets, Ingleby, Hoek & Panhuysen (1999), found that AN participants had more negative feelings and cognitions towards their bodies than the control group (normal & thin people) and stressed the importance of the influence of cognitions and emotions in body "image".
    - Probst, Vandereyken, Van Coppenolle & Pieters (1998) suggest that the latter be renamed body "experience" since it includes affective, cognitive and physical components and the notion of body "image" overemphasises the idea of visual perception of the body and distortions in these.
    - It is of interest to note that Garner & Bemis in 1982 already argued that the refractory self perceptions of anorexic patients did not seem to represent a true perceptual disturbance but were rather products of the same prepotent cognitions that supported the anorexic behaviour pattern.

B. Weight-related self-schemata & differential processing of information:

0.Clinical reports

a. Patients with Anorexia hold a negative self-image, characterising themselves as ineffective and dissatisfied (Garner & Garfinkel, 1981; Slade & Dewey, 1986.

1 Self-statements

b. Cooper & Fairburn (1992) collected self-statements from patients with eating disorders, dieters and non-dieting controls, whilst they performed three behavioural tests (looking at themselves in a full length mirror, weighing themselves and eating chocolate). They found that patients with eating disorders had more negative self-statements about eating, weight and shape during the task than normal controls, while dieters occupied an intermediate position.

c. Cooper & Fairburn (1992) found that concerns in the normal controls and dieters was similar to that found in patients with BN and was different from that found in AN. This suggested that there could be an extension of concern found in the general population in BN , while in AN concerns and preoccupation may be qualitatively different; ie. the meaning of weight could be more elaborated, idiosyncratic and emotionally charged for AN patients than for others. AN sufferers may hold a normative disturbed view about weight, where slimness equates with self control, virtue, beauty, mastery, and competence (Bemis Vitousek & Hollen, 1990).

Table 9.3: Summary of recently gathered evidence regarding the different aspects of the cognitive theories of AN developed **page 2**

2. Schema in a given domain tend to produce systematic errors in the processing of information relevant to that domain (Turk & Salovey, 1985)

d. Selective attention & memory: using the Stroop (Stroop, 1935) colour naming paradigm. Channon (1988) found indicators of “’selective attention“’ in AN patients. Anorexics proved slower than controls in colour-naming words, but were particularly slow when food-related words were presented. Similar results were obtained by Ben-Tovim, Walker, Fok & Yap (1988) who asserted that AN & BN participants were significantly slower in naming the colour of the ink in which food-related words were printed than in identifying the ink colour of neutral words in responding to the former stimuli. In addition BN participants manifested a delayed response to weight related words, with anorexics showing a trend in the same direction.

e. “’interpretative bias“’ (ie. confirmatory bias etc.): Cooper (1997) in a study of bias in interpretation of ambiguous scenarios in eating disorders found, that patients with AN & BN when presented with case scenarios that had a negative outcome, would respond spontaneously to open ended questions with a weight and shape interpretation. In the forced-choice format, they selected the weight and shape interpretation in preference to interpretations not connected to shape and weight. Cooper (1997) states that patients may project their concerns about eating, shape and weight into a wide range of situations (Cooper, 1997; Bemis Vitousek & Hollen, 1990).

C. Control:

1. Assessing perception of control over events study

a Dalgleish, Tchanturia, Serpell, Hems, de Silva & Treasure (2001) investigated the above in groups of patients with AN, BN and healthy controls. Results indicated that on the one hand the two eating disorder groups perceived themselves as having less personal control over events in the world, relative to healthy controls, even if depression levels were co-varied out. Furthermore, the eating disorder groups also exhibited a depressive attributional style (they made more internal, global, and stable attributions for negative events in the world). On the other hand for specific negative events that had actually occurred, they made a depressive attributional analysis that involved attributing the cause of those bad events to aspects of themselves. Based on this data the authors of this paper concluded that it could be tentatively argued that this reduced sense of agency represents a process central to the core eating disorder pathology, as discussed by Slade (1982), Fairburn, Shafran & Cooper (1999), whereas the depressive attributional style could be seen as a function of associated depressed mood (Dalgleish, Tchanturia, Serpell, Hems, de Silva & Treasure (2001).

D. Diffuse anxiety in stressful situations: resolving the "insoluble":

0.Clinical reports, self-statements, case scenarios, psychometric support

a. Marilov, Crisp & Ben-Tovim (2000) found that AN sufferers express diffuse anxiety in stressful situations and they appear to retreat into illness as a means of resolving the "insoluble".

b. This relates to what Cooper (1997) earlier suggested when she stated that patients faced with ambiguous scenarios give it a shape & weight interpretation. Ie. in a time of overwhelmedness and diffuse anxiety, core beliefs about ones own inadequacy surface and cognitive distortions go unchallenged.

c. This links to the suggestion that AN is functional underneath the superficial notions of weight and shape in that it serves to simplify, organise and stabilise the individuals experience of herself and the environment, providing a concise and inclusive set of rules from which appropriate attitudes & behaviour can be deducted and a blind panic avoided, as asserted by Bemis Vitousek & Hollen, 1999).

d. Finally, many anorexics (especially of the restrictive sub-type) show perfectionistic or obsessional tendencies (Dally & Gomez, 1979; Strober, 1980; Marilov, Crisp & Ben-Tovim, 2000).

9.9 References:

APA - American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).* Washington DC: APA.

April, J., Zhu, B.S., & Walsh, B.T. (2002). Pharmacologic Treatment of Eating Disorders. *Canadian Journal of Psychiatry, 47* (3), 227-234.

Beck, A.T. (1976). *Cognitive Therapy and the Emotional Disorders.* New York: International Universities' Press.

Beck, A.T., & Emery, G. (1979). *Cognitive Therapy of Anxiety and Phobic Disorders.* Philadelphia: Centre for Cognitive Therapy.

Beck, A.T. (1985). *Cognitive Therapy: Basics & Beyond.* New York: Guildford Press.

Ben-Tovim, D., Walker, M.K., Fok, D., & Yap, E. (1988). An Adaption of the Stroop Test for Measuring Shape & Food Concerns in Eating Disorders: A Quantitative Measure of Psychopathology? New York: *Paper Presented at the Third International Conference on Eating Disorders.*

Bemis, K.M. (1978). Current Approaches to the Etiology and Treatment of Anorexia Nervosa. *Psychological Bulletin, 85,* 593-617.

Bemis Vitousek, K., & Hollen, S.D. (1990). The Investigation of Schematic Content in Processing in Eating Disorders. *Cognitive Therapy & Research, 14* (2), 191-214.

Beumont, P.J.V., George, G.C.W., & Smart, D.E. (1976). Dieters and Vomiters and Purgers in Anorexia Nervosa. *Psychological Medicine, 6,* 617-622.

Bliss, E.L., & Branch, C.H.H. (1960). *Anorexia Nervosa: It's History, Psychology, and Biology.* New York: Paul Hoeber.

Boersma-Heller, J.G. (2001). *Towards a Representation of Participants' Experience of Attenuated Cognitive-behavioural Therapy of Bulimia Nervosa Incorporating a Self-help Manual – a Qualitative Retrospective Study.* Unpublished MSc Counselling Psychology Thesis. London: City University.

Bowers, A. (2001). Basic Principles for Applying Cognitive-behavioural Therapy to Anorexia Nervosa. *The Psychiatric Clinics of North America, 24* (2), 293-303.

Bruch, H. (1973). *Eating Disorders: Obesity, Anorexia Nervosa, and the Person Within.* New York: Basic Books.

Bruch, H. (1977). Psychological Antecendents of Anorexia Nervosa. In Vigersky R.A. (ed. *Anorexia Nervosa.* New York: Raven Press.

Casper, R.C., & Davis, J.M. (1977). On the Course of Anorexia Nervosa. *American Journal of Psychiatry, 134,* 974-978.

Channon, S. (1988). *Anorexia Nervosa: Clinical and Experimental Studies.* Inpublished PhD Dissertation. London: University of London.

Channon, S., & de Silva, P. (1985). Psychological Correlate of Weight Gain. *Journal of Psychiatric Research, 19,* 267-271.

Channon, S., de Silva, P., Hemsley, D., & Perkins, R. (1989). A Controlled Trial of Cognitive-behavioural and Behavioural Treatment in Anorexia Nervosa. *Behaviour Research & Therapy, 27* (5), 529-535.

Clark, D.M. (1997). Panic Disorder and Social Phobia. In D.M. Clark and C.G. Fairburn (Eds.) *Science and Practice of Cognitive Behavioural Therapy.* Oxford: Oxford Medical Publications

Collins, J.K., Beumont, P.J., Touyz, S.W., Krass, J., Thompson, P., & Philips, T.

(1987). Variability in Body Shape Perception in Anorexic, Bulimic, Obese & Control Subjects. *International Journal of Eating Disorders, 6,* 633-638.

Cooper, M. (1997). Bias in Interpretation of Ambiguous Scenarios in Eating Disorders. *Behaviour, Research & Therapy, 35* (7), 619-626.

Cooper, M. (1997). Cognitive Theory in Anorexia Nervosa and Bulimia Nervosa; A Review. *Behavioural and Cognitive Psychotherapy, 25,* 113-145.

Cooper, P.J., & Cooper, Z. (1988). Eating Disorders. In Miller E. & Cooper P.J. (Eds.) *Adult Abnormal Psychology.* Edinburgh: Churchill Livingstone.

Cooper, M.J., & Fairburn, C.G. (1992). Thoughts About Eating, Weight and Shape in Anorexia Nervosa & Bulimia Nervosa. *Behaviour Research & Therapy, 30* (5), 501-511.

Crisp, A.H. (1965). Clinical and Therapeutic Aspects of Anorexia Nervosa: A Study of 30 Cases. *Journal of Psychosomatic Research, 9,* 67-78.

Crisp, A.H., Norton, K., & Gowers, S. (1991). A Controlled Study of the Effect of Therapies Aimed at Adolescent and Family Psychopathology in Anorexia Nervosa. *British Journal of Psychiatry, 159,* 325-333.

Dalgleish, T., Tchanturia, K, Serpell, L., Hems, S., De Silva, P., & Treasure, J. (2001). Perceived Control Over Events in the World in Patients with Eating Disorders. *Personality & Individual Differences, 31* (3), 453-460.

Dally, P., & Gomez, J. (1979). *Anorexia Nervosa.* London: Heinemann.

Dare, C., Eisler, I., Russell, G., & Dodge, L. (2001). Psychological Therapies for Adults with AN: Randomised Controlled Trial of Outpatient Treatment. *British Journal of Psychiatry, 178,* 216-221.

De Silva, P. (1995). Cognitive-behavioural Models of Eating Disorders. In G. Szmukler, C. Dare, J. Treasure (Eds.) *Handbook of Eating Disorders - Theory, Treatment & Research.* Chichester: John Wiley & Sons.

Drenowski, A., Pierce, B., & Halmi, K.A. (1988). Fat Aversion in Eating Disorders. *Appetite, 10,* 119-131.

Duker, M., & Slade, P. (1988). *Anorexia Nervosa & Bulimia: How to Help.* Milton Keynes: Open University Press.

Eisler, I., Dare, C., Russell, G., Szmukler, G., le Grange, D., & Dodge, L. (1997). Family and Individual Therapy in Anorexia Nervosa: a 5 Year Follow-up. *Archives of General Psychiatry, 54,* 1025-1030.

Fairburn, C.G. (1997). Eating Disorders. In D.M. Clark & C.G. Fairburn (Eds.*) Science and Practice of Cognitive Behavioural Therapy pp. 209-241.* Oxford: Oxford University Press.

Fairburn, C.G., Cooper, Z., & Shafran, R. (2003). Cognitive Behavioural Therapy for Eating Disorders: A "Trans-diagnostic" Theory and Treatment. *Behaviour Research & Therapy, 41,* 509-28.

Fairburn, C.G., Shafran, R., & Cooper, Z. (1999). A Cognitive-*behavioural Theory of Anorexia Nervosa. Behaviour* Research & Therapy, 37 (1), 1-13.

Farquharson, R.F., & Hyland, H.H. (1966). Anorexia Nervosa: the Course of 15 Patients Treated from 20-30 Years Previously. *Canadian Medical Association Journal, 94,* 411-419.

Fernandez-Aranda, F., Dahme, B., & Meermann, R. (1999). Body Image in Eating

Disorders and Analysis of its Relevance: a Preliminary Study. *Journal of Psychosomatic Research, 47* (5), 419-428.

Fichter, M., & Quadfleig, N. (1999). Six-year Course and Outcome of Anorexia Nervosa. *International Journal of Eating Disorders, 26,* 359-385.

Fombonne, E. (1995). Anorexia Nervosa. No evidence of an Increase. *British Journal of Psychiatry, 166,* 462-471.

Freeman, C. (2002). *Overcoming Anorexia Nervosa: a Self-help Guide Using Cognitive-behavioural Techniques*. London: Robinson.

Freeman, R.J., Thomas, C.D., Solyom, L., & Koopman, R.F. (1985). Clinical & Personality Correlates of Body Size Overestimation in Anorexia Nervosa & Bulimia Nervosa. *International Journal of Eating Disorders, 4,* 439-456.

Freud, S. (1905). *Three Essays on Sexuality & Other Works.* London: Hogarth Press.

Galdston, R. (1974). Mind over Matter: Observations of 50 Patients Hospitalised with Anorexia Nervosa. *American Academy of Child Psychiatry Journal, 13*, 246-263.

Garfinkel, P.E. (2002). Eating Disorders. *Canadian Journal of Psychiatry, 47* (3), 225-226.

Garfinkel, P.E., Moldofsky, H., Garner, D., Stancer, H.C., & Coscina, D.V. (1978). Body Awareness in AN: Disturbances in "Body Image" and "Satiety". *Psychosomatic Medicine, 40,* 487-498.

Garner, D.M., & Bemis, K.M. (1982). A Cognitive-behavioural Approach to Anorexia Nervosa. *Cognitive Therapy and Research, 6* (2), 123-150.

Garner, D.M., & Bemis, K.M. (1985). A Cognitive-behavioural Approach to Anorexia Nervosa. In D.M. Garner & P.E. Garfinkel (Eds.) *Handbook of Psychotherapy for Anorexia Nervosa and Bulimia pp107-146.* New York: Guilford Press.

Garner, D.M., & Garfinkel, P.E. (1978). Socio-cultural Factors in Anorexia Nervosa. *Lancet, 2, 674.*

Garner, D.M., & Garfinkel, P.E. (1980). Socio-cultural Factors in the Development of Anorexia Nervosa. *Psychological Medicine, 10,* 649-656.

Garner, D.M., & Garfinkel, P.E. (1981). Body Image in Anorexia Nervosa: Measurement, Theory and Clinical Implications. *International Journal of Psychiatric Medicine, 11,* 263-284.

Garner, D.M., Garfinkel, P.E., & Bemis, K.M. (1982). A Multidimensional Psychotherapy for Anorexia Nervosa & Bulimia. *International Journal of Eating Disorders, 1,* 3-46.

Garner, D.M., Vitousek, K.M., & Pike, K.M. (1997). Cognitive-behavioural Therapy for Anorexia Nervosa. In D.M. Garner & P.E. Garfinkel (Eds.) *Handbook of Treatment for Eating Disorders pp 94-144.* New York: Guildord Press.

Gull, W. (1874). Proceedings of the Clinical Society of London. *British Medical Journal, 1,* 527-529.

Harri, E.C., & Barraclough, B. (1998). Excess Mortality of Mental Disorder. *British Journal of Psychiatry, 173,* 11-53.

Hauserman, N., & Lavin, P. (1977). Post-hospitalisation Continuation Treatment of Anorexia Nervosa. *Journal of Behaviour Therapy and Experimental Psychiatry, 8,* 309-313.

Hollon, S.D., & Beck, A.T. (1979). Cognitive Therapy of Depression. In . P.C. Kendall &

S.D. Hollon (Eds.) *Cognitive-behavioural Interventions: Theory, Research & Procedures.* New York: Academic Press.

Kaplan, A. S. (2002). Psychological Treatments for Anorexia Nervosa: A review of Published Studies and Promising New Directions. *Canadian Journal of Psychiatry, 47* (3), 235-242.

Kearney-Cooke, A., & Striegel-Moore, R. (1997). The Etiology of Body Image Disturbance. In D.M. Garner & D.E. Garfinkel (Eds.) *Handbook of Treatment for Eating Disorders pp295-305.* New York: New York Press.

Laseque, E.C. (1873). On Hysterical Anorexia. *Medical Times Gazette, 2,* 265-260.

Lee, S., Ho, T.P., & Hsu, L.K.G. (1993). Fat Phobic & Non-fat Phobic Anorexia Nervosa: a Comparative Study of 70 Chinese Patients in Hong Kong. *Psychological Medicine, 23,* 999-1017.

Marilov, V.V., Crisp, A.H., & Ben-Tovim D. (2000). Personal Behaviour & Mental State in Anorexia Nervosa. *The (Russian) Neurology and Psychiatric Journal, 2,* 19-22.

Pawluck, D.E., & Gorey, K.M. (1998). Secular Trends in the Incidence of Anorexia Nervosa: Integrative Review of Population-based Studies. *International Journal of Eating Disorders, 23,* 347-352.

Probst, M., Vandereycken, W., Van Coppenolle, H., & Pieters, G. (1998). Body Size Estimation in Anorexia Nervosa Patients: The Significance of Overestimation. *Journal of Psychosomatic Research, 44* (3-4), 451-456.

Rastam, M., Gillberg, C., & Garton, M. (1989). Anorexia Nervosa in a Swedish Urban Region. A Population-based Studies. *British Journal of Psychiatry, 155,* 642-646.

Russell, G., Szmukler, G., Dare, C., & Eisler, I. (1987). An Evaluation of Family *Therapy in Anorexia and Bulimia Nervosa. Archives* of General Psychiatry, 44, 1047- 1056.

Schmidt, U. (1997). Behavioural Therapy, Cognitive Behavioural Therapy and Cognitive-analytic Method in the Treatment of Anorexia Nervosa. *Psychotherapy, Psychosomatic Medicine & Psychology, 47* (9-10), 316-320.

Schmidt, U., Tiller, J., & Morgan, H.G. (1995). The Consequences of Eating Disorders. In G. Szmukler, C. Dare, & J. Treasure (Eds.) *Handbook of Eating Disorders.* Wiley: London.

Schmidt, U., & Treasure, J. (1998). Workbook: Motivational Enhancement Therapy. Unpublished manuscript. London: OEDU, Maudsley Hospital.

Serfaty, M.A. (1999). Cognitive Therapy versus Dietary Counselling in the Outpatient Treatment of Anorexia Nervosa: Effects of the Treatment Phase. *European Eating Disorder Review, 7,* 334-350.

Shafran, R., Cooper, Z., & Fairburn, C.G. (2002). Clinical Perfectionism: A Cognitive-behavioural Analysis. *Behaviour Research & Therapy, 40* (7), 773-791.

Slade, P. (1982). Towards a Functional Analysis of Anorexia Nervosa & Bulimia Nervosa. *British Journal of Clinical Psychology, 21,* 167-179.

Slade, P.E., & Dewey, ME. (1986). Development and Preliminary Validation of SCANS: a Screening Instrument for Identifying Individuals at Risk of Developing Anorexia and Bulimia Nervosa. *International Journal of Eating Disorders, 5,* 517-538.

Skrzypek, S., Wehmeier, P.M., & Remschmidt, H. (2001). Body Image Assessment

Using Body Size Estimation in Recent Studies on Anorexia Nervosa: a Brief Review. *European Child & Adolescent Psychiatry, 10,* 215-221.

Smeets, M.A.M., Ingleby, J.D., Hoek, H.W., & Panhuysen, G.E.M. (1999). Body Size Perception in Anorexia Nervosa. *Journal of Psychosomatic Research, 46* (5), 465-477.

Smeets, M.A.M., & Panhuysen, G.E.M. (1995). What can Be Learned From Body Size Estimation. *Eating Disorder Journal of Treat. & Prev., 3,* 101-114.

Strober, M. (1980). Personality and Symptomatological Features in Young, Non-chronic Anorexia Nervosa Patients. *Journal of Psychosomatic Research, 24,* 353-359.

Stroop, J.R. (1935). Studies of Inference in Serial Verbal Reactions. *Journal of Experimental Psychology, 18,* 643-662.

Sullivan, P.F. (1995). Mortality in Anorexia Nervosa. *American Journal of Psychiatry, 152,* 1073-1074.

Sunday, S.R., Einhorn, A., & Halmi, K.A. (1992). The Relationship of Perceived Macronutrient and Caloric Content & Affective Cognitions about Food: Eating Disordered, Restrained & Unrestrained Subjects. *American Journal of Clinical Nutrition, 55,* 362-371.

Sunday, S.R., & Halmi, K.A. (1990). Taste Perceptions and Hedonics in Eating Disorders. *Physiological Behaviours, 48,* 587-594.

Teasedale, J.D. (1985). Psychological Treatments for Depression – How do they Work? *Behavioural Research & Therapy, 23* (2), 157-165.

Teasedale, J.D., & Barnard, P.J. (1993). *Affect, Cognition & Change: Re-modelling Depressive Thought.* Hove: Lawrence Erlbaum Associates.

Teasedale, J.D. (1997). The Relationship between Cognition & Emotion: the Mind-in-place in Mood Disorders. In D.M. Clark & C.G. Fairburn (Eds) *Science and Practice of Cognitive Therapy.* Oxford: Oxford Medical Publications.

Treasure, J. (2002). Evidence Based Treatments for Anorexia Nervosa. *European Psychiatry, 17,* Suppl 1:17.

Treasure, J., & Schmidt, U. (2001). Anorexia Nervosa. *Clinical Evidence 6,* 705-714, BMJPubl.

Treasure, J.L., & Ward, A. (1997). Cognitive Analytic Therapy in Eating Disorders. *Clinical Psychology and Psychotherapy, 4,* 62-71.

Turk, D.C., & Salovey, P. (1985). Cognitive Structures, Cognitive Processes, and Cognitive-behavioural Modification: I. Client Issues. *Cognitive Therapy & Research, 9,* 1-17.

Turnbull, S., Ward, A., Treasure, J., Jick, H., & Derby, L. (1996). The Demand for Eating Disorder Care: an Epidemiological Study Using the General Practice Research Data Base. *British Journal of Psychiatry, 169,* 705-712.

Van Hoeken, D., Lucas, A.R., & Hoek, R.W. (1998). Epidemiology. In H.W. Hoek, J.L. Treasure, M.A. Katzman (Eds.). *Neurobiology in the Treatment of Eating Disorders.* John Wiley & Sons, Chichester.

Vitousek, K., Watson, S., & Wilson, G.T. (1998). Enhancing Motivation for Change in Treatment-resistant Eating Disorders. *Clinical Psychology Review, 18* (4), 391-420.

Wilson, G.I., & Fairburn, C.G. (1998). Treatment for Eating Disorders. In P.E. Nathan &

J.M. Gorman (Eds) *A Guide to Treatments that Work.* New York USA: Oxford University Press.

Wolff, G., & Serpell, L. (1998). A Cognitive-model & Treatment Strategies for AN. In H.W. Hoek & J.L. Treasure & M.A. Katzman (Eds.) *Neurobiology in the Treatment of Eating Disorders.* Chichester: John Wiley & Sons.

Wolpe, J. (1958). *Psychotherapy by Reciprocal Inhibition.* Stanford: Stanford University Press.

SECTION D

A CASE STUDY OF PROFESSIONAL PRACTICE

CHAPTER TEN: (ATTENTUATED) CBT for (ATYPICAL) ANOREXIA NERVOSA – *Loss of a girlhood & self in childhood & beyond*[1]

Because this case was profoundly challenging in many ways, and I learned so much from engaging in this work, I am presenting and sharing it herewith, whilst it fits within/adds to the portfolio, for the reasons outlined in section A.

All names have been changed for reasons of confidentiality.

10.1 Biographical Information

Holly was 29 years old on entering therapy. She is Afro-caribbean in origin, but was born and grew up in East London, the third oldest in a family of five girls. Holly reported that her father was a violent man, who beat up her mother and all the children, whilst being unfaithful to his wife. Holly said that her mother was the breadwinner in the family, as her father's income was spent on gambling and being generous to others. This led to Holly's father and mother separating from each other when Holly was fifteen. Her father remarried, moved to Canada and lost contact with the family. She noted that her youth was marred by her father's physical and verbal abuse of her, but also by severe sexual abuse, which was linked to the above family dynamics and was perpetrated by her grandfather and his brother from a very early age, who were amongst her carers. She reported that aged fifteen, she confided in a teacher about the sexual abuse, a time which coincided with her parents going through a divorce. However, no one in the family owned up to the

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[1] This case study was written during my Post-MSc Counselling Psychology training in September 2001

sexual abuse or the family dynamics involved in it. Holly was left to carry the blame for both the sexual abuse and for tearing the family further apart. She said that she became increasingly depressed by this, spent a lot of time in bed not eating, and has not been free from distress around food ever since. Holly did not return to school, and left without qualifications. She eventually started working as a trainee seamstress making dresses, and later worked in quality control. She did not enjoy this line of work and began training as a nursery nurse. However, she said that she unduly worried about the children in her charge and in the end had to give up training, due to a "nervous break-down" in 1992. She came under St. Clements hospital for the above difficulties.

She told me that in 1994 she started working for Mind in one of their shops, whilst campaigning on behalf of another project for people with mental health problems. Holly met T. in 1992 at St. Clements and has not only been a mere friend, but also in a girlfriend-boyfriend relationship with him, on and off. T. suffers from "paranoia" and colitis. Holly and T. do not live together, however, she shares her flat with two dogs and four cats, whose company she greatly enjoys. She has very little in the way of other friends. Holly's mother now lives in the North of England, and has recently remarried. Holly is in contact with her over the phone, and their relationship is reported to be better than it once was. Holly is in regular contact with her oldest sister, her brother in law and her two nephews and niece who live in London, to whom she says she feels closest of all her siblings.

10.2 The client's definition of the problem and the reasons for seeking help:

Holly was referred to the Maudsley Hospital Out-patient Eating Disorder Unit by her GP with a view to assessment, review and management of what he noted to be a severe long-standing eating disorder. He reported that Holly had been on a number of different anti-depressants over the years and had had a course of Cognitive Analytic Psychotherapy more recently. She told me that the anti-depressants lifted her mood somewhat and though therapy did not improve her eating very much, she had found it worthwhile as an introduction to therapeutic work and felt that she had started to understand herself a little bit better as a person. What with the eating disorder affecting Holly on a daily basis, and taking over more and more parts of her life, she reported that she now expressed the wish to obtain specialist help with her eating disorder and the unresolved trauma underlying it. She noted that she was particularly keen to work with a female therapist and do the latter, as her previous therapist had been male and she had been too ashamed to be able to freely talk about the childhood sexual abuse to him and she felt that she had only touched upon it in passing.

Upon assessment Holly was found to diagnostically fulfill the criteria for atypical anorexia nervosa, in that her Body Mass Index (BMI) was 18.29 (49.8kgs/2.7225m2), which was below the lower end of the normal healthy range, but was not enough to define anorexia itself (which is defined as a BMI < 17.5, i.e. a reduction of body weight to at least 15% below that expected for age and height). Holly presented with an absence of three consecutive menstrual cycles, when otherwise expected. She clearly featured anorexic ways of thinking and behaving. She weighed herself several times a day and was very unhappy and anxious about her weight. She craved losing weight and suffered from self-induced weight loss by means of starving herself, "binging", vomiting and using laxatives (AN "binge"/purge sub type). This, collectively, led to a DSM-IV classification and diagnosis of atypical anorexia nervosa (AN), "binge"/purge sub-type (APA, 1996).

Holly was allocated to me for individual therapy one month after her initial assessment at the Unit.

10.3 The nature of the contact agreed upon:

a. Goals:

The goals of the anorexia treatment offered to Holly in broad terms were as follows: To (a) *introduce medical monitoring, including weekly weighing, and to engage* Holly in coming to a cognitive and emotional re-appraisal of anorexia, using motivational techniques. To (b) explore the development of core schema about self and others and link these to the onset of anorexia, whilst coming to an understanding of the meaning of the symptoms. To (c) help the client reframe the beliefs derived from early social interactions and develop alternative self schema, whilst designing strategies to change behaviour, recruit support and plan for ending. The goals of *monthly follow-up were, to (i) consolidate on the above and to (ii) focus on relapse* prevention and maintenance of change.

b. Structure:

It was initially decided that twenty 60 minute sessions once weekly of one to one cognitive (behavioural) therapy would be offered with five follow-up sessions at monthly intervals. The model used at the Unit integrates motivational interviewing into an essentially cognitive (behavioural) framework, using homework assignments as an accompaniment to treatment, in the shape of a therapy workbook, given at assessment. Medical monitoring forms a vital part of treatment, and the importance and purpose of weekly weighing and regular blood-tests are thus emphasised. It is explained to any participant in the therapy programme, that if weight falls significantly or there are physical symptoms, an urgent medical assessment would be arranged with a view to in-patient treatment.

After assessment Holly signed a treatment contract with the Unit in which it was suggested that in the event she was unable to make a session she would try to give me 24 hours notice by phoning the Unit and that the session would be lost if she failed to notify me in time. She would have to start the referral process again in the event she did not turn up for two consecutive sessions without giving sufficient reason. It was made clear that the latter measure had been put in place considering the Unit has a waiting list and had to be time and resource efficient.

c. Boundaries:

It was emphasised that client-therapist discussions would be confined to the allocated sessions only and that concerns would not normally be discussed over the phone.

d. Confidentiality and Supervision:

Holly was familiar, from previous therapy, with a therapist (trainee at the time) keeping extensive case notes and the concept that material would be submitted to an in-hospital supervisor for further reflection upon my therapeutic interventions, as well as to my university tutor for evaluation purposes (with name changes to ensure confidentiality). Considering Holly's history of childhood sexual abuse and the sensitivity of taping material that she may never have told, and the possible overwhelmedness that she might experience at the prospect of having such detail recorded, I did not tape our sessions as a whole (Bor & Watts, 1999). However, during session 28 we decided together that it would be beneficial for Holly and I to each have a tape of our "goodbye" sessions, since this would entail a session in which we planned to re-evaluate our work together, whilst considering ways of moving forward in the month ahead and in follow-up. Bearing in mind that it would be our last once-weekly session of working together for well over a year, we gathered that a lot of difficult emotions would surface and that tapes would allow us to go back to anything that we might have missed as a result of this. Thus informed consent for taping this session was obtained.

10.4 Approaches, strategies, techniques and application of psychological knowledge and theory to understanding of work with the client:

Anorexia nervosa has been known in the Western and non-Western world throughout the ages, however, became more specifically medicalised in the latter half of the 19th century with the publications of the accounts of the physician Gull (1874) and Laseque (1873). Anorexia is considered to form a quintessentially women's disorder, as only 4% of those suffering from AN are male. It effects women of all social classes, has a median age onset of 17, and represents the third most common condition in adolescence (Lucas, Beard & O'Fallon, 1991). The incidence of anorexia in the general population of the UK is estimated at 7 per 100.000, which has remained stable over time (Turnbull, Ward, Treasure, Jick & Derby, 1996). However, Nielsen (1990) advocates that re-admission rates have increased, taking into account that AN appears now to be running a more chronic and severe course. The mortality rate of anorexia is twice that of other psychiatric illnesses, and is 20 times that of the general population. The suicide rate is 200 times that of the general population (Nielsen, Moller-Madsen, Isager, Jorgenson, Pagsberger & Theander, 1998).

The existence of anorexia, as a severe mental and potentially fatal illness, has generated the need for the development of a theoretical model explaining the disorder, whilst in the main providing a rationale for the design of a framework of care.

According to Smukler, Dare & Treasure, 1995) in its most basic form, AN may be conceptualised as a learned behaviour, which is maintained by positive reinforcement. Losing weight, being in control and achieving a slim figure in Western society, meets with approval and attention, whilst avoiding the social disapproval, anxiety and failure, that is associated with weight gain (Smukler, Dare & Treasure, 1995). This positive reinforcement can be so powerful that the individual maintains the anorexic behaviour, despite eventually suffering from obvious severe emaciation and an increased risk of physical ill health, such as circulatory, gastro-intestinal problems, and osteoporosis.

In more recent years, the role of cognitions (thoughts, images, ideas, attitudes and so on) and particularly that of maladaptive thinking (distorted ideas about weight, shape, eating, food, control and so on), in mood and human behaviour, have come to be implicitly recognised (Garner & Bemis, 1985; Bruch, 1973). This has lead to the development of cognitive behavioural model of anorexia, similar to that of Beck's on depression, which promotes change through identifying, evaluating and altering unhelpful thoughts and beliefs (Beck, 1976). However, no such (manualised) approach to the treatment of anorexia, grounded in empirical research, has currently been developed. Whereas, the treatment of atypical AN has been even more poorly characterised and studied (Clark & Fairburn, 1997). Any recommendations that are available for the treatment of anorexia come from observations and theoretical accounts of experienced clinicians who specialise in the treatment of these clients (Hawton, Salkovskis, Kirk & Clark, 2000). Therefore, the Maudsley Outpatient Eating Disorder Unit (OEDU) team, has developed a model and manual of therapy, which is called "the Maudsley model of outpatient care for AN". This is essentially an in-depth cognitive (behavioural) model, which integrates motivational interviewing and which the team has found to provide a relevant starting point for therapy with anorexia, whilst forming the treatment of choice for the case study under review (Wolff & Serpell, 1998; Treasure, 2000).

The above model of therapy for anorexia nervosa has evolved from earlier cognitive behavioural models and takes into account the relevance of more general features in the psychopathology of anorexia. It not only considers cognitive distortions around weight, body image as "core" features of the disorder, but also includes the presence of abnormalities in aspects of self-esteem and the relevance of relatively stable, deep seated beliefs or interpersonal-schemata about self and others and the historical development of these (Wolff & Serpell, 1998; Vitousek – nee Bemis - & Hollen, 1990; Treasure, 2000).

The model does not assume that clients are fully committed to the therapeutic journey towards recovery, when entering therapy (Treasure & Ward, 1997). The disorder can be quite ego-syntonic, in that clients might deny the problem, which is often in stark contrast with the obvious state of emaciation that their body is in. This particular client group is unusual in that it rarely seeks help without any reservations, and the motivation to get help varies considerably.

Therefore motivational interviewing, as described by Miller & Rollnick (1991), which is successfully used in the field of addictions[2], is engaged in as an adjunct to, and integrated with a cognitive conceptualisation of AN. This makes up the first component of this therapeutic model and strongly informs the patient manual used in the OEDU (Treasure, 2000) and the accompanying workbook (Treasure, 1998). Motivational interviewing allows the client to explore and discover for herself, how much of a problem the eating disorder presents, whilst the therapist reflectively acknowledges the benefits and costs involved in staying with the illness.

The model proposes a "picking at the surface" of AN, using motivational interviewing and grounding strategies, and a "going deeper" by tackling abnormalities in low self-worth/efficacy and deep seated beliefs/schemata about self/others.

Throughout therapy the focus is on ending. As one of the critical features of this intervention is that it is time limited. The process of ending is formalised in goodbye letters (as used in Cognitive Analytic Therapy – Ryle, 1990), and follows on from the assessment letter and writing exercises engaged in during therapy. This letter serves to allow a bird's eye view of the process of therapy and a reflecting on the good things derived from it, whilst allowing a moving on and a further consolidation in follow-up. This letter may also serve the purpose of becoming a safety and recovery plan.

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[2] Like the alcoholic the anorexic denies she has a problem

The Maudsley model of out-patient treatment of anorexia nervosa excludes those clients who are refractory to out-patient care in that they have not responded to previous attempts at out-patient therapy. And/or when weight is falling/has fallen below a BMI of 13, which requires in-patient treatment as organs (muscle, bone, marrow, heart) are beginning to fail and re-feeding is necessary with death otherwise being imminent (Todd & Treasure, 1997).

Working with a sufferer from a-typical anorexia, and a patient who forms part of a client group which is rather heterogeneous, is very challenging. I found that I tailored my approach of working with Holly, to her as a person, to her problem presentation, and to what she indicated was needed. A detailed description of my application and tailoring of the above to the actual therapeutic work carried out with Holly, is contained in the next section.

10.5 Contents:

The goodbye letter that I wrote to Holly at the end of the intensive part of treatment (for a copy see appendix 10.1), which forms an integral part of this section, allows a bird's eye view of the therapeutic work carried out with Holly, which I am further elaborating on as follows.

"Picking" at the surface, Holly and I engaged in motivational interviewing, to consider how AN helped, and yet did not help her to deal with the issues that she had been facing. We in the meanwhile, contemplated how she could get some positive effect in a different way. Looking at a future with/without the problem and the possibility of change, also fostered a realisation that what she was doing was something that went against herself. Working non-confrontationally served to foster the development of a climate of trust, so that she would feel safe to go deeper once she had clarified what it was she wanted to address/change and what could lay behind the eating, that needed addressing.

“Going deeper” and trying to “map a way out” of the anorexic cycle, involved focusing on the sexual abuse that Holly had experience as a child and considering the maladaptive schema of herself, that she had developed as a result of this. We sough to modify these by means of cognitive restructuring. This involved weakening the strength of the negative cognitions by means of constructing alternative schema. Giving new meaning to thoughts and emotions, whilst breaking the old pattern of beliefs, assumptions, behaviours and feelings that followed from these.

There are various ways to facilitate this, and structured letter/essay writing exercises form one of these (Schoutrop, Lange, Duurland, Bermond, Sporry & Goederen, 1997). Holly was encouraged to engage in “ritualised” structured letter/essay writing, typically during a 3 day period in between once-weekly sessions. Through these she could express her deepest thoughts and feelings about the trauma of her childhood sexual abuse in a graded fashion, whilst using appropriate soothing activity, to allow herself to cope with the immediate distress generated, by processing the material in this way. The exercises addressed issues that had been discussed in therapy e.g. exploring attachment relationships and the most significant people that were the object of Holly's grief, whilst during each session the experience and effect of the assignments were discussed in turn. Challenging some of her attitudes and assumptions that she made at the time, Holly was able to take the perspective of herself as a child, whilst using her current adult insight and peruse what she really had needed then as a child and what she now needed as an adult (Burke & Drauker, 1992). Through processing the experiences in this way, the memory of the trauma became more organized and less confused, whilst Holly's core beliefs about herself, the abuse and the world were elucidated (I am guilty, worthless etc.). Linking the old self-schema to the abuse and her eating disorder, we discovered how Holly used disordered eating as a way to distract herself and decrease the guilt, dysphoria and self-hatred generated by the abuse. To interrupt feelings and experience a temporarily, but extremely reinforcing sense of emotional relief and control (Briere & Runtz, 1993; Serpell, Treasure & Teasedale, 1997). I.e. Holly described the use of laxatives as a way of "flushing away" the dirt that she felt that clung on her (see goodbye letter appendix 10.1, page 4). Mapping a way out of the anorexic cycle involved the development of new beliefs about herself (I am worthy) and the abuse (I am not guilty), and thus a removal of beliefs of worthlessness and feelings of guilt and shame (Marmar, Joy, Kagan, Pynoos, 1993; Arntz & Weertman, 1999).

The above was interleaved with a series of sessions devoted to grief work and dealing with suicidal ideation, as will be described in the following section.

10.6 The development of the therapeutic relationship, difficulties encountered, attempts to overcome them and critical assessment of these:

As outlined in the previous two sections, motivational interviewing is a tool that facilitates the client to feel that her beliefs and values are accepted as genuine for her. I expressed empathy and concern at how difficult things must feel, whilst addressing the question of where Holly was at, where she was coming from, and collaboratively help her to explore the use of the various different treatment strategies at different stages, depending on her readiness and preference.

Holly was ready to work with the abuse earlier than I had expected. When we were working together to carefully prepare the ground, built trust and make it safe to go "deeper", Holly became upset with the fact that we were still "picking" at the surface and had as yet not started to address what really had happened to her. She found it hard to engage in motivational interviewing, which included looking at the possibility of change, whilst she had not as yet had the chance to tell her story about the abuse, and she had no means of changing her disordered eating, which had become a way of coping with the unresolved trauma. She was afraid that we were maybe not going to talk about it at all (as her family had done), or just briefly work on it and then never mention it again (as in previous therapy). Everill & Waller (1995) assert that if the abuse does not get specifically addressed, other impulsive or self-destructive behaviours will arise, and this applied to Holly, as she had started drinking. We overcame this by discussing what was happening to her and, how I was treading maybe too carefully, so we could move on and talk openly and honestly about the abuse and what Holly had had to endure, as this was at the core of Holly's eating disorder, which she only knew so well, but could not as yet link in a consistent way. Following this, her drinking soon stopped, and though her eating behaviour fluctuated, Holly and I knew that she would ultimately gain more control over this. Holly was my first case who had been willing to address abuse at all, and indeed "head on". I am thankful that monitoring her behaviour and what we were considering together, and talking about this, allowed us to be in tune again, and work shoulder to shoulder on reflecting on cognitions, emotions, etc, whilst Holly communicated to me what she all along had tried to communicate.

Working with Holly, as with any client, required a good degree of flexibility. Holly lost a very dear companion pet around session 18 and we needed to take "time out" from focusing on the abuse to creating a space to look at the loss of this pet instead. Pets were Holly's life, as they were the only beings that made her feel positive about herself. However, her ability to care for them was terribly shaken when this particular cat died an untimely death in a road traffic accident (see goodbye letter, appendix 10.1, page 4). Holly had not had the opportunity to say goodbye to this pet, as the caretaker of the school across the road from her had found the body and had to bury it, as it took a couple of days before he was able to find Holly. Holly explained the death of this cat as God's punishment of her for the jay walking that she had engaged in as a child, and kept thinking that it should have been her that should have lost her life, rather than her cat etc. This loss threw up a host of issues to do with the meaning of this death in relation to the old beliefs she had about herself, as well as existential questions as to where we go when we die etc. So we spent time allowing Holly to accept the reality of this death by saying the goodbye she had not been able to say to her cat. Holly was able to experience the pain of her grief by addressing the feelings of profound sadness and reframing the feelings of guilt. She eventually readjusted to life without this pet, whilst withdrawing involvement from that relationship and reinvesting it elsewhere (Goser, 1965; Lendrum & Syme, 1992). In this process I also involved another member of the multi-disciplinary team, our OEDU chaplain, for a one-to-one, (potentially one off) session with Holly in order that she be given some positive spiritual input away from the "fearsome God" scenario, that her grandparents had harmed her with, and ask any further pastoral questions that she had. Holly engaged in one session with the chaplain, which she reported as having been very beneficial. By then therapy had been extended by a further 10 sessions (see section 10.8.). Upon the death of yet another companion pet towards session 25, we again took time to integrate this into Holly's therapy and her life. Shortly after that Holly had to go without anti-depressants, due to a GP re-prescription delay, which added to the sadness, which was still so fresh, and made her feel very suicidal. We addressed this by acknowledging Holly's pain, looking not only at her hopelessness, but also at her hopeful side, whilst problem solving on issues that she was facing. We developed a crisis plan as to whom to contact, how to avoid danger, use distracting and self-soothing strategies in the event the self-harm impulses recurred. This was in accordance with the cognitive behavioural framework for working with suicidal ideation as described by Linehan (1993) and Ellis & Newman (1996). We grew particularly close dealing with the grief and hopelessness, and this was the first time that Holly was really able to express her tears and get in touch with her emotions. When we returned to further working on the abuse, when Holly was ready for it (in order we ensured that we addressed the trauma to the extent that Holly really wanted to address it) she was able to go "deeper" than she had ever done before, and her beliefs about herself slowly started to shift further.

10.7 Client's progress, critical assessment of the therapist's interventions, development of psychological understanding and skills:

It was a great help that Holly had worked therapeutically some years previously. It was a joy working with her, as she was tremendously well able to use therapy and reflect upon what was going on for her, whilst starting to make connections between the function of her disorder and the unresolved trauma.

Working with Holly for thirty sessions and over once monthly follow-up, I was able to witness a considerable progression in her, towards the end of once-weekly intensive treatment, but more pronounced in follow-up. Holly reported in our goodbye session at the end of the intensive part of treatment, that she had been able to open up with me as she had never before and that this had enabled her to put things together and shed the feelings of guilt and shame that she had previously carried. She had an intense desire to leave the anorexia behind. This was expressed in a change in the way she carried herself. She had started to wear her hair out of her face, rather than hiding behind it, expressing a clear voice, rather than the "young girl's" voice she had come to me with, dressing in a way which put her body less "under wraps", whilst having a purposefulness about her being and slowly putting on a tiny bit of weight. She had started to mix with people again, attended craft workshops, went swimming, completed an application form with the RSPCA and had joined a support group for survivors of childhood sexual abuse etc. However, I was acutely aware of the limitations of what could be achieved in what was still such relatively short-term therapy. I also knew that miracle cures do not exist and that further recovery would not happen overnight, but that we had to be pragmatic and patient about further progress (Boersma-Heller, 2001).

In reviewing my own development in terms of psychological understanding, this case very much underlined for me, what I already know from my own personal experience of anorexia nervosa, dating back some twenty five years, that AN is not a "mere slimmers disease gone out of control" or "women behaving badly", as trivialised and portrayed in the press. However, that it is a complex illness that is in the end not about eating/not eating and which is a far cry from any hyped up public perception. Holly saw herself as having no choice, and did the only thing she could, considering the predicament she found herself in, which was to become anorexic[3]. Becoming anorexic made perfect sense to her as it would allow her to dissociate

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[3] This I had a lot of time for, though the anorexic 'choice' that I had made when a 13 year old, had been, thankfully, for totally different reasons. Having dealt with that in much self-therapy, as well as my own personal therapy, as part of my training as a counselling psychologist, and having healed from this also through a lasting/loving/nourishing/giving/accepting/problem solving relationship, allowed me to know what was my stuff and what was Holly's in this. However, it allowed me in the main, to express a high level of compassion for her predicament, yet without becoming too enmeshed and colluding with this 'choice', as I never lost the clarity that as a therapist I needed to have in terms of where therapeutically we wanted to be heading together.

from the intense negative emotions of guilt, shame, and worthlessness that she felt following the abuse that she had suffered, whilst attempting to cut her life short with the anorexia. Holly had found no comfort or safety in the attachment relationship, because when she 'came out' about the abuse, the grown ups closed ranks and denied what had happened (Todd & Treasure, 1997). Anorexia somehow allowed Holly to make sense of the environment that she was in as it gave her a "triumph" of mind over body, although a harmful "solution" to such a traumatic situation. It was exactly this that made my heart bleed for Holly. Holly's predicament clarified for me how self-denigrating beliefs following sexual abuse can be associated with symptomatology in eating disorders (Pitts & Waller, 1993). It highlighted for me the importance of addressing the abuse and everything that comes with it, for any real relief to be felt, and for lasting change to occur.

Reviewing my own development in terms of skills, I sensed that the skills and experience that I had gleaned from previous work were coming together in working with Holly, in the sense of "knowing" how to work with sufferers from anorexia nervosa, engaging in grief work, working around suicidal ideation etc. However, no piece of work is ever the same and one never becomes over-confident, but is rather humbled by the fact that there is such a variety of such very individual cases out there. This piece of work formed a real challenge in working with the trauma of childhood sexual abuse as related to disordered eating, which is such a delicate issue and was something I had never broached before. It opened up a whole area of further reading, of working practically, of making links, of using supervision.

However, working with Holly was not about collating clinical skills or experience, but rather about having the privileged opportunity of being a witness to Holly's story and finding a way of helping her to reframe this harrowing experience that was marring her life, and ultimately move on from it.

10.8 Use of supervision:

Supervision was crucial in several respects to my work with Holly. (1) I used supervision extensively to recruit medical support in containing my concerns about the physiological complications of Holly's starvation, "binging", vomiting and particularly her chronic and severe laxative abuse. As well as addressing the fact that behavioural change (ultimately leading to the so needed weight restoration) only would start to occur when Holly did not need her disordered eating as a coping strategy any more. Having a supervisor who had initially trained as a psychiatrist was very reassuring for me in respect of this.

(2) Furthermore, supervision helped me in that I was able to discuss extensively how to go about working with the sensitivities of childhood sexual abuse, as well as relating back some of the horrors that Holly had shared with me, whilst making sense of this. When Holly and I met upon the loss of her pet and the existential issues this threw up for her, my supervisor suggested I collaborate with the OEDU chaplain, something I was able to follow-up from.

(3) Vis a vis the timing of this loss, my supervisor and I discussed the wisdom of allowing a discussion with Holly as to what she felt she needed at this so difficult moment in time and perusing the possibility of extending therapy to give her some

further space to grapple with the multitude of issues that she was facing. My supervisor explored with me that there was always the possibility that I would sense that however, many/few sessions Holly and I would further contract upon, that considering the extend of the pain that she had had to endure, any extension of our work together would feel hardly adequate in the light of what had happened to her. Also I was aware that bringing the option of further session in there might have been an indication that I had no faith in Holly going it "on her own", as she would ultimately with the strength she had, and I trusted she would. So this needed to be negotiated with Holly, and she was able to ask for 10 more sessions.

(4) In supervision, as in therapy, one always works in anticipation of and planning for the final goodbye that is approaching with any client one brings. I was very keen to see that, when Holly and I said our final goodbye, that she was well integrated into some long-term survivor support group. She had told me that she had been to an Eating Disorder Association self-help group but had found the group too heterogeneous, but was now willing to engage with a support group more specifically around the abuse. My supervisor and I discussed how this would build upon the work done, whilst she could empathise with others who had similar histories, and they with her, whilst increasing her hope in seeing others managing significant distress and difficult situations in their lives. I was able to give her the address of a facilitated group in her area, which she herself then joined and followed-up from, whilst we were still seeing each other in follow-up.

10.9 References:

APA - American Psychiatric Association (1996). *Diagnostic Manual of Mental Disorders (DSM-IV-R) Revised Edition.* Washington DC: APA.

Arntz, A., & Weertman, A. (1999). Treatment of Childhood Memories, Theory, and Practice. *Behavioural Research and Therapy, 37,* 715-740.

Beck, A.T. (1976). *Cognitive Therapy and Emotional Disorders.* New York: International University Press.

Boersma-Heller, J.G. (2001). *Towards a Representation of Participant's Experience of Attenuated Cognitive Behavioural Therapy for Bulimia Nervosa, Incorporating a Self-help Manual – a Qualitative Retrospective Study. Unpublished MSc dissertation.* London: City University.

Bor, R., & Watts, M. (1999). *A Trainee Handbook – a Guide for Counselling and Psychotherapy Trainees.* London: Sage Publications.

Briere, J.N., & Runtz, M. (1993). Childhood Sexual Abuse: Long-term Sequelae and Implications for Psychological Assessment. *Journal of Interpersonal Violence, 8* (3), 312-330.

Bruch, H. (1973). *Eating Disorders.* New York: Basic Books.

Burke, D., & Drauker, C. (1992). *Counselling Survivors of Childhood Sexual Abuse.* London: Sage Publications.

Clark, D.M., & Fairburn, C.G. (1997). *Science & Practice of Cognitive Behavioural Therapy.* Oxford: Oxford University Press.

Ellis, T.E., & Newman, C.F. (1996). *Choosing to Live – How to Defeat Suicide Through Cognitive Therapy.* California: New Harbinger Publications Inc.

Everill, J., & Waller, G. (1995). Disclosure of Sexual Abuse and Psychological Adjustment in Female Undergraduates. *Child Abuse & Neglect, 19*, 93-100.

Garner, D.M., & Bemis, K.M. (1985). Cognitive Therapy for Anorexia Nervosa. In D.M. Garner & P.E. Garfinkel (Eds.) *Handbook of Psychotherapy for Anorexia Nervosa and Bulimia.* New York: Guilford Press.

Goser, G. (1965). *Death, Grief & Mourning in Contemporary Britain.* London: The Cresset Press.

Gull, W. (1974). Proceedings of the Clinical Society of London. *British Medical Journal, 1*, 527-9.

Hawton, K., Salkovskis, P.M., Kirk, J., & Clark, D.M. (2000). *Cognitive Behavioural Therapy for Psychiatric Problems – A Practical Guide.* Oxford: Oxford University Press.

Laseque, E.C. (1873). On Hysterical Anorexia. *Medical Times Gazette, 2*, 265-269.

Lendrum, S., & Syme, G. (1992). *Gift of Tears – A Practical Approach to Loss and Bereavement Counselling.* London: Routledge.

Linehan, M. (1993). *Training Manual for Treating People Who Self-harm.* New York: Guilford Press.

Lucas, A.R., Beard, C.M., & O'Fallow, W.M. (1991). 50-Year Trends in the Incidence of Anorexia Nervosa in Rochester Minnesota: a Population Based Study. *American Journal of Psychiatry, 148*, 917-922.

Marmar, C., Foy, D., Kagan, B., & Pynoos, R. (1993). An Integrated Approach for Treating Post-Traumatic Stress. *American Psychiatric Press Review of Psychiatry, 12*, 239-272.

Miller, W.R., & Rollnick, S. (1991). *Motivational Interviewing, Preparing People to Change Addictive Behaviour.* New York: Guilford Press.

Nielsen, S. (1990). The Epidemiology of Anorexia Nervosa in Denmark from 1973-1987: a Nationwide Register Study of Psychiatric Admission. *Acta Psychiatrica Scandinavica, 81,* 507-514.

Nielsen, S., Moller-Madsen, S., Isager, T., Jorgenson, J., Pagsberger, K., & Theander, S. (1998). Standardised Mortality in Eating Disorders – a Quantitative Summary of Previously Published and New Evidence. *Journal of Psychosomatic Research, 44,* 413-434.

Pitts, C., & Waller, G. (1993). Self-denigrating Beliefs Following Sexual Abuse: Associated with Symptomology of Eating Disorders. *International Journal of Eating Disorders, 13,* 407-410.

Ryle, A. (1990). *Cognitive Analytic Therapy, Active Participation in Change.* Chichester: John Wiley.

Serpell, L., Treasure, J., & Teasedale, J. (1997). Anorexia: Friend or Foe? A Qualitative Analysis of the Themes Expressed in Letters Written by Anorexia Nervosa Patients. *International Journal of Eating Disorders, 14,* 129-136.

Schoutrop, M., Lange, A., Duurland, C., Bermond, B., Sporry, A., & Goederen, A. (1997). The Effect of Structured Writing in Reprocessing Traumatic Events – an Uncontrolled Trial. *Journal of Clinical Psychology and Psychotherapy, 4,* 179-185.

Szmukler, C., Dare, C., & Treasure, J. (1995). *Handbook of Eating Disorders –*

Theory, Treatment & Research. Chichester: Wiley & Sons.

Todd, G., & Treasure, J. (1997). Concepts and Treatment of Eating Disorders. In Stuart & Sundeen (Eds.). *Principles & Practice of Mental Health Nursing.* London: Mosby International.

Treasure, J.L. (1997). *Anorexia Nervosa – a Survival Guide for Families, Friends and Sufferers.* Hove: Psychological Press.

Treasure, J.L. (1998). *Getting out of the Gilded Cage.* London: Maudsley & Bethlem Trust.

Treasure, J.L. (2000). *A Clinician's Guide to the Treatment of Anorexia Nervosa.* Hove: Psychology Press.

Treasure, J., & Ward, A. (1997). A Practical Guide to the Use of Motivational Interviewing of Anorexia Nervosa. *European Eating Disorder Review, 1,* 102-114.

Treasure, J.L., Todd, G., Szmukler, G.I. (1995). The Inpatient Treatment of Anorexia Nervosa. In G.I. Szmukler, C. Dare C. & J.L. Treasure (Eds.) *Handbook of Eating Disorders: Theory, Treatment & Research.* Chichester: Wiley.

Turnbull, S., Ward, A., Treasure, J., Jick, H., & Derby, L. (1996). The Demand for Eating Disorder Care: an Epidemiological Study Using the General Practice Research Data Base. *British Journal of Psychiatry, 169,* 705-712.

Vitousek, K.B., & Hollen, B.D. (1990). The Investigation of Schematic Content & Processing In Eating Disorders. *Cognitive Therapy & Research, 14,* 191-214.

Wolff, G., & Serpell, L. (1998). A Cognitive Model and Treatment Strategies for

Anorexia Nervosa. In H.W. Hoek, J.L. Treasure & M.A. Katzman (Eds) *Neurobiology in the Treatment of Eating Disorders.* Chichester: Wiley.

SECTION E

A SECOND CASE STUDY OF PROFESSIONAL PRACTICE

CHAPTER ELEVEN: C(B)T FOR NON-BIPOLAR/NON-PSYCHOTIC DEPRESSIVE DISORDER – *Loss of a child and sense of self as a "good mother" in young adulthood and beyond*[1]

Because this case was profoundly challenging in many ways, and I learned so much from engaging in this work, I am presenting and sharing it herewith, whilst it fits within/adds to the portfolio, for the reasons outlined in section A.

All names have been changed for reasons of confidentiality.

11.1 **Biographical Information:**

Mandy was 46 years old on entering therapy. She is Caucasian-white, of English origin, born and raised in South London, the first child in a family of two girls. Mandy reported that her father had been a driver to the catering industry, working long and awkward hours, whilst her mother supplied the family income working as a cleaner. Mandy described that her parents were largely absent during her childhood. They had left her and her sister Lisa, who was two years younger, to fend for themselves on the rather rough council estate that they lived at. She narrated that both Lisa and she felt that their parents were not particularly interested in them as children and that their mother was a very harsh and critical woman. They sensed that their parents were glad to "be rid of them", when they both left home to get married in their late teens. Mandy said that she met John, her husband to be, aged 14, discontinued her education aged 15 to start work as a cleaner, and married John

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[1] This case study was written during my Post-MSc Counselling Psychology training in February 2002

at the age of 18. The following year saw them blessed with the birth of a much wished for son Jeffrey. Another son, called Frank, followed one-and-a-half years later. However, she narrated that tragedy befell them when Frank, at the age of two-and-a-half-year, died in a "drowning" accident during a holiday in the West country. She related, that this shattered their existence, as both Mandy and John became weighed down by feelings of immense sadness and self-reproach. It made them determined to make good to Jeffrey and any subsequent children that they conceived. Following this, David was born two years later, and Ian three years following David's birth. Jeffrey is now 26 years old and lives and works in Manchester. David, now twenty, lives with Mandy and John and so does Ian, aged seventeen. Ian, David, Jeffrey & John all work in the building industry, though John has been off work for some months now, with the reoccurrence of an old ankle injury. Mandy supplies the sick benefit that John receives, doing cleaning, nannying and ironing for various local families. Mandy's sister and her family live in Bristol, whilst the parents moved there upon retirement, as well.

11.2 The client's definition of the problem and the reason for seeking help.

Having had four sessions in 1996 for a history of depression, Mandy presented to her GP in February 2001 feeling very low a lot of the time, and unable to control her eating. She stated that she very much wished to loose weight through gastric surgery and coming to see the GP she hoped would help her with that. However, since her weight was not of a level that justified the risk of surgery, her GP suggested she make an appointment with the psychologists attached to the practice for therapy, so she could look at her mood and food issues. Having joined the community counselling services' waiting list, Mandy was seen by me in April 2001. From our initial interview I got a real sense that Mandy's presentation translated into a diagnosis of non-bipolar/non-psychotic depressive disorder, as described in traditional psychiatric classifications (see Appendix 11.1 for a resume). Mandy's difficulties fitted the above in that she reported that she had started experiencing difficulties with her mood and food following the death of her son Frank, 22 years ago. Mandy's mood problems sounded quite different from the transient low mood that most people experience as a normal reaction to loss. Her affect felt accentuated in intensity and duration, since relating this loss 22 years later, brought on a fresh expression of emotions, as if Frank had died only recently. Mandy noted that she had experienced an inhibition of mental life in the shape of depressed mood, loss of interest/motivation, feelings of failure/inadequacy/incompetence, ever since the accident. As well as a slowing up physically in terms of a decrease of energy. Fatigue, however, she "staved off" by keeping active and drinking a couple of litres of cola a day. She said that she could not allow herself to relax, due to feelings of self-reproach and guilt following her son's death. Mandy found it hard to get to sleep, yet felt exhausted. On other occasions she could sleep all day. Her food intake had increased and so had her weight. She had no current suicidal ideation, or intent, yet at times in the past had felt that "it would be nice to go to sleep and not wake up". I gathered that her depression was also "primary", in that she had never been diagnosed with another non-affective disorder. In taking into consideration the amount of symptoms that Mandy presented with, I gathered that she suffered from a moderate to major depressive disorder, which had had a chronic course, and had never really lifted, since John and Mandy had buried their son. Mandy indicated that in therapy she wanted to work with me on both the food and mood issues that she was facing, especially, the overwhelming feelings of guilt that she carried surrounding her son's death.

11.3 The nature of the contact agreed upon:

a. Goals

The goals of treatment offered to Mandy in broad terms were, to create a space for Mandy to confidentially talk about and explore the issues that she is facing.

b. Structure:

A "contract" of a series of twenty 60 minute sessions of once weekly, one to one, cognitive (behavioural) therapy was offered, with five follow-up sessions at monthly intervals.

c. Boundaries:

It was emphasised that client-therapist discussions would be confined to the allocated sessions only and that concerns would not normally be discussed over the phone. In the event Mandy would be unable to make a session she would try to give me 24 hours notice by phoning the community counselling services' offices, or the GP surgery, where we met. The session would be lost to her, if she failed to notify me in time. She would have to start the referral process again in the event she did not turn up for two consecutive sessions without giving sufficient reason.

d. Confidentiality and Supervision:

Having considered the structure and boundaries of therapy, I explained to Mandy that the service I was offering her was a confidential service. However, though I would deal with her private issues respectfully and confidentially, I would also have to deal with them safely. I outlined that, therefore the community counselling service had put a "Red Flag Policy" in place, to work within the law and cover for circumstances when it would be in the interest of the client that relevant agencies be informed. I.e. that in circumstances of acute mental health crisis etc. (Mind, 2000), release of information would apply. I further elaborated, that being a Counselling Psychologist trainee, I would submit material to my clinical supervisor/university tutor for evaluation of/reflection upon my therapeutic interventions. Mandy agreed to be bound by this, upon which assessment of Mandy's issues and goal setting for our sessions together proceeded.

11.4 Approaches, strategies, techniques and application of psychological knowledge and theory to understanding of work with client:

Having systematically reviewed the thematic content of depressed peoples' cognitions, Beck (1976) developed a theory of depression and a model of intervention for this particular client group. He found that the depressed individual is characterised by a cognitive triad; consisting of a negative view of self, others and the world, of current experiences and the future, and that this influences the organisation of thought in a way that selectively attends to depressive ideas. Beck (1976) considered that the cognitive triad of the depressed client is maintained even in the face of contradictory evidence because of a style of thought, a "schema" that the depressed individual acquires early in life, partly in response to childhood experience. This may lie dormant or is inactive for a long period, but is then evoked by adverse circumstances. Once re-activated, this negative cognitive "schema" organises all perceptions and overcomes the individual's capacity for voluntary control over his/her thoughts, and negative ideas and attitudes spring up in an autonomous or automatic way. This leads to the typical symptoms associated with depression, ie. behavioural, motivational, emotional, cognitive and psychological, that traditional psychiatric classifications group together. A schematic illustration of this model, taken from Hawton, Salkovskis, Kirk & Clark (2000), can be found in Appendix 11.2. Beck's (1976) model of intervention, based on the above, therefore, was focused at changing the way the person feels by changing the way s/he thinks and to find different ways of being. Either at "surface" level, working with negative automatic thoughts, questioning these and challenging the assumptions on which they are based. Working in the here and now, targeting symptomology, engaging cognitively and behaviourally, using ABC diaries, positive data logs, scheduling activities etc, raising awareness of and challenging/breaking both thought and behavioural patterns, which subsequently impacts upon the person's affect (Beck, Rush, Shaw, Emery, 1979). And/or, digging "deeper" and unraveling the formation of dysfunctional assumptions and working around the critical incident that re-activated the assumptions and reframing these experiences and the assumptions derived from them. Working at "schema" level, which then has a knock on effect onto the later chains, and the person's emotional life (Greenberger & Padesky, 1995; Schoutrop, Lange, Duurland, Bermond, Sporry & de Goederen, 1997)

Beck (1976) and Hawton, Salkovskis, Kirk & Clark (2000) stated that cognitive distortions do not cause depression, but are part of it, as depression can be due to a variety of issues, around early experiences and negative life events, as discussed above. Cognitions may, however, have some temporal priority in the development of mood disturbance, and they can act to trigger, enhance, and maintain other symptoms. For this reason Beck (1976) considered them to form and ideal point of intervention.

Since cognitive (behavioural) therapy for depression has been specifically designed for the use in "neurotic" depression, whilst fitting with Mandy's presentation, it formed the treatment of choice for the work that I and Mandy engaged in. It has become one of the most extensively evaluated approaches for depression, which is widely and successfully adopted in various settings and parts of the world (Murray, Hill & McGuffin, 1997).

However, the approach was tailored to Mandy's individual circumstances to take into account the fact that Mandy's depressive illness had developed following her son Frank's death. Frank's death could be conceptualised as forming the critical incident that re-activated the dysfunctional assumptions that she had formed about herself and the world in early childhood. It was therefore that we engaged in grief work to get to Mandy's dysfunctional assumptions about herself that were re-activated by this negative life event. To come to an expression of the pain of her grief by addressing the feelings of profound sadness and immense guilt and the beliefs that she had about herself. This was informed by the above outlined cognitive principles of reframing the experience and beliefs derived from it. To eventually, come to an integration of this event into her life, where the energy previously invested in this relationship, would become reinvested elsewhere, which Goser (1965) and Lendrum & Syme (1992) propose to be the tasks of mourning. A detailed description of my application and tailoring of the above to the actual therapeutic work carried out with Mandy is contained in the next section.

11.5 Contents

Having considered Mandy's definition of her problem and the reason for seeking help, whilst taking her history and having agreed on the nature of our contact together, Mandy and I set to the task of working collaboratively on, firstly, targeting symptomology. We did this by focusing, cognitively, on her food issues, whilst trying to link these to her depressive illness. She told me that she would eat small amounts of food continually until she felt sick and bloated. Mandy had come from a Spartan household where her mum did not think that children needed breakfast, however, could make do with dinner and tea. Mandy, as a result, promised herself that her household would be a place of plenty rather than of rationing. She stated that food in marriage became for her a means of lavishing the love and care onto her family that she had never experienced at home. This grew even stronger following the loss of Frank. Since then food not only became a means of giving to her family the very best she could, but also a way of dealing with feelings of happiness, upset, and guilt. In this way food became linked to what she experienced in childhood and early marriage. However, dealing with food in this way, Mandy acknowledged, did not allow her to deal with the feelings of sadness and guilt surrounding the loss of Frank.

Mandy and I therefore spent time going "deeper". We explored the development of Mandy's core schema about herself in early childhood, the re-activation of these following the loss of Frank and linked these to her mood (and food) symptoms, whilst engaging in grief work regarding the death of her son, as further elaborated upon below. Revisiting early experiences and negative life events, vis a vis core beliefs, Mandy and I discussed how getting married to John she really came into her own. As a timid teenager she had been bullied a lot, whilst Mandy and her sister were left to their own devices, where only granny seemed to care. Therefore, as a child and teenager, Mandy had come to the belief that she was worthless and did not matter. However, when she met John aged 14, and got involved with him a little later, her confidence was boosted as he was one of the "in crowd", handsome and dark and showed her he loved her and cared.

Having first Jeffrey and then Frank was the further making of her as she found some self-worth in her "niche" as a mother, homemaker, wife, soul-mate, lover, income earner etc.

We then zoomed in to the tragic events that shattered the above and Mandy's new found sense of self and re-activated the old assumptions that Mandy had about herself of being worthless. We did this by speaking in detail about Frank, who he was, what happened on that ill fated holiday, as well as the aftermath of the events and the impact of this on their lives. She spoke about the detail of that morning. However everything went so quiet outside and how she went to search for Frank. Her agony at rescuing him from the slick that she did not know was there and holding him, until a girl came and took him. Though, Frank had been there for a very short while, resuscitation proved unsuccessful and the other means that we maybe nowadays have to deal with accidents like these, were not available to keep his faint pulse going. We talked about what followed and particularly focused on what Frank's death meant to Mandy and her family.

Mandy told me that the above involved the first time in her life that she had to face death and loss, though John had incurred multiple losses already. She reported that having David and Ian following the death of Frank, she often found herself over-caring/vigilant about their well-being and that of Jeffrey their first born. She could see that she was overcompensating, due to Frank's death. Her new found sense of self as a good mother, and of being worthy, had evaporated and the old feelings of worthlessness that she had known as a child and teenager had taken back its place. However, following the events she saw herself, furthermore, as a complete failure and a totally deficient mother who was guilty for not having supervised her children sufficiently whilst playing outside in the fields. This lead to really low self-esteem and a lot of franticness on Mandy's behalf to amend and be more than a 100% good mother, in order to deal with feelings of badness and guilt. She added that she lived Frank through her sons and somehow felt that maybe if she stopped caring for them, or would start forgiving herself for what had happened, that Frank would stop to be remembered. Though we perused that Frank would forgive her for her minute lapse in vigilance and encourage her to move on, she found it hard to have compassion on herself. Notwithstanding forgiving herself or not, we spoke about how Frank would go on living in her heart, in their conversations, on pictures, by tending his grave etc, no matter what. Finishing once weekly therapy Mandy experienced a sense of relief at the routine of coming every week being broken, as well as a sense of sadness of having to go it on her own. From here, we planned to see each other for four more follow-up sessions over half a year's period.

11.6 The development of the therapeutic relationship, difficulties encountered, attempts to overcome them and critical assessment of these.

As a therapist I am acutely aware that treatment needs to take place in the context of a good therapeutic relationship in which I seek to maximise the extent to which my client feels understood and wishes to actively engage in changing her predicament (Nelson-Jones, 1995).

Mandy reported that she found it easy to talk to me during our first few sessions together. She did not feel she knew me then and that made talking in a way easier for her. As I moved from being a stranger to someone more familiar, who listened to her, who remembered what she had brought before and made links for and with her, whilst feeling in some way understood in terms of the immense feelings of sadness and guilt that she was experiencing, Mandy thought at times that I knew too much, that I knew her every deep thought and that I had gone to far with her in this "window in her head", for comfort. I.e. that we got too emotionally connected and close. As we moved deeper, which "coincided" with the "midway mark" in therapy, I noticed that Mandy started withdrawing from therapy a little, creating some distance between her and myself by not coming once weekly, but cancelling ahead with work commitments etc. Naturally, engaging in the above was a real wrench for Mandy. Having that little "window in her head" opened that accessed all this detail, she tried to put into words the agony that she experienced at finding Frank the way she did. The emotional pain came out in tears as we took time to assemble this part of her life-story. The work physically and emotionally drained her and she often needed a walk after our sessions to regain her calm or to go home and sleep it off. The whole process overwhelmed her and Mandy needed more time to digest and pace things, which was reflected in the cancellations (see also section 08.). I acknowledged how hard it was for her to come and talk about the tremendous painful issues that she was carrying, and she admitted that at times it just felt easier to not come at all. However, we discussed that the pain of grief was perhaps the price she paid for her love for Frank and the cost of her commitment to him (Parkes, 1972). Again at our goodbye session at the end of the intensive part of treatment, before moving into follow-up, she said, that she had found it very hard to come, as she knew we would review therapy together and that we would do that to acknowledge that which we had looked at in order to be able to then look towards the future. This session was tremendously powerful for her and me, as it evoked a lot of feelings on both sides and allowed us to review and applaud the hard work done and Mandy's courage to stick with it, whilst she was able to express how therapy had helped her, what had been difficult, and how she could further move on (see also section 11.7).

It was hard for me as well to sit with the powerful material that Mandy brought regarding the loss of her two-and-a-half-year old. I used supervision extensively to recruit support to talk about it (see also section 11.8). At times I found it very hard going, especially when I needed to respect Mandy's need for the space to pace her therapy. Maybe I wanted to move from the darkness into the light much sooner, than she was ready to. I.e. where she would come once weekly, so we could get there in a less protracted way. However, in supervision I received the support I needed to hang on in there for Mandy, which she reflected had been a very important thing to her.

11.7 Client's progress, critical assessment of therapist's interventions, development of psychological understanding and skills:

I was pleased that notwithstanding the above difficulties, Mandy stuck with it. Engaging in this process she was able to make considerable progress and gain a different perspective on the negative life-events that she had experienced, whilst allowing some good to come to the fore that she had never seen before.

Mandy told me that she now could see that only through the loss of Frank, their lives had been enriched with two more sons, something which would not have happened as John and herself saw their family previously as complete. Added to this she felt that the event made them as a family much closer, where they would not take anything for granted and even David and Ian, born after Frank, shared in that. She said that it had been good to get it all out in a way that she had never done before and be listened to and have me remember what she brought. Mandy shared with me that she now heard my voice in her mind and used it to go over the issues and find solutions to these, which entailed a major improvement in "executive functioning" (cognitively), away from previous feelings of overwhelmedness, and engaging in old patterns of being and interrelating, and doing what one knows best (Eysenck & Keane, 1996). She could now see again, as during her early days of her marriage, before Frank's death, that she was not altogether worthless. That, actually, reviewing her accomplishments in life, a lot of people depended on her and valued her for her care and goodness to them. She moved on, in that she did not see everything in terms of her deficiency, but rather in terms of some sufficiency on her part. Mandy reported that she was glad that she came to therapy, as a gastric operation would not have allowed her to deal with the issues in the same way as she had now. She added that maybe she would never come to fully accept the loss of Frank, but that she was trying to live with it. Therapy had opened up the possibility of being able to view her guilt in a slightly different way. She could now see that her own internal moral and ethical standards and how she saw her role in the accident, was maybe not a view similar to the view Frank might have had, had he lived, or that others held of her. That an accident is an accident, and that having been unable to prevent it from happening did not mean that she was a complete failure. She finally added that she had coped with the anniversary of Frank's death this September much better than she had in the last 22 years and that she was now able to talk to others about Frank, without crying floods of tears. She also asserted that food was less of a problem now.

Reviewing my own development in terms of psychological understanding and skills, this case underlined for me how I could apply cognitive (behavioural) therapy for depression to "reactive" depression following the loss of a child, whilst adapting it to Mandy's unique individual circumstances. Though I had engaged in grief work before, this piece of work highlighted the specifics of dealing with the loss of a child, which allowed me to engage in further reading and reflect on the subject matter (Saraswati, 1976; Wilkinson, 1997). I wondered (and discussed this extensively in supervision, see section 11.8), from the work engaged in with Mandy, quite what the end-task of mourning may be, as described by Goser (1965) and Lendrum & Syme (1992) in terms of withdrawing involvement from the relationship with the deceased and re-investing it elsewhere. I.e. what this exactly means in terms of acceptance of and adaptation to the loss of a child and the integration of this experience into ones' life. Or Parkes' (1970) stages of grief vis a vis Goser's (1965) and Lendrum & Syme's (1992) tasks of mourning. And whether there is such a thing as an uniform adjustment, or rather whether adjustment depends on individual circumstances vis a vis families' loss histories, early experience and core beliefs, circumstantial factors etc. Though one does not built expertise from one case on the topic, this case did allow me to contemplate openness as to the variety of experiences that people have in terms of dealing with profound loss and the need to consider the possibility of varied goals in terms of outcome of therapy. In Mandy's case we could, possibly, never seek to aim for an ultimate diversion of energy from the relationship with Frank, as lived through her sons, onto other areas of her life. For her it did not mean a full acceptance of this loss, but a living with the reality of it and a slight change in her view of the circumstances, where she stopped a little, living in the shadow of it, and for ever "atoning" for it (Bor, Miller, Latz, Salt, 1998).

11.8 Use of supervision:

Supervision was crucial in several respects with regard to my work with Mandy. Firstly, I used supervision to recruit support to contain my feelings in response to the content of the material that Mandy brought. The agony of Mandy's story, profoundly affected and moved me. Her story had me at times at the brink of tears, as Mandy really poured her heart out to me. I was glad that in supervision at the end of that day I could talk about it and make sense. In work like this, it is important to not project ones' own fears onto the client through a facing up by oneself to the ultimate questions that death poses to anyone of us. It entailed a being open and loving, and available to Mandy and not being afraid to hear all the detail of her story. It involved letting her grief as a natural part of bereavement and as a natural part of life and what had happened to her (Wilkinson, 1997). I think that I managed to allow Mandy to do that to some extend, since, though Mandy knew I had not lost a child myself at that time, she said she did feel understood by me, and I had come alongside her as much as she felt I could. Working with her I felt so much for her and the tragic circumstances of Frank's death. I felt so strongly that it had been due to an accident and never questioned Mandy's responsibility in this. I kept wondering where this "gut" feeling came from and it was only after a lot of reflection on my own family history that it dawned on me that my father's mother and father had known what it meant to lose a child through accidental death. Though I did not share this with Mandy, as I did not want to take away from her story, it did help me to retrace some of my own families' history and I asked my dad many a question (without telling him what or how and breaking confidentiality) what this had meant to them and my own family dynamics following this loss[2]. I would imagine that maybe a few times in a lifetime or so, we have the privilege of working with parents who lose a child[3]. However, the work can be profound and my supervisor helped me normalise the feelings that it aroused in me and acknowledged how hard going it was.

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[2] A conversation I resumed following the untimely death of my sister in July 2003, through a different cause, and what that meant to all of us.

[3] Though since March 2003 (see the research section of this portfolio), I have been working a lot with women/couples considering the loss off the "potential child" they always thought they would one day have, and which they maybe will never have, at least in the way they thought they would. Again in November 2005, I needed to consider my own and my husbands issues surrounding the loss of "potential children". Thankfully, these issues were discovered following surgery in November 2005 following completion of the trial and in the course of writing up the research, when I had decided to not see patients in one to one or in groups about their issues, with a priority of finishing the research and sorting my own issues. This provided some personal space to digest the events, though it did make keeping going with the project, at times, quite hard, especially in November 2005, as well as when initial treatment failed in April/May 2006, when I was aiming to finalise the thesis. However, much one thought one "knew the area", from the varied pieces of work engaged in on the topic and family circumstances, it made it become all of a sudden even more near than it already had.

Secondly, I used supervision to peruse Mandy's pacing of therapy and what that was about and how I could hang on in there for her, as previously discussed in section 11.6. As well as what the "outcome" of the therapeutic work with Mandy could be, given the circumstances of the loss of Frank, as already described in section 11.7.

11.9 References:

APA - American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-R) Revised Edition.* Washington DC: APA.

Beck, A.T. (1976). *Cognitive Therapy and Emotional Disorders.* New York: International University Press.

Beck, A.T., Rush, A.J., Shaw, B.F., & Emery, G. (1979). *Cognitive Therapy of Depression.* New York: Guilford Press.

Bor, R., Miller, R., Latz, M., & Salt, H. (1998). *Counselling in Health Care Settings.* London: Cassell.

Eysenck, M.W., & Keane, M.T. (1996). *Cognitive Psychology.* Hove: Psychology Press.

Goser, G. (1965). *Death, Grief & Mourning in Contemporary Britain.* London: the Cresset Press.

Greenberger, D., & Padesky, C.A. (1995). *Mind over Mood – Change How you Feel by Changing the Way you Think.* New York: Guilford Press.

Hawton, K., Salkovskis, P.M., Kirk, J., & Clark, D.M. (2000). *Cognitive Behavioural Therapy for Psychiatric Problems – A Practical Guide.* Oxford: Oxford University Press.

Lendrum, S., & Syme, G. (1992). *Gift of Tears – A Practical Approach to Loss & Bereavement Counselling.* London: Routledge.

Mind (2000). Policy on Confidentiality B09/F1-F3. *Policy & Procedure Manual.* WF: Community Counselling Service.

Murray, R., Hill, P., & McGuffin, P. (1997). *The Essentials of Postgraduate Psychiatry.* Cambridge: Cambridge University Press.

Nelson-Jones, R. (1995). *The Theory and Practice of Counselling.* Trowbridge: Redwood Books.

Parkes, C.M. (1970). The First Years of Bereavement: a Longitudinal Study of the Research of London Widows to the Death of their Husbands. *Psychiatry, 33,* 444-467.

Parkes, C.M. (1972). *Bereavement Studies of Grief in Adult Life.* Harmondsworth: Tavistock Publications.

Robinson, E., & Guze, S.B. (1972). Classification of Affective Disorders: the Primary-secondary, the Endogenous-reactive, and the Neurotic-psychotic Concepts. In R.A. Williams, M.M. Katz & J.A. Shield J.A. (Eds.). *Recent Advances in Psychobiology of Depressive Illnesses.* Washington DC: US Government Printing Office.

Saraswati, S.S. (1976). *Conversations with S.S. Saraswati on Grief and Bereavement.* India: HPTG.

Schoutrop, M., Lange, A., Duurland, C., Bermond, B., Sporry, A., & de Goederen, A. (1997). Reprocessing Traumatic Events – an Uncontrolled Trial. *Journal of Clinical Psychology and Psychotherapy, 4,* 179-185.

Wilkinson, T. (1997). *The Death of a Child.* London: Julia MacRae Books

World Health Organisation (1992). *The ICD-10 Classification of Mental and Behavioural Disorders.* Clinical Descriptions and Diagnostic Guidelines. Geneva: WHO.

APPENDICES

Appendix 2.1

Data Extraction form blank

Title:
Author:
Setting:

Aim/focus of paper/study:
Explicit:
Implicit:
Not stated:

Subjects:
Number of cases described, pool this was drawn from, in-clusion, exclusion criteria): n=
Inclusion criterion:

Sample characterised in term of (give details):
Basic sociodemographics e.g. age, education, marital status:
- Mean age … years (SD.. , range .. to .. years)

Diagnosis (e.g.how diagnosed/diagnostic criteria)
– see above

Method of MRKH treatment used:

How were cases identified/selected? (e.g. retrospectively, cross-sectionally, prospectively)

Any control group?

Method of data collection (e.g. Medical case-note review; Review of therapy material; Self-report questionnaire; Semi-structured quantitative or qualitative interview; other – give details)

Psychological intervention:

Follow-up: Yes/no:
Yes – see above
If yes:
Duration of follow-up:

Proportion of original cohort accounted for:

Analysis:

Additional comments:

Question 1: Immediate psychological impact of diagnosis:

Quantitative information e.g.:

age of discovery that something is wrong;

age of diagnosis: .... years (SD ....; range ... to ... years)

Reaction to diagnosis:

Other info, e.g. anecdotal or qualitative info, opinion:

Question 2: Long-term psychological impact of MRKH
Quantitative info:

Other info, e.g. anecdotal info, opinion:

Question 3: Interpersonal/sexual/relationship impact of MRKH:
Quantitative info: (e.g. include proportion of people dating, sexually active or married)

Other info, e.g. anecdotal info, opinion:

Question 4: Impact of MRKH treatment:
Quantitative info:

Other info, e.g. anecdotal info, opinion:

Question 5: Need for psychological intervention

Quantitative info:

Other info, e.g. anecdotal info, opinion:

Other info, e.g. anecdotal info, opinion:

Relaxation Script (adapted from Sternbach, 1987):
Whilst you are sitting comfortably, or laying comfortably, with your spine straight, close your eyes and relax all your muscles as best as you can. Thinking about each part of your body from the top of your head to the soles of your feet, relaxing each in turn and keeping relaxed……. pause………..

Now concentrate on your breathing, breathing naturally through your nose, with your lips lightly closed, with your jaw relaxed and your teeth apart….. Focus your attention on your breathing, and as you breathe out say the word "calm" silently to yourself, and each time you breathe out say "calm", and feel the tensions drain away as you do so. …… pause…..
And when your mind wanders, as it always will, just be patient and focus your attention again and again on the feeling of your breath as you breathe out and say "calm". So just keep focusing on your breathing, breathing in…. and…. out. In….. and …… out, saying "calm" silently to yourself……. pause………

And as you are breathing in and out, and saying "calm" silently to yourself I'd like you to start focusing on your feet, and I'd like you to tense all the muscles in your feet and curl your toes and tighten them as much as you can….. and notice all the muscles in your feet tense…. And I would like you to hold on to that tension…. And then relax your feet completely, noticing how your toes uncurl and the muscles feel tired an heavy……
And then focus your attention on your calves, and try and tense all the muscles in your calves as best as you can, making your calves as stiff and rigid as you possibly can… and notice how that feels……. And then relax, and let go completely, just notice how the muscles feel tired and heavy.
And then focus your attention on your upper legs and your buttocks, and try and tense your muscles in these areas…. And just hold on to that tension and notice how that feels…. And then relax and let go completely, and notice the muscles feeling tired and heavy……
And then focus on your stomach area, and try and clench the muscles in your stomach area, just really crunch the muscles in your tummy, and notice that feeling of tightness there…… And then relax and let go ….. notice the muscles feeling tired and heavy.
And then focus your attention on your back, your shoulders and your neck, and tense the muscles in these areas, and make your back and your shoulders and your neck as stiff and rigid as you possibly can….. and then relax and let go completely, just notice how relaxed and how warm the muscles feel, and how tired…..
And then focus your attention on your face, and tighten the muscles in your face, particularly, your jaw area, maybe just clench your teeth and just hold on to that….. And then relax and let go… notice the heaviness in your face….
And then focus on your arms and your hands and just tighten the muscles in these areas, just make fists out of your hands, tense the muscles in your arms, keep it rigid and stiff… And then relax and let your fingers uncurl, just allow your hands to feel heavy and tired…

And as you have tensed and relaxed each set of muscles in your body, just allow the feeling of relaxation to flow through your body. Just checking all the parts that you have tensed and relaxed for feeling relaxed, just your feet, your calves, your upper legs, buttocks, stomach, back, shoulders, neck, face, arms and hands, and let these relax completely..........

And as you are breathing in and out, saying "calm" silently to yourself, and feeling fully relaxed....I would like you to start focusing on your feet again and I would like you to say to yourself "my feet are heavy and warm, very heavy and warm". And you might imagine that your feet are sitting in warm water, and you just visualise them becoming heavier and warmer. And then I would like you to focus on your calves, and say to yourself "my calves are heavy and warm, very heavy and warm", and to visualise them to become heavier and warmer.... And then focus your attention on your upper legs and buttocks, and say to yourself "my upper legs and buttocks are heavy and warm, very heavy and warm", and just visualise them becoming heavier and warmer. And then focus on your stomach, and say to yourself "my stomach is heavy and warm", and visualise your stomach becoming heavier and warmer. And then focus your attention on your back and shoulders and neck, and say to yourself "my back and shoulder and neck are heavy and warm, very heavy and warm", just maybe imagine the sun shining on your back and shoulders and neck, and your are just soaking up that warmth. And then focus your attention on your face and feel the warmth in your face, "say to yourself my face is heavy and warm", imagine the sun shining on it. And then focus your attention on your arms and hands and say to yourself "my arms and hands are heavy and warm, very heavy and warm", and visualise them becoming heavier and warmer.... And as you are breathing in and out and saying "calm" silently to yourself, and as you have tensed and relaxed each part of your body, and as the feelings of full relaxation are flowing through your body, and as you are feeling warm and heavy, and relaxed, I would like you to just imagine that you have fallen asleep on a sunny beach, and to just stay with those feelings and to soak them up................

And as you are feeling relaxed and calm and warm, I would like you to start focusing from inside yourself to the sounds in the room that you are in, registering the outside as well, and bring yourself slowly back, when you are ready for it, and to open your eyes, still feeling warm, and relaxed and calm, but also fully refreshed. So just open your eyes, and just move your legs a bit, your arms, and just bring yourself back, relaxed and calm, and refreshed.........

Guided Imagery Script "from - to +" (adapted from, as before & Garner & Garfinkel, 1997)

Whilst you are sitting comfortably, or laying comfortably, with your spine straight, close your eyes and relax all your muscles as best as you can. Thinking about each part of your body from the top of your head to the soles of your feet, relaxing each in turn and keeping relaxed……. pause………..

Now concentrate on your breathing, breathing naturally through your nose, with your lips lightly closed, with your jaw relaxed and your teeth apart….. Focus your attention on your breathing, and as you breathe out say the word "calm" silently to yourself, and each time you exhale say "calm", and feel the tensions drain away as you do so. So breathe in… and out…., focusing, particularly, on the outward breath and say calm and feel the tensions drain away. And when your mind wanders, as it always will, just be patient and focus your attention again and again on the feeling of your breath as you breathe out and say "calm". So just stay with focusing on your breathing, breathing in…. and…. out. In….. and …… out, in….. out….. Just keep focusing on that……. pause………

And as you are breathing in and out, and saying "calm" silently to yourself I'd like you to start focusing on your feet, and I'd like you to tense all the muscles in your feet and curl your toes and tighten them as much as you can….. and notice all the muscles in your feet tense…. And I would like you to hold on to that tension…. And then relax your feet completely, noticing how your toes uncurl and the muscles feel tired an heavy……

And then focus your attention on your calves, and try and tense all the muscles in your calves as best as you can, making your calves as stiff and rigid as you possibly can… and notice how that feels……. And then relax, and let go completely, just notice how the muscles feel tired and heavy.

And then focus your attention on your upper legs and your buttocks, and try and tense your muscles in these areas…. And just hold on to that tension and notice how that feels…. And then relax and let go completely, and notice the muscles feeling tired and heavy……

And then focus on your stomach area, and try and clench the muscles in your stomach area, just really crunch the muscles in your tummy, and notice that feeling of tightness there…… And then relax and let go ….. notice the muscles feeling tired and heavy.

And then focus your attention on your back, your shoulders and your neck, and tense the muscles in these areas, and make your back and your shoulders and your neck as stiff and rigid as you possibly can….. and then relax and let go completely, let your shoulders go all floppy, and relax your back and your neck, just move it a bit, yes, and notice how that feels,…… tired and heavy…..

And then move your attention up to your face, and tense the muscles in your face, particularly, your jaws, maybe just clench your teeth and

just hold on to that….. And then relax and let go… notice the heaviness in your face….
And then focus on your arms and your hands and just tighten the muscles in these areas, just make fists out of your hands, tense the muscles in your arms, keep it rigid and stiff… And then relax and let your arms go limb and floppy, unfold your hands and move your fingers… let them really relax alongside your body, and notice the feeling of heaviness and relaxedness…….
And as you have tensed and relaxed each set of muscles of your body, remain still whilst you mentally check your muscles and experience them being very heavy and relaxed. Just check your feet, your calves, your upper legs, buttocks, stomach, back, shoulders, neck, face, arms and hands, and notice the feeling of deep muscle relaxation flowing through your body……….

And as you have tensed and relaxed all the muscles in your body and as you are feeling really relaxed, and as you are breathing in and out, particularly focusing on the outward breath … I would like you to imagine yourself walking along a beach….. And as you are walking along that beach you can hear the crashing waves and the sound of seagulls… and you can see cliffs in the distance…….. And as you are looking towards the cliffs in the distance, and as you are scanning the skyline…. You begin to see a figure on the cliffs, and you realise the figure is wise and compassionate, and knows your life story, and is behind you a 100% in the change process. This figure knows about your MRKH and knows about the difficulties that you might have been experiencing. But this figure is wise and compassionate, knows all about that. This figure could be a spiritual figure, a person you have known or read about, or a person you create. And you can look at his or her face, and you can sense the kindness and the gentleness, and you feel the love and the acceptance of this person…….

As you sense this person, and their compassion, and kindness and gentleness, and their support for you in the change process…………………. you actually begin to see negative images of yourself………………………………. and you hear yourself saying negative things to yourself about your body. And you maybe imagine others talking in negative ways about yourself, or you maybe have actually heard them talking in negative ways. But you imagine that the wise figure turns to you and reaches out his or her hand, and his/her hand is like a magnet and those negative images and thoughts begin to leave you……….

Now look to the sky and realise there is a screen in the sky, where you can see new images of yourself. You are aware that this is your life, you hear yourself talking to yourself in a more positive way, what are you saying to yourself………
………
You experience yourself listening to the information your body is teaching you about hunger, about fullness, about tiredness…. Instead of ignoring your needs you see yourself stopping eating when you are full, resting when you are tired, feeding yourself when you are hungry, and attending to your needs, whatever they are in terms of hunger, or tiredness, or fullness, of feeling low, of feeling happy…….

And you have the courage to accept and express yourself as a woman, and you are no longer looking outside yourself to try to reach an external standard. You feel empowered as you attain a realistic picture of yourself… and you see yourself teaching others how to treat you………. What are you telling them……. And who see yourself telling this to………….. You see yourself buying fabrics and colours that feel good on your body, feel these fabrics, what do they feel like….. You feel a shift taking place within and feel the support of the figure behind you….. Just allow the images to unfold……. A new way of experiencing yourself…. Feeling more whole and more solid……. And just stay with that, let the images unfold……….

And as the images are unfolding, I would like you to take them with you, when you slowly start focusing on the noises outside of yourself in the room and outside of the room that you are in. And as you slowly bring yourself back into the room, and as you are slowly starting to move your arms and your legs a little bit, and as you are slowly preparing yourself to open your eyes… I would like you to take the images that have unfolded and the positive ways of experiencing yourself into the room, and take that with you wherever you go. Feeling relaxed, refreshed and encouraged…….. And to follow up from that, to tell others what your needs are, to teach others, to keep teaching yourself, staying away from the negative and focusing on the positive, and who you really are, and what is there rather than what is not there, building yourself in the here and now, focusing on a future, and having a future, and feeling empowered. So open your eyes, and take all that goodness with you……………………………….

A26/version 5/N 2001

Appendix: 5.1

Hammersmith Hospitals
QCCH headed paper

NATIONAL CENTRE FOR ADOLESCENT AND ADULT WOMEN
WITH CONGENITAL ABNORMALITIES OF THE GENITAL TRACT
Tel. 0208 383 5363

Psychological Group Therapy for Women with Rokitansky Syndrome
Study

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether or not you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

1. What is the purpose of the study

The National Centre specialises in helping adolescent and adult women with Congenital Abnormalities of the Genital Tract, of which the Rokitanksy (MRKH) Syndrome is one condition. At the Centre we are always looking for ways of offering the best possible care. Currently, integrated with the medical input, the psychological support offered consists of talking to you at the time of diagnosis, input on the ward around dilator therapy, access to the twice yearly run support group meetings, one to one counselling therapy, information sheets regarding the condition, information on the web and access to a protected chatroom site. Looking at extending our psychological interventions, we have become aware that, particularly, the one to one counselling therapy and support group, which you have indicated to be helpful, could be further developed, and psychological group therapy added. This would be the "rolling into one" of the two, though these two avenues will still remain available to anyone in their own right. Group therapy will have more structure than our current support groups have, and be run following a programme. It takes the form of one to one counselling

therapy in terms of looking at specific issues living with MRKH, and meeting weekly for 7 sessions with one follow-up session at 3 months. Within the supportive structure of a small group of 6-8/10 participants, the focus is not solely on you, but on yourself and each other.
There is research that tells us how difficult it is to be diagnosed with MRKH and the particular issues you might be facing in terms of feelings of difference and isolation, difficulties relating etc. However, there is no research to date that tells us how to help you develop "tools" for the "journey" and find a way of overcoming negative feelings and thoughts, alleviating difficulties relating, of giving MRKH a place in your life, without being frozen by it. At the Centre we have been developing our own one to one therapy programme, based on more general research that relates to dealing with difficult life events, retelling your story, challenging misperceptions, gaining new understandings, finding different ways of relating and looking after yourself, mourning losses, pursuing old/new life goals, alternative avenues etc.

2. Why have you been chosen

You have been chosen for this study as you are known to the Centre, having been referred here in the past with a diagnosis of MRKH or to be diagnosed. All the other women that we know at the Centre with MRKH will be approached like you, as we would like to give you all the opportunity to take part in this study if you feel it is something you wish to do. We need a large number of women to come forward to take part in this study in order to be able to draw any conclusions from it.

3. Do you have to take part

It is up to you to decide whether or not to take part. If you decide to take part you are asked to keep this information sheet and sign and return one Consent form (& Reply Form), keeping the other copies yourself, in the envelope provided. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive at the Centre.

4. What will happen to you if you take part

Sometimes because we do not know which way of treating patients is best, we need to make comparisons. Where people will be put into a group and then compared. These groups are selected by a draw from a hat, ie. by chance. Patients in each group then have a different treatment and these are compared. In this study we would like to compare people who have group therapy with people who do not have treatment, to really test the effect of the programme and that the differences are due to the programme and not simply due to chance. As a result, when you decide to take part, you have a 50% chance of being given a place in a treatment group and a 50% chance of being put on a waiting list. However, those who draw the waiting list, will receive treatment at a slightly later date, so they do not miss out.

5. What do you have to do & the treatment being tested

As referred to above, taking part involves attending 7 weekly sessions of (small) group therapy and another session at 3 months follow-up. It further involves completing a number of questionnaires relating to mood, self-esteem, interpersonal relating, coping and general psychological wellbeing, at session 1, 7 and at 3 months follow-up. These I will take and analyse statistically when all groups have been run, so I can guage the effect the group has had on your mood, sense of self etc. The study involves that you engage in writing exercises as part of the therapy programme, particularly for session 2, 3 and 7. Every session involves "homework" tasks, things to take home, think about, write about, do; to allow yourself to get the most out of a relative short time of being together. Both the treatment and waiting list groups will complete these questionnaires and engage in writing exercises at week 1, 2 and 6 regarding what their deepest feelings and thoughts were/are about being diagnosed with MRKH, how they saw/see themselves, how it was/is effecting them and how they were/are coping. Those in the therapy groups also write about what they learned from therapy, what was helpful etc at week 7 in the form of a "goodbye" letter. I will analyse these writings to glean whether any changes take place without therapy, and when having engaged in therapy what the specific changes are, what you tell me you learned, found helpful; ie. the effect attending has had for you. Topics of the programme include: seeking help, diagnosis, own/other's reactions to diagnosis, understanding MRKH, who/what to tell, asking support, how MRKH is effecting your life, coping strategies, meaning of diagnosis, conclusions drawn, challenging misconstruing, fertility issues, mourning losses, pursuing alternative avenues, dilation therapy, relationships, when/what to tell, standing up for your needs, sexual intimacy etc. The detailed programme will be handed to you at commencement of therapy, but is also available on request now.

6. What are the possible disadvantages

Though coming along to join a group may seem daunting, all of you will experience feelings of anxiety at the onset, and that is normal. However, biting through that initial difficulty and allowing yourself to get to know the others in your group and me better, you will become comfortable and gradually feel more free to share and deal with the difficulties that you are facing. Though reflecting on your thoughts and feelings can be challenging, we will look at the issues in a bite sized, contained and safe fashion, which will, hopefully, eventually lead you to a better place. You will prepare yourself for every session through "homework" tasks and therefore know what is coming next, whilst being taught further coping skills. If you require additional help on a one to one basis, post programme, or in the rare event whilst on the programme, this is always a resource that is available and will be specifically explained in session 1 when we look at the rules of the group vis a vis confidentiality and personal safety. People often find that dealing with the issues they are facing is a better, though initially more difficult strategy, than pushing them away. Looking the issues "in the eye" gives you the freedom to, eventually, be more "in control" of a predicament, which previously might have felt very much out of your control, and would make you feel sad, angry etc. when you least expected it, when it was least convenient. Working in the group, you look together at giving MRKH a place in your life, without being overwhelmed by it, or cut off from it, (see further no. 8 below).

7. What are the possible benefits of taking part

The groups are concise and brief, so you commit yourself to a manageable amount of sessions. The groups are run on weekends to allow for varied travel distance and are planned so that they do not interfere with your weekday commitments. The groups combine the benefits of both one to one counselling therapy, with that of a support group setting. They are run for those who come from afar or more local, but who are usually not able to attend, what with normal sessions being run on Tuesday and Thursday, or anyone who now wishes to attend for whatever reason. There are two blocks of groups being run, one block starting at the end of November 2004 and the other at the end of January 2005, with those drawing waiting list being offered therapy in June/July 2005 (weekends). A total of 4 groups will be run in November, with two on the Saturday (11am-2pm and 3-6pm) and again two on the Sunday, at the same times. Another 4 groups will be run in January with again two on the Saturday and two on the Sunday same times. We have a total of 160 potential places available on the programme!!! Kindly, have a look at the Reply Form enclosed and tick your preference as to when it would suit you best to attend, whilst enclosing it with your signed Consent Form, in the envelope provided. It is the intention that therapy will allow you to develop "tools" for the "journey", reducing feelings of difference and isolation, (as outlined above) giving MRKH a place in your life and not being so cut up by it. It gives you a chance to share with others and be strengthened by this to hear stories like yours, different viewpoints and experiences and discuss varied ways of looking at and dealing with MRKH. To get to know a small group of women with MRKH more personally, and to possibly, after you cease to meet, for the groups members, to keep in touch on a self organised basis.

8. What happens when the research study stops

The above group treatment is run for the duration of the study. However, it cannot be assumed that the opportunity to come for such an intervention during weekends will be automatically available in future. However, our normal one to one interventions and twice annually run support group meetings will continue to be run. Possibly, any therapy groups, when they are organised again, will only be offered at the usual time that I am paid to work at Queen Charlotte's, which is Tuesday & Thursday. The group programme, is a complete treatment in and of itself with 3 months follow-up, after which we will stop to meet as a group in that way. However, one to one interventions, are always available following that, if the need arises to work on a personal issue in depth etc.

9. Confidentiality

Please note that all information collated will be handled with the utmost respect and personal identifiers will be avoided. Your writings will be

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returned to you, once they are no longer needed for analysis. Kindly, also note that the sessions will be audio-taped for treatment fidelity purposes, which means that my supervisor rates them for faithfulness to therapeutic model; in other words she will check whether I am giving you the therapy that I say I do; because remember it is this therapy that we are trying to test for it's effectiveness. I would also like to have a tape to go back to, to reflect on my practice, jog my memory, alongside keeping notes. However, the tapes will be erased when they are no longer needed for these purposes.

10. What will happen to the results of the research study

We hope to put the material used and themes discussed during each session into a booklet, together with the findings of the study, possibly excerpts of writings engaged in & articles, which you can have a copy of when this becomes available. This we can also use as patient self help material for anyone who comes through our service and would like to know what living with MRKH is all about. Or possibly in future it may be put as a self-help package on our website. We furthermore hope to publish the findings in scientific journals about the programme and the effect of it, so other Centres Internationally and Health Professionals who come into contact with women with MRKH Nationally, can learn from this study, which is much need to improve our knowledge and your predicament. We will update you about the above in our newletters and at our annual support group meetings. Kindly, rest assured that you will not be identified in any of the above write ups.

11. Who is organising and funding the research

This study is self funded by me as part of a DPsych programme of research at City University and neither yourself or me will be paid for our participation in the material sense. However, we will, I trust be paid back for our input in the emotional sense, as it is such a privilege for me to work with you all and for each of you to work, and share with each other and form a mutual understanding and way of forging forward. Kindly, note that those on social benefit will be able to have their travel expenses reimbursed via the appropriate NHS forms, and that limited funds are available for others who are under financial strain. So, do not hesitate to discuss your circumstances with me.

12. Who has reviewed this study

This study was reviewed by Hammersmith and Queen Charlotte's & Chelsea Hospitals Research Ethics Committee.

Those of you who are already receiving therapy elsewhere might want to leave taking part in the above for now, engaging in one intervention at the time, but you are welcome to contact me with any queries, now or in the future.

Those of you who have had one to one input with me here at the Centre, but who now have completed their sessions, or are in follow-up, you are still free to join, if you feel you would have added benefit from now doing, - what you have previously looked at -, in a group format and this would appeal to you. Those who are currently in weekly/fortnightly counselling therapy with me, but who are interested, please discuss this with me, when I see you next.

Those who have language difficulties, might find it more helpful to engage in one to one therapy. Those who self-harm, please contact me for help, to get you the one to one attention you need, where you may do the group work later.

If you would like any further information, please do not hesitate to contact me on 0208 383 5363, our help-line number, on which you can leave a message any time, and I will get back to you soonest.

Thank you for reading this and we look forward to hearing from you all.
With very best wishes,

Jacoline Heller
Chartered Counselling Psychologist
The National Centre

Centre Number:
Study Number:04/Q0406/96
Patient Identification Number for this trial:

Appendix: 5.2

HH QCCH headed paper

NATIONAL CENTRE FOR ADOLESCENT AND ADULT WOMEN WITH CONGENITAL ABNORMALITIES OF THE GENITAL TRACT

Tel. 0208 383 5363

CONSENT FORM

Title of Project: Psychological Group Therapy for Women with Rokitansky Syndrome

Name of Researcher: Jacoline Heller, Counselling Psychologist

Please initial box

1. I confirm that I have read and understand the information sheet dated September 2004 (A26 version 3) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care being effected. ☐

3. I agree to take part in the above study. ☐

....	....	....
Name of Patient	Date	Signature
....	....	....
Researcher	Date	Signature

1 for patient 1 for researcher; one copy to be kept with hospital notes

A26

REPLY FORM TO:

THE NATIONAL CENTRE FOR ADOLESCENT AND ADULT WOMEN WITH CONGENITAL ABNORMALITIES OF THE GENITAL TRACT

YES, (encircle if applicable) I would like to take part in a psychological group therapy programme for women with the Rokitansky (MRKH) Syndrome, and I would like to attend the following block, of 7 weekly sessions, with one follow-up session at 3 months, at Queen Charlotte's:

Tick (V...) your preference in terms of which block of months (ie block 1 or 2), which day and what time (ie Saturday 11am-2pm or 3pm-6pm, or Sunday 11am-2pm or 3pm-6pm).

BLOCK 1

End November/December 2004/3rd week January 2005

SATURDAYS

11am-2pm	(...)
or	
3pm-6pm	(...)

dates run	27/11/04 & 4/12/04 & 11/12/04 & 18/12/04
	2 weeks break re Christmas & continue on:
	8/1/05 & 15/1/05 & 22/1/05
	3 months follow-up on 16/4/05

SUNDAYS

11am-2pm	(...)
or	
3pm-6pm	(...)

dates run	28/11/04 & 5/12/04 & 12/12/04 & 19/12/04

2 weeks break re Christmas & continue on:

9/1/05 & 16/1/05 & 23/1/05

3 months follow-up on 17/4/05

==

BLOCK 2

End January/February/mid March 2005

SATURDAYS

11am-2pm (...)

or

2pm-6pm (...)

dates run 29/1/05 & 5/2/05 & 12/2/05 & 19/2/05 &

26/2/05 & 5/3/05 & 12/3/05

3 months follow-up on 4/6/05

SUNDAYS

11am-2pm (...)

or

2pm-6pm (...)

dates run 30/1/05 & 6/2/05 & 13/2/05 & 20/2/05 &

27/2/05 & 6/3/05 & 13/3/05

3 months follow-up on 5/6/05

.... NOTE that those who draw treatment control/waitinglist for block 1 & 2 will eventually receive treatment (in somewhat larger groups) in:

Mid June/July 2005

SATURDAYS

11am-2pm (or 10am-12.30pm & 1pm-3.30pm & 4pm-6.30pm depending on

or number of participants)

2pm-6pm

dates run 11/6/05 & 18/6/05 & 25/6/05 & 2/7/05 &

9/7/05 & 16/7/05 & 23/7/05

3 months follow-up on 15/11/05

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SUNDAYS

11am-2pm (or 10am-12.30pm & 1pm-3.30pm & 4pm-6.30pm depending on number of participants)
or
3pm-6pm

dates run 12/6/05 & 19/6/05 & 26/6/05 & 3/7/05 &
10/7/05 & 17/7/05 & 24/7/05
3 months follow-up on 16/11/05

NO I am not interested at this moment in time to come along (encircle if applicable)

Name:...

Telephone numbers I can contact you on.....................................

Email...

Address...

....

Date of Birth:...

Again, if you have any queries please contact me on 0208 383 5262. Also, if you would like to come along for an informal discussion, kindly, let me know.

Jacoline Heller, Counselling Psychologist ("top-up DPsych Post Chartered candidate City University) - Queen Charlotte's & Chelsea Hospital, Outpatient Gynaecology Department, Du Cane Road, London W12 0HS
A32

Appendix: 5.3

Table .... Random permuted blocks within strata (2x2) for Group Therapy Trial for MRKH (A=treatment, B=waitinglist controls), as per Pocock (1983)

Age:	<25	>/25	<25	>/25
MRKH Type I/II ("simple"/ complex)	I	I	II	II
		B B A A	B A A B	A B A B
	B A B A			B A B A
	A B B A			B A B A
	B B A A			
			B A A B	
		A A B B	A B A B	B A B A
		A A B B	B B A A	
		B A B A	B A B A	A B B A
			B A B A	A B B A

Age:	<25	>/25	<25	>/25
MRKH Type I/II	I	I	II	II
	-	A B A B	-	A A B B
	B A A B	A A B B	-	-
	B A B A	A B B A	A B A B	A A B B
	A B A B	B B A A	B A B A	B B A A
	A A B B	B B A A	-	A B B A
	A B A B	B A A B	B A A B	-
	-	A A B B	A A B B	-
	A A B B	A A B B	B B A A	-
	A B A B	A B A B	A B B A	-
	-	B B A A	-	-

Age:	<25	>/25	<25	>/25
MPKU Type I/II	I	I	II	II
	-	-	-	A B B A
	-	A B A B	B B A A	B A B A
	A B B A	B B A A	A A B B	B A B A
	B A A B	A B A B	A B A B	-
	B A B A	B B A A	-	-
	-	B B A A	-	-
	A B B A	-	A A B B	B A B A
	-	A B A B	B A A B	B A A B
	-	A A B B	A B A B	-
	A A B B	B A A B	-	B A B A

Age:	<25	>/25	<25	>/25
MPKU Type I/II	I	I	II	II
	-	-	-	B A A B
	-	A B B A	B A B A	B A B A
	-	B A A B	A B A B	A B A B
	-	B B A A	-	-
	B A B A	-	B B A A	-

Appendix: 5.4

HH QCCH Headed paper

THE NATIONAL CENTRE
FOR ADOLESCENT AND ADULT WOMEN
WITH CONGENITAL ABNORMALITIES
OF THE GENITAL TRACT

Dr
.
. .

Date:

Dear Dr

Re:

The above patient is currently attending a programme of 7 sessions of weekly psychological group therapy for women with the Mayer-Rokitansky-Kuster-Hauser Syndrome at the above Centre, as part of a study on the effect of such an intervention on participants and their experience of it, with one follow up session at 3 months.

The sessions deal with varied issues that these women are facing in terms of living with the diagnosis and gives them the space to explore these together with others.

At the Centre we are always looking for ways of offering the best possible care to women with this or related conditions of which the above forms an initiative, alongside the input I offer at the time of diagnosis, on the ward, in one to one outpatient therapy, at our twice yearly support group meetings, via our newsletter, website etc.

If you have any queries on the above please do not hesitate to contact me on 0208 383 5363.

With best wishes,

Jacoline Heller
Counselling Psychologist

WRITING EXERCISE 1 - HOMEWORK GIVEN AT SESSION 1 FOR SESSION 2

General:

- Find a time of the day and a place where you can relatively undisturbed write for a period of 20-45 minutes at a time
- Engage in this for 4 consecutive days (attending to varied aspects of the exercise as you see fit, writing it in parts, or writing it all in one go in draft and then re-editing it in the 2nd, 3rd & 4th sitting, whatever, comes best to you). Try to write at the same time in the same place as much as you can on each of these days.
- Have enough paper and pen, tissue's etc. ready.
- After every sitting put your papers in a safe place, have a cup of tea, a bath, listen to music, get some fresh air, whatever, you feel is helpful to soothe yourself, or engage in any of the other distress tolerance techniques that you are learning during our therapy sessions together, such as the relaxation exercise etc. Engaging in these exercises does stir emotions and that is normal, where you might feel worse first, before you start feeling better. So look after yourself in this process, to get safely to the others side.
- If you become too distressed writing, the rule is to stop, and to gather yourself with the above techniques, and go back to it when you feel able to it. If you are not able to, leave it and we can discuss this in the coming session.

  However, the idea is to expose yourself to previously avoided emotions through a writing process that is under your control. Where you stay with feelings that otherwise might have been avoided, with you determining the rate and degree of confrontation. To write till you feel there is nothing more to write and you are satiated.
- If you find yourself unable to write, and are blocked, think of times you have experienced such blanks before and what the current and past situation have in common in terms of thoughts, feelings; and write about that. This might loosen you up, to then following on from that, start engaging in the above exercise next time you sit down.
- If you cannot write at all, get yourself a tape recorder and start talking onto tape in free flow, and transcribe it from there, to see it black on white, making sense of it, reflecting on it & bring this along.

Note that what you write does not get scrutinised by your group, so try to write freely. I will look at it eventually for the studies' purposes, but in the group we discuss what has been written by varied people in general terms, so you share what you want to share, as much as you feel able to share at any one point, from your writings and what occurs to you in the sessions, following what others say etc. The goodbye letter, our final writing exercise, will be shared, in terms of each of you reading your's out in turn, including me reading my goodbye letter to the group, about our joint experiences in the group, which we will then all discuss.

Focus for this writing exercise: *Going back to the difficult life event, expressing all your thoughts and feelings:*

Go back in time, to the time that you started becoming aware that something might be wrong. Look back at the process of seeking help that you engaged in, of investigations being done, of expectations you had re what might be found/could be done. Describe your experiences of medical interventions, being diagnosed and what happened. What were your own/other's reactions to this, what did you understand about MRKH from what you were told, what did you not understand. Who did you tell about your condition, what did you share with them, and what support did you ask for, from them......

Pour your deepest feelings and thoughts out on paper about the above events, writing about all the characters (people) in the story, zooming into you........

WRITING EXERCISE 2 - HOMEWORK GIVEN AT SESSION 2 FOR SESSION 3

General:

- Find a time of the day and a place where you can relatively undisturbed write for a period of 20-45 minutes at a time
- Engage in this exercise for 4 consecutive days, writing at the same time in the same place as much as you can on each of these days
- Have enough paper and pen, tissue's etc. ready.
- After every sitting put your papers in a safe place, have a cup of tea, a bath, listen to music, get some fresh air, whatever, you feel is helpful to soothe yourself, or engage in any of the other distress tolerance techniques that you are learning during our therapy sessions together, such as the relaxation exercise etc. Engaging in these exercises does stir emotions and that is normal, where you might feel worse first, before you start feeling better. So look after yourself in this process, to get safely to the others side.
- If you become too distressed writing, the rule is to stop, and to gather yourself with the above techniques, and go back to it when you feel able to it. If you are not able to, leave it and we can discuss this in the coming session.

  However, the idea is to expose yourself to previously avoided emotions through a writing process that is under your control. Where you stay with feelings that otherwise might have been avoided, with you determining the rate and degree of confrontation. To write till you feel there is nothing more to write and you are satiated.
- If you find yourself unable to write, and are blocked, think of times you have experienced such blanks before and what the current and past situation have in common in terms of thoughts, feelings; and write about that. This might loosen you up, to then following on from that, start engaging in the above exercise next time you sit down.
- If you cannot write at all, get yourself a tape recorder and start talking onto tape in free flow, and transcribe it from there, to see it black on white, making sense of it, reflecting on it & bring this along.
- Note that what you write does not get scrutinised by your group, so try to write freely. I will look at it eventually for the studies' purposes, but in the group we discuss what has been written by varied

people in general terms, so you share what you want to share, as much as you feel able to share at any one point, from your writings and what occurs to you in the sessions, following what others say etc.

Focus for this writing exercise: *Considering the impact of MRKH & coping:*

Consider how the experience/MRKH is effecting your life in its varied facets/areas (eg. studies, work, experience of self/self-esteem, family, friends, intimate relationships etc). How are you coping....

Just engage in a free flow of thoughts and feelings, there is no right or wrong as to what and how your write......

WRITING EXERCISE 3 – HOMEWORK GIVEN AT SESSION 3 FOR SESSION 4

General:

- Find a time of the day and a place where you can relatively undisturbed write for a period of 20-45 minutes at a time
- Engage in this exercise for 4 consecutive days (addressing I at the first, II at the 2nd and III at the 3rd sitting, and IV at sitting 4 whilst reflecting on what you have written for I, II & III). Try and write at the same time in the same place as much as you can on each of these days
- Have enough paper and pen, tissue's etc. ready
- after every sitting put your papers in a safe place, have a cup of tea, a bath, listen to music, get some fresh air, whatever, you feel is helpful to soothe yourself, or engage in any of the other distress tolerance techniques that you are learning during our therapy sessions together, such as the relaxation exercise etc. Engaging in these exercises does stir emotions and that is normal, where you might feel worse first, before you start feeling better. So look after yourself in this process, to get safely to the others side.
- If you become too distressed writing, the rule is to stop, and to gather yourself with the above techniques, and go back to it when you feel able to it, if you are not able to do so, we can discuss this in the coming session.

  However, the idea is to expose yourself to previously avoided emotions through a writing process that is under your control. Where you stay with feelings that otherwise might have been avoided, with you determining the rate and degree of confrontation. To write till you feel there is nothing more to write and you are satiated.
- If you find yourself unable to write, and are blocked, think of times you have experienced such blanks before and what the current and past situation have in common in terms of thoughts, feelings; and write about that. This might loosen you up, to then following on from that, start engaging in the above exercise next time you sit down.
- If you cannot write at all, get yourself a tape recorder and start talking onto tape in free flow, and transcribe it from there, to see it black on white, making sense of it, reflecting on it & bring this along.

- Note that what you write does not get scrutinised by your group, so try to write freely. I will look at it eventually for the studies' purposes, but in the group we discuss what has been written by varied people in general terms, so you share what you want to share, as much as you feel able to share at any one point, from your writings and what occurs to you in the sessions, following what others say etc.

Focus for this writing exercise: *Obtaining varied angles/perspectives on what living with MRKH, means; challenging misconstructions:*

I.

Think about what being diagnosed with MRKH meant to you; what conclusions you drew following from it; about yourself, others the world, the future (I am..., others are..., the world is...., the future is....)

II.

Think about the above, reread what you wrote in sitting I. Now shift yourself to a place where you have grown mature and wise and look back at the experience: what conclusions would you draw regarding yourself, others, the world, the future, looking through the eyes of this mature/wise person/self. What does this self suggest would be the most helpful way of looking at the situation, what comfort/advice does this self give you to get through the current phase of life.

III.

Think about what you have written under I, now look at experiences that you have had in your life, that tell you a different story about yourself..... You could write this for yourself, for varied audiences; such as a close compassionate friend, another involved in the experience, an authority figure.

IV.

- If you think of what makes one a woman as consisting of parts of a pie chart, what are the parts that she is made of. What makes a person lobeable/acceptable, what makes you a loveable/acceptable person.

WRITING EXERCISE 4   HOMEWORK GIVEN AT SESSION 4 FOR SESSION 5

General:

- Find a time of the day and a place where you can relatively undisturbed write for a period of 20-45 minutes at a time
- Engage in this exercise for 4 consecutive days (you could take one part at a time, if you want to, doing part I in sitting one, II in sitting two, III in sitting 3, reflecting on this in sitting 4, or put the ones together that make sense to you that they be addressed together). Try to write at the same time in the same place on each of these days.
- Have enough paper and pen, tissue's etc. ready
- After every sitting put your papers in a safe place, have a cup of tea, a bath, listen to music, get some fresh air, whatever, you feel is helpful to soothe yourself, or use any of the other distress tolerance techniques that you are learning during our therapy sessions together, such as the relaxation exercise etc. Engaging in these exercises does stir emotions and that is normal, where you might feel worse first, before you start feeling better. So look after yourself in this process, to get safely to the others side.
- If you become too distressed writing, the rule is to stop, and to gather yourself with the above techniques, and go back to it when you feel able to it, if you are not able to do so, leave it and we can discuss this in the coming session.

  However, the idea is to expose yourself to previously avoided emotions through a writing process that is under your control. Where you stay with feelings that otherwise might have been avoided, with you determining the rate and degree of confrontation. To write till you feel there is nothing more to write and you are satiated.
- If you find yourself unable to write, and are blocked, think of times you have experienced such blanks before and what the current and past situation have in common in terms of thoughts, feelings and write about that. This might loosen you up, to then following on from that, start engaging in the above exercise next time you sit down.
- If you cannot write at all, get yourself a tape recorder and start talking onto tape in free flow, and transcribe it from there, to see it black on white, making sense of it, reflecting on it & bring both

along.

. Note that what you write does not get scrutinised by your group, so try to write freely. I will look at it eventually for the studies purposes, but in the group we discuss what has been written by varied people in general terms, so you share what you want to share, as much as you feel able to share at any one point, from your writings and what occurs to you in the sessions, following what others say etc.

Focus for this writing exercise: *Considering losses, gains & goals:*

I.

Write about your thoughts and feelings in terms of what you felt you lost as a result of being diagnosed with MRKH.
What are you mourning for, how do you mourn and mark these losses. What are your needs and how do you stand up for these, have these met.

II

What were your life goals before diagnosis, what are they now, any new goals, alternative ways of moving forward in the here and now and future, reaching these goals, old or new. How do you see the role of time, how might you deal with the issues that you can see might be arising.

III

Anything you feel you have learned about yourself, others, the world, from your experiences.

Write freely, don't criticise your writings, let go of your thoughts and feelings....

WRITING EXERCISE 5 - HOMEWORK GIVEN AT SESSION 5 FOR SESSION 7

General:

As before. Maybe write this letter over four days, commencing with the part you find most easy to start with, and putting it all together in the final sitting. Or write freely a summary of your experiences of the group and what we looked at in the form of a goodbye letter to the group. Then check post event, the areas you covered, vis a vis the areas suggested on this sheet, and add in/to where needed.

You may vary the order that you are following from A,B, C to A, C & B, or C, B & A, or any order that makes sense to you.

Do go back to the varied writing exercises you have done before this one, if you need to jog your memory re where you were when you came etc....

We will all read our letter out to the group in Session 7. However, do not feel your letter is being given a mark by anyone. We may "pick up" on varied things, so our letters might be different, but also maybe sometimes re-echo what others are saying. Whatever you bring is valid. Firstly, your letter is valuable, to yourself; to have the opportunity to reflect on your group/individual experiences. Secondly, it is valuable for each of us to join, and complement each other in putting together what we have looked at. I, as part of that, will also read my goodbye letter out to you, about our joint experiences during the sessions. And we will then discuss all of this further in the group.

Focus for this writing exercise: *Goodbye letter: wrapping it into a meaningful story/putting it all together:*

A. When you came:

- How did you describe yourself at the start of therapy in terms of your beliefs about yourself, others, the world, your future

- What was life like for you in terms of how the experience/MRKH was effecting your life in its varied facets/areas (eg. studies, work, experience of self/self-esteem, family, friends, intimate relationships etc.). How were you coping

B How you are now:

- How would you describe yourself now in terms of beliefs about yourself, others, the world, your future. Any changes in understandings, feelings about yourself/ways of behaving/being/treating yourself?
- What factor does MRKH play in your life now. What impact does it have in the varied areas of your life. How are you coping.
- Any problems that you are still facing. How you are dealing with these
- Any issues you are anticipating in the future. How do you think you might deal with these.

C What happened coming to the sessions:

- What were your expectations coming to the small group sessions. What did you hope to accomplish for yourself. What did you accomplish.
- What was your experience of your relationship with the therapist, your experience of the group, compared to other relationships
- What was the most memorable event/helpful aspect of therapy, what lead up to it, what was said, done. How was it helpful, what did you do following it, or take away from it.
- What was not helpful/or difficult about the group, and what was happening at that time in therapy. Anything you did to overcome the obstacle. Anything you would have liked to be different, like to see changed.

Appendix 5.6

BRIEF WRITING EXERCISE 1:

Kindly, spend about 15-20 minutes thinking and writing about how MRKH is effecting your life in its varied facets (self to self, vis a vis others etc.), how your are coping. Just engage in a free flow of thoughts and feelings, there is no right or wrong as to what and how to write........

Have a cup of tea, a bath, get some fresh air, and soothe yourself following your witings.....

Post the above with the questionnaires send to you.

Appendix: 5.6

BRIEF WRITING EXERCISE 2:

Kindly, spend about 15-20 minutes thinking and writing about how you see yourself now, including your MRKH, your beliefs about yourself (I am....) others (others are....), the world is, considering the here and now and future etc. Just engage in a free flow of thoughts and feelings, there is no right or wrong as to what & how you write ....

Listen to some music, burn a fragrant candle, soothe yourself... following your writings

And post this together with the questionnaires, if you can

FROM PENNEBAKER Writing to Heal (2004), after every writing exercise (1-5)

Post writing thoughts following the final session

You have now completed the last day of expressive writing. Please complete the following questionnaire using a number between 0 and 10 by each question, where the numbers mean

0	1	2	3	4	5	6	7	8	9	10
not at all					somewhat					a great deal

1. To what degree did you express your deepest thoughts and feelings? ___

2. To what degree do you currently feel sad or upset? ___

3. To what degree do you currently feel happy? ___

4. To what degree was today's writing valuable and meaningful for you? ___

5. Below, describe briefly how your writing went today

SCL - 90 - R   Name   Date

Appendix: 5.7

Below is a list of problems and complaints that people have. Please read each one carefully. After you have done so, please put a cross in one of the boxes that best describes HOW MUCH THAT PROBLEM HAS BOTHERED OR DISTRESSED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Do not try to impress; just answer honestly. Tick only one box for each problem and do not skip any items. If you have by mistake ticked the wrong box, please strike it out and tick the right one.

Example

	not at all 0	a little bit 1	mode-rately 2	quite a bit 3	extre-mely 4
How much were you bothered by pains in lower back	☐	☐	☐	☐	☐

If for you 'extremely' is the answer that describes your problem best, please tick the box 'extremely'

How much were you bothered by:

	not at all 0	a little bit 1	mode-rately 2	quite a bit 3	extre-mely 4
001. Headaches	☐	☐	☐	☐	☐
002. Nervousness or shakiness inside	☐	☐	☐	☐	☐
003. Unwanted thoughts, words or ideas that won`t leave your mind	☐	☐	☐	☐	☐
004. Faintness or dizziness	☐	☐	☐	☐	☐
005. Loss of sexual interest or pleasure	☐	☐	☐	☐	☐
006. Feeling critical of others	☐	☐	☐	☐	☐
007. The idea that someone else can control your thoughts	☐	☐	☐	☐	☐
008. Feeling others are to blame for most of your troubles	☐	☐	☐	☐	☐
009. Trouble remembering things	☐	☐	☐	☐	☐
010. Worried about sloppiness or carelessness	☐	☐	☐	☐	☐
011. Feeling easily annoyed or irritated	☐	☐	☐	☐	☐
012. Pains in heart or chest	☐	☐	☐	☐	☐
013. Feeling afraid in open spaces or street	☐	☐	☐	☐	☐
014. feeling low in energy or slowed down	☐	☐	☐	☐	☐

	Not at All 0	a little bit 1	mode-rately 2	quite a bit 3	extre-mely 4
015. Thoughts of ending your life	☐	☐	☐	☐	☐
016. Hearing voices that other people do not hear	☐	☐	☐	☐	☐
017. Trembling	☐	☐	☐	☐	☐
018. Feeling that most people cannot be trusted	☐	☐	☐	☐	☐
019. Poor appetite	☐	☐	☐	☐	☐
020. Crying easily	☐	☐	☐	☐	☐
021. Feeling shy or uneasy with the opposite sex	☐	☐	☐	☐	☐
022. Feeling of being trapped or caught	☐	☐	☐	☐	☐
023. Suddenly scared for no reason	☐	☐	☐	☐	☐
024. Temper outbursts that you could not control	☐	☐	☐	☐	☐
025. Feeling afraid to go out of the house alone	☐	☐	☐	☐	☐
026. Blaming yourself for things	☐	☐	☐	☐	☐
027. Pains in lower back	☐	☐	☐	☐	☐
028. Feeling blocked in getting things done	☐	☐	☐	☐	☐
029. Feeling lonely	☐	☐	☐	☐	☐
030. Feeling blue	☐	☐	☐	☐	☐
031. Worrying too much about things	☐	☐	☐	☐	☐
032. Feeling no interest in things	☐	☐	☐	☐	☐
033. Feeling fearful	☐	☐	☐	☐	☐
034. Your feelings being easily hurt	☐	☐	☐	☐	☐
035. Other people being aware of your private thoughts	☐	☐	☐	☐	☐
036. Feeling others do not understand you or are unsympathetic	☐	☐	☐	☐	☐
037. Feeling that people are unfriendly or dislike you	☐	☐	☐	☐	☐
038. Having to do things very slowly to insure correctness	☐	☐	☐	☐	☐

	not at all 0	a little bit 1	mode-rately 2	quite a bit 3	extre-mely 4
039. Heart pounding or racing	☐	☐	☐	☐	☐
040. Nausea or upset stomach	☐	☐	☐	☐	☐
041. Feeling inferior to others	☐	☐	☐	☐	☐
042. Soreness of your muscles	☐	☐	☐	☐	☐
043. Feeling that you are watched or talked about by others	☐	☐	☐	☐	☐
044. Trouble falling asleep	☐	☐	☐	☐	☐
045. Having to check and double check what you do	☐	☐	☐	☐	☐
046. Difficulties making decisions	☐	☐	☐	☐	☐
047. Feeling afraid to travel on buses, underground or trains	☐	☐	☐	☐	☐
048. Trouble getting your breath	☐	☐	☐	☐	☐
049. Hot or cold spell	☐	☐	☐	☐	☐
050. Having to avoid certain things, places or activities because they frighten you	☐	☐	☐	☐	☐
051. Your mind going blank	☐	☐	☐	☐	☐
052. Numbness or tingling in parts of your body	☐	☐	☐	☐	☐
053. A lump in your throat	☐	☐	☐	☐	☐
054. Feeling hopeless about the future	☐	☐	☐	☐	☐
055. Trouble concentrating	☐	☐	☐	☐	☐
056. Feeling week in parts of your body	☐	☐	☐	☐	☐
057. Feeling tense or keyed up	☐	☐	☐	☐	☐
058. Heavy feelings in your arms or legs	☐	☐	☐	☐	☐
059. Thougths of death or dying	☐	☐	☐	☐	☐
060. Overeating	☐	☐	☐	☐	☐
061. Feeling uneasy, when people are watching or talking about you	☐	☐	☐	☐	☐
062. Having thoughts that are not your own	☐	☐	☐	☐	☐

	not at all 0	a little bit 1	moderately 2	quite a bit 3	extremely 4
063. Having urges to beat, injure or harm someone	☐	☐	☐	☐	☐
064. Awakening in the early morning	☐	☐	☐	☐	☐
065. Having to repeat the same actions, such as touching, counting washing	☐	☐	☐	☐	☐
066. Sleep that is restless or disturbed	☐	☐	☐	☐	☐
067. Having urges to break and smash things	☐	☐	☐	☐	☐
068. Having ideas of beliefs that others do not share	☐	☐	☐	☐	☐
069. Feeling very self-conscious with others	☐	☐	☐	☐	☐
070. Feeling uneasy in crowds, such as shopping or at a cinema	☐	☐	☐	☐	☐
071. Feeling everything is an effort	☐	☐	☐	☐	☐
072. Spells of terror or panic	☐	☐	☐	☐	☐
073. Feeling uncomfortable about eating or drinking in public	☐	☐	☐	☐	☐
074. Getting into frequent arguments	☐	☐	☐	☐	☐
075. Feeling nervous when you are left alone	☐	☐	☐	☐	☐
076. Others not giving you proper credit for your achievments	☐	☐	☐	☐	☐
077. Feeling lonely even when you are with people	☐	☐	☐	☐	☐
078. Feeling so restless you couldn`t sit still	☐	☐	☐	☐	☐
079. Feelings of worthlessness	☐	☐	☐	☐	☐
080 Feeling that familiar things are strange or unreal	☐	☐	☐	☐	☐
081. Shouting or throwing things	☐	☐	☐	☐	☐
082. Feeling afraid you will faint in public	☐	☐	☐	☐	☐
083. Feeling that people will take advantage of you if you let them	☐	☐	☐	☐	☐
084. Having thoughts about sex that bother you a lot	☐	☐	☐	☐	☐
085. The idea that you should be punished for your sins	☐	☐	☐	☐	☐
086. Feeling pushed to get things done	☐	☐	☐	☐	☐

	not at all 0	a little bit 1	mode-rately 2	quite a bit 3	extre-mely 4
087. The idea that something serious is wrong with your body	☐	☐	☐	☐	☐
088. Never feeling close to another person	☐	☐	☐	☐	☐
089. Feelings of guilt	☐	☐	☐	☐	☐
090. The idea that something is wrong with your mind	☐	☐	☐	☐	☐

ROSENBERG SELF-ESTEEM SCALE

Name:...

Date:.. **Record Number:**..

Here is a list of statements dealing with your general feelings about yourself. If you **agree** with the statement, circle A. If you **strongly agree**, circle SA. If you **disagree**, circle D. If you **strongly disagree**, circle SD. Thank you.

	1 Strongly agree	2 Agree	3 Disagree	4 Strongly disagree
1. On the whole, I am satisfied with myself.	SA	A	D	SD
2. At times I think I am no good at all.	SA	A	D	SD
3. I feel that I have a number of good qualities.	SA	A	D	SD
4. I am able to do things as well as most other people.	SA	A	D	SD
5. I feel I do not have much to be proud of.	SA	A	D	SD
6. I certainly feel useless at times.	SA	A	D	SD
7. I feel that I'm a person of worth, at least on an equal plane with others.	SA	A	D	SD
8. I wish I could have more respect for myself.	SA	A	D	SD
9. All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
10. I take a positive attitude toward myself.	SA	A	D	SD

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NAME :________________________ DATE:________________

REVISED IMPACT OF EVENTS SCALE

On ____________ you experienced ________________________

Below is a list of comments made by people after the stressful life event of being diagnosed with MRKH. Please check each item, indicating how frequently these comments were true for you **DURING THE PAST SEVEN DAYS**. If they did not occur during that time, please mark the "not at all" column.

FREQUENCY

Comment	Not at all	Rarely	Some-times	Often
1. I thought about it when I didn't mean to				
2. I avoided letting myself get upset when I thought about it or was reminded of it				
3. I tried to remove it from memory.				
4. I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into my mind				
5. I had waves of strong feeling about it.				
6. I had dreams about it.				
7. I stayed away from reminders of it.				
8. I felt as if it hadn't happened or it wasn't real.				
9. I tried not to talk about it.				
10. Pictures about it popped into my mind.				
11. Other things kept making me think about it.				
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.				
13. I tried not to think about it				
14. Any reminder brought back feelings about it.				
15. My feelings about it were kind of numb.				

Name . . . . Date . . . . .

INVENTORY OF INTERPERSONAL PROBLEMS - 32

Here is a list of problems that people report in relating to other people. Please read the list below, and for each item, select the number that describes how distressing that problem has been for you. Then circle that number.

EXAMPLE

How much have you been distressed by this problem?

It is hard for me to:	Not at all	A little bit	Moderately	Quite a bit	Extremely
get along with my relatives	0	1	2	[✓ 3]	4

Part I. The following are things you find hard to do with other people.

It is hard for me to:	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. join in on groups	0	1	2	3	4
2. be assertive with another person	0	1	2	3	4
3. make friends	0	1	2	3	4
4. disagree with other people	0	1	2	3	4
5. make a long-term commitment to another person	0	1	2	3	4
6. be aggressive toward other people when the situation calls for it	0	1	2	3	4
7. socialize with other people	0	1	2	3	4
8. show affection to people	0	1	2	3	4
9. feel comfortable around other people	0	1	2	3	4
10. tell personal things to other people	0	1	2	3	4
11. be firm when I need to be	0	1	2	3	4
12. experience a feeling of love for another person	0	1	2	3	4
13. be supportive of another person's goals in life	0	1	2	3	4
14. really care about other people's problems	0	1	2	3	4
15. put somebody else's needs before my own	0	1	2	3	4
16. take instructions from people who have authority over me	0	1	2	3	4
17. open up and tell my feelings to another person	0	1	2	3	4
18. attend to my own welfare when somebody else is needy	0	1	2	3	4
19. be involved with another person without feeling trapped	0	1	2	3	4

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PTO =>

Part II. The following are things that you do too much.

		Not at all	A little bit	Moderately	Quite a bit	Extremely
20.	I fight with other people too much	0	1	2	3	4
21.	I get irritated or annoyed too easily	0	1	2	3	4
22.	I want people to admire me too much	0	1	2	3	4
23.	I am too dependent on other people	0	1	2	3	4
24.	I open up to people too much	0	1	2	3	4
25.	I put other people's needs before my own too much	0	1	2	3	4
26.	I am overly generous to other people	0	1	2	3	4
27.	I worry too much about other people's reactions to me	0	1	2	3	4
28.	I lose my temper too easily	0	1	2	3	4
29.	I tell personal things to other people too much	0	1	2	3	4
30.	I argue with other people too much	0	1	2	3	4
31.	I am too envious and jealous of other people	0	1	2	3	4
32.	I am affected by another person's misery too much	0	1	2	3	4

EDI name .... date ....

This questionnaire includes a variety of attitudes, feelings and behaviours. Some of the questions refer to food and eating behaviour. Other questions ask how YOU feel about YOURSELF. As there are no right or wrong answers please try to be completely honest in your answers. Your answers will be treated in strictest confidence.
Read each question and put a cross in the box you think most appropriate. This concerns the period shortly before you were in contact with this service.
Please answer each question very carefully. Thankyou.

	always 1	usually 2	often 3	sometimes 4	seldom 5	never 6
001. I eat sweets and carbohydrates without feeling nervous.	☐	☐	☐	☐	☐	☐
002. I think that my stomach is too big.	☐	☐	☐	☐	☐	☐
003. I wish that I could return to the security of childhood.	☐	☐	☐	☐	☐	☐
004. I eat when I am upset.	☐	☐	☐	☐	☐	☐
005. I stuff myself with food.	☐	☐	☐	☐	☐	☐
006. I wish that I could be younger.	☐	☐	☐	☐	☐	☐
007 I think about dieting.	☐	☐	☐	☐	☐	☐
008. I get frightened when my feelings are too strong.	☐	☐	☐	☐	☐	☐
009. I think that my thighs are too large.	☐	☐	☐	☐	☐	☐
010. I feel ineffective as a person.	☐	☐	☐	☐	☐	☐
011. I feel extremely guilty after overeating.	☐	☐	☐	☐	☐	☐
012 I think that my stomach is just the right size.	☐	☐	☐	☐	☐	☐
013. Only outstanding performance is good enough in my family.	☐	☐	☐	☐	☐	☐
014 The happiest time in life is when you are a child.	☐	☐	☐	☐	☐	☐
015. I am open about my feelings.	☐	☐	☐	☐	☐	☐
016. I am terified of gaining weight	☐	☐	☐	☐	☐	☐

	always 1	usually 2	often 3	sometimes 4	seldom 5	never 6
017. I trust others.	☐	☐	☐	☐	☐	☐
018. I feel alone in the world.	☐	☐	☐	☐	☐	☐
019. I feel satisfied with the shape of my body.	☐	☐	☐	☐	☐	☐
020. I feel generally in control of things in my life.	☐	☐	☐	☐	☐	☐
021. I get confused about what emotion I am feeling.	☐	☐	☐	☐	☐	☐
022. I would rather be an adult than a child.	☐	☐	☐	☐	☐	☐
023. I can communicate with others easily.	☐	☐	☐	☐	☐	☐
024. I wish I were someone else.	☐	☐	☐	☐	☐	☐
025. I exaggerate or magnify the importance of weight.	☐	☐	☐	☐	☐	☐
026. I can clearly identify what emotion I am feeling.	☐	☐	☐	☐	☐	☐
027. I feel inadequate.	☐	☐	☐	☐	☐	☐
028. I have gone on eating binges where I felt that I could not stop.	☐	☐	☐	☐	☐	☐
029. As a child, I tried very hard to avoid disappointing my parents and teachers.	☐	☐	☐	☐	☐	☐
030. I have close relationships.	☐	☐	☐	☐	☐	☐
031. I like the shape of my buttocks.	☐	☐	☐	☐	☐	☐
032. I am preoccupied with the desire to be thinner.	☐	☐	☐	☐	☐	☐
033. I don`t know what`s going on inside me.	☐	☐	☐	☐	☐	☐
034. I have trouble expressing my emotions to others.	☐	☐	☐	☐	☐	☐
035. The demands of adulthood are too great.	☐	☐	☐	☐	☐	☐
036. I hate being less than best at things.	☐	☐	☐	☐	☐	☐
037. I feel secure about myself.	☐	☐	☐	☐	☐	☐
038. I think about bingeing (overeating).	☐	☐	☐	☐	☐	☐
039. I feel happy that I am not a child anymore.	☐	☐	☐	☐	☐	☐
040. I get confused as to whether or not I am hungry.	☐	☐	☐	☐	☐	☐
041. I have a low opinion of myself.	☐	☐	☐	☐	☐	☐

	always 1	usually 2	often 3	some-times 4	seldom 5	never 6
042. I feel that I can achieve my standards.	☐	☐	☐	☐	☐	☐
043. My parents have expected excellence of me.	☐	☐	☐	☐	☐	☐
044. I worry that my feelings will get out of control.	☐	☐	☐	☐	☐	☐
045. I think my hips are too big.	☐	☐	☐	☐	☐	☐
046. I eat moderately in front of others and stuff myself when they`re gone.	☐	☐	☐	☐	☐	☐
047. I feel bloated after eating a normal meal.	☐	☐	☐	☐	☐	☐
048. I feel that people are happiest when they are children.	☐	☐	☐	☐	☐	☐
049. If I gain a pound, I worry that I will keep gaining.	☐	☐	☐	☐	☐	☐
050. I feel that I am a worthwhile person.	☐	☐	☐	☐	☐	☐
051. When I am upset, I don`t know if I am sad, frightened, or angry.	☐	☐	☐	☐	☐	☐
052. I feel that I must do things perfectly or not do them at all.	☐	☐	☐	☐	☐	☐
053. I have the thought of trying to vomit in order to lose weight.	☐	☐	☐	☐	☐	☐
054. I need to keep people at a certain distance (feel uncomfortable if someone tries to get too close).	☐	☐	☐	☐	☐	☐
055. I think that my thighs are just the right size.	☐	☐	☐	☐	☐	☐
056. I feel empty inside (emotionally).	☐	☐	☐	☐	☐	☐
057. I can talk about personal thoughts or feelings.	☐	☐	☐	☐	☐	☐
058. The best years of your life are when you become an adult.	☐	☐	☐	☐	☐	☐
059. I think my buttocks are too large.	☐	☐	☐	☐	☐	☐
060. I have feelings I can`t quite identify.	☐	☐	☐	☐	☐	☐
061. I eat or drink in secrecy.	☐	☐	☐	☐	☐	☐
062. I think that my hips are just the right size.	☐	☐	☐	☐	☐	☐
063. I have extremely high goals.	☐	☐	☐	☐	☐	☐
064. When I am upset, I worry that I will start eating.	☐	☐	☐	☐	☐	☐

Description of Subscales of Psychometric Measures Used & Varied Types of Calculations of Scores

1. The Symptom Check List, SCL-90-R (Derogatis, 1992)

The Somatisation (SOM) dimension (item 1, 4, 12, 27, 40, 42, 48, 49, 52, 53, 56, and 58) reflects distress arising from perceptions of bodily dysfunction. Complaints focus on cardiovascular, gastrointestinal, respiratory, and other systems with strong autonomic mediation. Pain and discomfort of the gross musculature and additional somatic equivalents of anxiety are also components of Somatisation. The Obsessive-Compulsive (O-C) dimension (item 3, 9, 10, 28, 38, 45, 46, 51, 55, and 65) includes symptoms that are often identified with the standard clinical syndrome of the same name. This dimension focuses on thoughts, impulses, and actions that are experienced as unremitting and irresistible and that are of an ego-alien or unwanted nature. Behaviour and experiences of a more general cognitive performance deficit are also included in this measure. The Interpersonal Sensitivity (I-S) dimension (item 6, 21, 34, 36, 37, 41, 61, 69, and 73) focuses on feelings of inadequacy and inferiority, particularly in comparison with other people. Self-deprecation, self-doubt, and marked discomfort during interpersonal interactions are characteristic manifestations of this syndrome. In addition, individuals with high scores on I-S report acute self-consciousness and negative expectations concerning interpersonal behaviour with others and other's perceptions of them. The symptoms of the Depression (DES) dimension (item 5, 14, 15, 20, 22, 26, 29, 30, 31, 32, 54, 71, and 79) reflect a representative range of the manifestations of clinical depression. Symptoms of dysphoric mood and affect are represented, as are signs of withdrawal of life's interests, lack of motivation, and loss of vital energy. In addition, feelings of hopelessness, thoughts of suicide, and other cognitive and somatic correlates of depression are included. General signs of Anxiety (ANX) such as nervousness, tension, and trembling are included in the definition, as are panic attacks and feelings of terror, apprehension, and dread. Some somatic correlates of anxiety are also included as dimensional components. These are captured by item 2, 17, 23, 33, 39, 57, 72, 78, 80, and 86. The Hostility (HOS) dimension (item 11, 24, 63, 67, 74 and 81) reflects thoughts, feelings, or actions that are characteristic of the negative affect state of anger. The selection of items includes all three modes of expression and reflects qualities such as aggression, irritability, rage and resentment. Phobic Anxiety (PHOB) is defined as persistent fear response – to a specific person, place, object, or situation – that is irrational and disproportionate to the stimulus and leads to avoidance or escape behaviour. The items of this dimension (item 13, 25, 47, 50, 70, 75, and 82) focus on the more pathognomonic and disruptive manifestations of phobic behaviour. The Paranoid Ideation (PAR) dimension (item 8, 18, 43, 68, 76, and 83) represents paranoid behaviour fundamentally as a disordered mode of thinking. The cardinal characteristics of projective thought, hostility, suspiciousness, grandiosity, centrality, fear of loss of autonomy, and delusion are viewed as primary reflections of this disorder, and items selection was oriented toward representing this conceptualization. The Psychoticism (PSY) dimension (item 7, 16, 35, 62, 77, 84, 85, 87, 88 and 90) was designed to represent the construct as a continuous dimension of human experience. Items indicative of a withdrawn, isolated, schizoid lifestyle were included as were first-rank symptoms of schizophrenia, such as hallucinations and thought control. The Psychotic dimension provides for a graduated continuum from mild interpersonal alienation to dramatic psychosis. Kennedy, Richard, Morris, Lawrence, Pedley and Schwab (2001) note that "the items on this particular scale are not those of classic psychosis such as hallucinations or of an elaborated delusional system. Instead, they focus on how unrealistically the patient views her or his problem, trying to report distorted thinking and negativity, rather than frankly psychotic symptoms".

Raw scores are derived by first summing the values (ie. 0-4) for the item responses in each of the nine symptom dimensions and the seven additional items. The sum of each symptom dimension is then divided by the number of endorsed items in that dimension (except for the additional items).

Derogatis (1992) suggests that a "Global Severity Index (GSI) can be computed by first summing the scores on the nine symptom dimensions and the additional items. The sum is then divided by the total number of responses (ie. 90 if there are no missing responses. Derogatis (1992) notes that the GSI is "the best indicator of the current degree of distress, when one simple summary score is needed, and that it combines information concerning the number of symptoms reported with the intensity of perceived distress".

Other aspects of this scale can also be computed such as “The Positive Symptom Total (PST)”, which The PST is derived by counting the number of items endorsed with a positive (nonzero) response. It is meant to be simply a reflection of the number of symptoms endorsed by the respondent, regardless of the level of distress reported, and can be interpreted as a measure of symptom breadth. “The Positive Symptom Distress Index (PSDI)” can, finally be computed, by dividing the sum of all items values by the PST. It functions as a measure of response style by indicating whether the respondent was augmenting or attenuating symptom distress. That is, the PSDI reflects the average level of distress reported for the symptoms that were endorsed, and can interpreted as a measure of symptom intensity.

2. Impact of Event Scale (IES; Horowitz, Wilner & Alvarez, 1979)

The scores for the intrusive subscale range from 0 to 35, and is the sum of the scores for items 1, 4, 5, 6, 10, 11 and 14. The scores for the avoidance subscale range from 0-40, and is the sum of the scores for item 2, 3, 7, 8, 9, 12, 13 and 15. The sum of the two subscales is the total stress score. It is suggested that the cut-off point is 26, above which a moderate or severe impact is indicated. However, the IES can also be interpreted according to the following dimensions: a score from 0 to 8: Subclinical range, a score from 9 to 25: Mild range, a score from 26-43: Moderate range or a score of 44+ : Severe range (Horowitz, Wilner & Alvarez, 1979).

4. Rosenberg Self Esteem Scale (Rosenberg, 1965)

See main text

3. Inventory of Interpersonal Problems, IIP-32 (Barkham & Hardy, 1996)

People with high scores on the “Hard to be assertive” scale (items 2, 4,6, 11) report problems in telling others what they want and what they don’t want. They have difficulties in expressing their opinion to others, in confronting others and being aggressive. They see themselves as less self-confident when they are together with others and they have difficulties in taking on a leadership role. The opposite scale is “Too aggressive”. Similar scales are “Hard to be sociable” and “Too dependent.

People with high scores on the ”Too dependent” scale (items 22, 23, 27,31) report problems in distancing themselves from others. They have problems in saying no and in showing their anger. They describe themselves as being very trustful and as someone who can be easily persuaded. They have difficulties in arguing with others and are often easily exploited. The opposite scale is “Hard to be supportive”. Similar scales are “Hard to be assertive” and “Too caring”.

People with high scores on the “Too caring” scale (items 18, 25, 26, 32) report that they overlook their own interests and wishes because of the needs of others. They are too generous. They have difficulty in building boundaries between themselves and others. The opposite scale is “Hard to be involved”. Similar scales “Too dependent” and “Too open”.

People with high scores on the“Too open” scale (items 10, 17, 24, 29), report difficulties in keeping things to themselves. They report things about themselves too often and open up too much. They want to be noticed by others and play the clown too often. They have difficulties being alone. They feel responsible for others and have difficulties in staying out of other people’s business. The opposite scale is “Hard to be sociable”. Similar scales are “Too caring” and “Too aggressive”.

People with high scores on the “Too aggressive” scale (items 20, 21,28, 30) report problems accepting others. They have problems because they want to change or influence others too much, control others too much and often have quarrels with others. They point out their independence and often have difficulties fitting in as part of a group. The opposite scale is “Hard to be assertive”. Similar scales are “Too open” and “Hard to be supportive”.

People with high scores on the “Hard to be supportive” scale (items 13, 14, 15, 16) report problems with trusting others. They have difficulties supporting others and in caring about others’ problems and needs. They describe themselves as envious and jealous people who argue too much and often try to get revenge. The opposite scale is too dependent. Similar scales are “Too aggressive” and “Hard to be involved”.

People who have high scores on the “Hard to be involved” scale (items 5, 8, 12, 19) have difficulties creating close relationships. They have difficulties feeling love for others in making long lasting commitments. They describe themselves as keeping others at a distance and have difficulties in reconciling after an argument. The opposite scale is “Too caring”. Similar scales are “Hard to be supportive” and “Hard to be sociable”.

People with high scores on the “Hard to be sociable” scale (items 1,3, 7, 9) report problems in making contact with others. They find it difficult to go out with others or to make the first step when meeting somebody. They describe difficulties in showing their feelings. The opposite scale is “Too open”. Similar scales are “Hard to be involved” and “Hard to be assertive”.

4. Eating Disorder Inventory, EDI (Garner, Olmstead, & Polivy, 1983)

The EDI consists of 8 subscales measuring 1. Drive for thinness (items 1, 7, 11, 16, 25, 32, and 49): This subscale indicates excessive concern with dieting, preoccupation with weight and an extreme pursuit of thinness. 2. Interoceptive awareness (items 8, 21, 26, 33, 40, 44, 47, 51, 60, and 64): This subscale reflects one’s lack of confidence in identifying emotions and sensations of hunger and satiety. 3. Perfectionism (items 13, 29, 36, 43, 52, and 63): This scale indicates excessive personal expectations for superior achievement. 4. Interpersonal distrust (items 15, 17, 23, 30, 34, 54, and 57): This subscale reflects a sense of alienation and a general reluctance to form close relationships and relates to an inability to form attachments or feel comfortable expressing emotions towards others. 5. Ineffectiveness (items 10, 18, 20, 24, 27, 37, 41, 42, 50, and 56): This subscale assesses feelings of general inadequacy, insecurity, worthlessness and the feeling of not being in control of one's life. 6. Body Dissatisfaction (items 2, 9, 12, 19, 31, 45, 55, 59, and 62): This sub-scale reflects the belief that specific parts of the body associated with shape changed or increased at puberty and are too large. 7. Maturity fears (items 3, 6, 14, 22, 35, 39, 48, 58). This sub-scale measures one's wish to retreat to the security of the pre-adolescent because of the overwhelming demands of adulthood. 8. Bulimia (items 4, 5, 28, 38, 46, 53, and 61). This sub-scale indicates the tendency towards uncontrollable overeating (bingeing) and may be followed by the impulse to engage in self-induced vomiting.

[redacted]

[redacted]

Appendix 5.9

From : PD book Vol 6.

DISTRESS TOLERANCE HANDOUT I:
Crises Survival Strategies (cont.)

DISTRACTING

A useful way to remember these skills is the phrase
"Wise Mind ACCEPTS."

With **Activities:**

Engage in exercise or hobbies; do cleaning; go to events; call or visit a friend; play computer games; go walking; work; play sports; go out to a meal, have decaf coffee or tea; go fishing; chop wood, do gardening; play pinball.

With **Contributing:**

Contribute to someone; do volunteer work; give something to someone else; make something nice for someone else; do a surprising, thoughtful thing.

With **Comparisons:**

Compare yourself to people coping the same as you or less well than you. Compare yourself to those less fortunate than you. Watch soap operas; read about disasters, others' suffering.

With opposite **Emotions:**

Read emotional books or stories, old letters; go to emotional movies; listen to emotional music. *Be sure the event creates different emotions.* Ideas: scary movies, joke books, comedies, funny records, religious music, marching songs, "I Am Woman" (Helen Reddy); going to a store and reading funny greeting cards.

With **Pushing away:**

Push the situation away by leaving it for a while. Leave the situation mentally. Build an imaginary wall between yourself and the situation.

Or push the situation away by blocking it in your mind. Censor ruminating. Refuse to think about the painful aspects of the situation. Put the pain on a shelf. Box it up and put it away for a while.

With other **Thoughts:**

Count to 10; count colors in a painting or tree, windows, anything; work puzzles; watch TV; read.

With intense other **Sensations:**

Hold ice in hand; squeeze a rubber ball very hard; stand under a very hard and hot shower, listen to very loud music; sex; put rubber band on wrist, pull out, and let go.

DISTRESS TOLERANCE HANDOUT 1:
Crisis Survival Strategies (cont.)

SELF-SOOTHE

A way to remember these skills is to think of soothing each of your
FIVE SENSES:

With **Vision:**

Buy one beautiful flower; make one space in a room pretty; light a candle and watch the flame. Set a pretty place at the table, using your best things, for a meal. Go to a museum with beautiful art. Go sit in the lobby of a beautiful old hotel. Look at nature around you. Go out in the middle of the night and watch the stars. Walk in a pretty part of town. Fix your nails so they look pretty. Look at beautiful pictures in a book. Go to a ballet or other dance performance, or watch one on TV. Be mindful of each sight that passes in front of you, not lingering on any.

With **Hearing:**

Listen to beautiful or soothing music, or to invigorating and exciting music. Pay attention to sounds of nature (waves, birds, rainfall, leaves rustling). Sing to your favorite songs. Hum a soothing tune. Learn to play an instrument. Call 800 or other information numbers to hear a human voice. Be mindful of any sounds that come your way, letting them go in one ear and out the other.

With **Smell:**

Use your favorite perfume or lotions, or try them on in the store; spray fragrance in the air; light a scented candle. Put lemon oil on your furniture. Put potpourri in a bowl in your room. Boil cinnamon; bake cookies, cake, or bread. Smell the roses. Walk in a wooded area and mindfully breathe in the fresh smells of nature.

With **Taste:**

Have a good meal; have a favorite soothing drink such as herbal tea or hot chocolate (no alcohol); treat yourself to a dessert. Put whipped cream on your coffee. Sample flavors in an ice cream store. Suck on a piece of peppermint candy. Chew your favorite gum. Get a little bit of a special food you don't usually spend the money on, such as fresh-squeezed orange juice. Really taste the food you eat; eat one thing mindfully.

With **Touch:**

Take a bubble bath; put clean sheets on the bed. Pet your dog or cat. Have a massage; soak your feet. Put creamy lotion on your whole body. Put a cold compress on your forehead. Sink into a really comfortable chair in your home, or find one in a luxurious hotel lobby. Put on a silky blouse, dress, or scarf. Try on fur-lined gloves or fur coats in a department store. Brush your hair for a long time. Hug someone. Experience whatever you are touching; notice touch that is soothing.

DISTRESS TOLERANCE HANDOUT 1:
Crisis Survival Strategies (cont.)

IMPROVE THE MOMENT

A way to remember these skills is the word **IMPROVE.**

With **Imagery**:

Imagine very relaxing scenes. Imagine a secret room within yourself, seeing how it is decorated. Go into the room whenever you feel very threatened. Close the door on anything that can hurt you. Imagine everything going well. Imagine coping well. Make up a fantasy world that is calming and beautiful and let your mind go with it. Imagine hurtful emotions draining out of you like water out of a pipe.

With **Meaning**:

Find or create some purpose, meaning, or value in the pain. Remember, listen to, or read about spiritual values. Focus on whatever positive aspects of a painful situation you can find. Repeat them over and over in your mind. Make lemonade out of lemons.

With **Prayer**:

Open your heart to a supreme being, greater wisdom, God, your own wise mind. Ask for strength to bear the pain in this moment. Turn things over to God or a higher being.

With **Relaxation**:

Try muscle relaxing by tensing and relaxing each large muscle group, starting with your hands and arms, going to the top of your head, and then working down; listen to a relaxation tape; exercise hard; take a hot bath or sit in a hot tub; drink hot milk; massage your neck and scalp, your calves and feet. Get in a tub filled with very cold or hot water and stay in it until the water is tepid. Breathe deeply; half-smile; change facial expression.

With **One thing in the moment**:

Focus your entire attention on just what you are doing right now. Keep yourself in the very moment you are in; put your mind in the present. Focus your entire attention on physical sensations that accompany nonmental tasks (e.g. walking, washing, doing dishes, cleaning, fixing). Be aware of how your body moves during each task. Do awareness exercises.

DISTRESS TOLERANCE HANDOUT 1:
Crisis Survival Strategies (cont.)

With a brief **Vacation**:

Give yourself a brief vacation. Get in bed and pull the covers up over your head for 20 minutes. Rent a motel room at the beach or in the woods for a day or two; drop your towels on the floor after you use them. Ask your roommate to bring you coffee in bed or make you dinner (offer to reciprocate). Get a schlocky magazine or newspaper at the grocery store, get in bed with chocolates, and read it. Make yourself milk toast, bundle up in a chair, and eat it slowly. Take a blanket to the park and sit on it for a whole afternoon. Unplug your phone for a day, or let your answering machine screen your calls. Take a 1-hour breather from hard work that must be done.

With **Encouragement**:

Cheerlead yourself. Repeat over and over: "I can stand it," "It won't last forever," "I will make it out of this," I'm doing the best I can do."

Thinking of PROS AND CONS

Make a list of the pros and cons of *tolerating* the distress. Make another list of the pros and cons of *not tolerating* the distress—that is, of coping by hurting yourself, abusing alcohol or drugs, or doing something else impulsive.

Focus on long-term goals, the light at the end of the tunnel. Remember times when pain has ended.

Think of the positive consequences of tolerating the distress. Imagine in your mind how good you will feel if you achieve your goals, if you don't act impulsively.

Think of all of the negative consequences of not tolerating your current distress. Remember what has happened in the past when you have acted impulsively to escape the moment.

Topic: Assertiveness: Finding your voice
(1)

Additional suggested Reading
Anne Dickinson (1982 or more recent editions)
A woman in your own right
assertiveness & you
London: Quartet Books)

APPENDIX 4 – ASSERTION FEARS

Here are ten common fears and concerns about being more assertive taken from Bond, M and Kilty, J W (1982) *Practical Methods of Dealing with Stress*. Human Potential Research Project, Department of Educational Studies, University of Surrey, Guildford, Surrey GU2 5XH

1 It is uncaring to be assertive.

2 I'm here to satisfy other people's expectations/needs or they're here to satisfy mine.

3 I have no right to say 'No' or to change my mind, neither has anyone else.

4 If someone says 'No' to my request it's because they don't like/love me.

5 If I don't get what I want, it will be the end of the world for me.

6 It's rude/selfish to say what you want.

7 People should keep their feelings to themselves.

8 I shouldn't have to say what I need: people close to me should know.

9 A woman loses her femininity if she asserts herself.

10 I'll lose face if I ask for what I want.

(From: Reference see over)

THE BASIC TENETS OF AN ASSERTIVE PHILOSOPHY*

1. By standing up for our rights we show we respect ourselves and achieve respect from other people. Sacrificing our rights usually results in training other people to mistreat us.

2. By trying to govern our lives so as to never hurt anyone, we end up hurting ourselves and other people. When we are assertive everyone involved usually benefits.

3. Sacrificing our rights usually results in destroying relationships or preventing new ones from forming. When we do what we think is right for us, we feel better about ourselves and have more authentic and satisfying relationships.

4. Not letting others know how we feel and what we think is a form of selfishness. If we don't tell other people how their behavior negatively effects us, we are denying them an opportunity to change their behavior.

5. We can decide what's important for us; we do not have to suffer from the tyranny of the should and should not. We all have a natural right to courtesy and respect.

6. We all have a right to express ourselves as long as we don't violate the rights of others. There is more to be gained from life by being free and able to stand up for ourselves and from honoring the same rights of other people.

Adapted from: Jakubowski, Patricia Ann, "Self-Assertion Training Procedures for Women." In Rawlings, Edna I. and Carter, Dianne K. (Eds.): Psychotherapy for Women Treatment Toward Equality. Springfield, Illinois: Charles C. Thomas, 1977.

Three Basic Styles of Interpersonal Behavior

Aggressive Style Typical examples of aggressive behavior are fighting, accusing, threatening and generally stepping on people without regard for their feelings. The advantage of this kind of behavior is that people do not push the aggressive person around. The disadvantage is that people do not want to be around him or her.

Passive Style A person is behaving passively when he lets others push him around, when he does not stand up for himself, and when he does what he is told, regardless of how he feels about it. The advantage of being passive is that you rarely experience direct rejection. The disadvantage is that you are taken advantage of, and you store up a heavy burden of resentment and anger.

Assertive Style A person is behaving assertively when he stands up for himself, expresses his true feelings, and does not let others take advantage of him. At the same time, he is considerate of others' feelings. The advantage of being assertive is that you get what you want, usually without making others mad. If you are assertive, you can act in your own best interest, and not feel guilty or wrong about it. Meekness and withdrawl, attack and blame are no longer needed with the mastery of assertive behavior. They are seen for what they are — sadly inadequate strategies of escape that create more pain and stress than they prevent. Before you can achieve assertive behavior, you must really face the fact that the passive and aggressive styles have often failed to get you what you want.

THE LADDER TECHNIQUE

Look at your rights, what you want, what you need, and your feelings about the situation. Let go of blame, the desire to hurt, and self pity. Define your goal and keep it in mind when you negotiate for change.

Arrange a time and place to discuss your problem that is convenient for you and for the other person. This step may be excluded when dealing with spontaneous situations in which you choose to be assertive, such as when a person cuts ahead of you in line.

Define the problem situation as specifically as possible.

Describe your feelings using "I messages." An "I message" expresses your feelings without evaluating or blaming others. Rather than say, "You are inconsiderate" or "You hurt me," the I message would be, "I feel hurt." I messages connect the feeling statement with specific behaviors of the other person. For example, "I felt hurt when you left without saying goodbye." Contrast the clarity of this message with the blame statement, "I felt hurt because you were inconsiderate."

Express your request in one or two easy-to-understand sentences. Be specific and firm!

Reinforce the possibility of getting what you want by stating the positive consequences should the other person cooperate with you. If necessary, state the negative consequences for failure to cooperate.

Successful LADDER scripts do the following:

1. When appropriate, establish a mutually agreeable time and place to assert your needs.
2. Describe behavior objectively, without judging or devaluing.
3. Describe clearly, using specific references to time, place and frequency.
4. Express feelings calmly and directly.
5. Confine your feeling response to the specific problem behavior, not th whole person.
6. Avoid delivering put-downs disguised as "honest feelings."
7. Ask for changes that are reasonably possible, and small enough not to inc a lot of resistance.
8. Ask for no more than one or two very specific changes at a time.
9. Make the reinforcements explicit, offering something that is rea desirable to the other person.
10. Avoid punishments that are too big to be more than idle threats.
11. Keep your mind on your rights and goals when being assertive.

Techniques of overcoming standard blocking gambits

Broken Record. Calmly repeating your point without getting sidetracked by irrelevant issues (*Yes, but . . . Yes, I know, but my point is . . . I agree, but . . . Yes, but I was saying . . . Right, but I'm still not interested.*)

Assertive Agreement. Responding to criticism by admitting an error when you have made a mistake, but separating that mistake from you as a bad person. (*Yes, I did forget our lunch date. I'm usually more responsible.*)

Assertive Inquiry. Prompting criticism in order to gather additional information for your side of the argument. (*I understand you don't like the way I acted at the meeting last night. What is it about it that bothered you? What is it about me that you feel is pushy? What is it about my speaking out that bothers you?*)

Content-to-Process Shift. Shifting the focus of the discussion from the topic to an analysis of what is going on between the two of you. (*We're getting off the point now. We've been derailed into talking about old issues. You apear angry at me.*)

Clouding. Appearing to give ground without actually doing so. Agree with the person's argument, but don't agree to change. (*You may be right. I probably could be more generous. Perhaps I shouldn't be so confrontive, but . . .*)

Defusing. Ignoring the content of someone's anger, and putting off further discussion until he has calmed down. (*I can see that you're very upset and angry right now, let's discuss it later this afternoon.*)

Circuit Breaker. Responding to provocative criticism with one word, or very clipped statements. (*Yes . . . no . . . perhaps*)

Assertive Irony. Responding to hostile criticism positively.(Answer *You're a real loudmouth* with *Thank you.*)

Assertive Delay. Putting off a response to a challenging statement until you are calm, and able to deal with it appropriately. (*Yes . . . very interesting point . . . I'll have to reserve judgement on that . . . I don't want to talk about that right now.*)

Some typical blocking gambits that will be used to attack and derail your assertive requests :

Laughing it off. Your assertion is responded to with a joke. (*Only three weeks late? I've got to work on being less punctual!*) Use the Content to Process Shift (*Humor is getting us off the point.*) and the Broken Record (*Yes, but. . .*)

Accusing Gambit. You are blamed for the problem. (*You're always so late cooking dinner, I'm too tired to do the dishes afterward.*) Use Clouding (*That may be so, but you are still breaking your commitment.*) or simply disagree (*8:00 is not too late for the dishes.*)

The Beat-up. Your assertion is responded to with a personal attack, such as, "Who are you to worry about being interrupted, you're the biggest loudmouth around here." The best strategies to use are Assertive Irony (*Thank you*) in conjunction with the Broken Record or Defusing (*I can see you're angry right now, let's talk about it after the meeting.*)

Delaying Gambit. Your assertion is met with, "Not now, I'm too tired" or "Another time, maybe." Use the Broken Record, or insist on setting a specific time when the problem can be discussed.

Why Gambit. Every assertive statement is blocked with a series of "why" questions, such as, "Why do you feel that way . . . I still don't know why you don't want to go . . . why did you change your mind?" The best response is to use the Content-to-Process Shift. (*Why isn't the point. The issue is that I'm not willing to go tonight.*) or the Broken Record.

Self Pity Gambit. Your assertion is met with tears and the covert message that you are being sadistic. Try to keep going through your script using Assertive Agreement. (*I know this is causing you pain, but I need to get this resolved.*)

Quibbling. The other person wants to debate with you about the legitimacy of what you feel, or the magnitude of the problem, etc. Use the Content-to-Process Shift (*We're quibbling now, and have gotten off the main concern.*) with the assertion of your right to feel the way you do.

Threats. You are threatened with statements like, "If you keep harping at me like this, you're going to need another boyfriend." Use the Circuit Breaker (*Perhaps*) and Assertive Inquiry (*What is it about my requests that bother you?*) as well as Content-to-Process Shift (*This seems to be a threat.*) or Defusing.

Denial. You are told, "I didn't do that" or "You've really misinterpreted me." Assert what you have observed and experienced, and use Clouding. (*It may seem that way to you, but I've observed . . .*)

EXPRESSING feelings

It is really important to be able to express your feelings rather than bottling them up However, especially with anger, you need to be careful how you tell people how you feel, to avoid winding others up and precipitating a potentially problematic situation

What to say

Explain that what you say is very important in determining how someone will respond to an expression of feelings ____________ The DESO formula is one helpful way of deciding what to say so as to get your point over without provoking an incident whilst at the same time actually increasing the likelihood that you will get what you want

DESO formula

Describe - what you are annoyed about, but don't be insulting
    Express - how you feel
        Specify - what you want the other person to do
            Outcome - tell him what good outcome will come of it for him if he does it (give him a *positive* reason for doing it)

Here is an assertiveness formula that you should memorize and practice until it becomes automatic.

I feel ______________________________

When you ______________________________

I would prefer it if ______________________________

When you feel angry with people, you start by describing how you feel. Then, in behavioral terms, describe what they did that led to your feelings. Then, again in behavioral terms, tell them what you want them to do.

Let's try it in a situation to show how the assertiveness formula works.

The Aggressive Response

Bob comes home from work one hour late. Barbara, his spouse, is hurt and angry.

Barbara: Where have you been! You're such an incredible jerk!

How is Bob going to be feeling: attacked, hurt, angry, defensive? He might retaliate and say:

Bob: What a nag! You're always mad at me!

The Assertive Response

Barbara: I feel hurt and angry when you're late. I would prefer it if you would call me and tell me when you're not going to be on time.

The assertiveness formula gives other persons accurate information that they can use to remedy the situation. They know what they did, and they know what to do differently.

Try the assertiveness formula at least two times today. After each use, write the situation down and how it turned out. Notice the feelings you have. If you are like most people, you will feel much more in control of your feelings. You will also get more of what you want.

(Chemical Dependency Counseling Perkinson RR 1997 page
Publications California) 410

WORKSHEET FIVE

Plans for Change [illegible]

The changes I want to make are:

The most important reasons why I want to make these changes are:

The steps I plan to take in changing are:

The ways other people can help me are:

Person Possible ways to help

I know that my plan is working if:

Some things that could interfere with my plan are

(*Adapted from Miller et al., 1994*)

From Schmidt U & Treasure J (1993)

Getting Better Bit(e) By Bit(e)

A survival kit for sufferers of

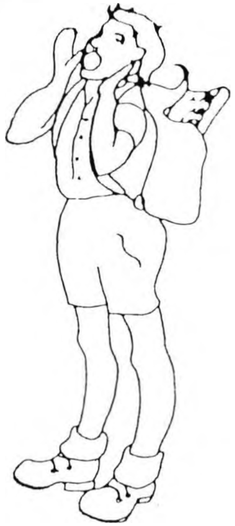
BN & BED London: Brunner

Routledge

Topic Assertiveness (2)

CHAPTER ELEVEN

Finding Your Voice



Did you recognise yourself in the plastic pleaser or the subject of control or standards as described in chapter 10? Are you a person whose life is ruled and ruined by shoulds, drained by giving and giving and giving, until you feel totally tired out?

Do others take advantage of you because you will say "yes" to whatever they ask you, even if you would like to shout "no, no, no"? Are you unable to refuse any favours for fear of hurting the feelings of the other person irrevocably and beyond repair? Do you worry that, if you ever say what you want, you might be seen as totally self-obsessed and selfish?

If your answer is "yes" to any of these questions, read on. You suffer from lack of assertiveness! This is often the result of having extremely low self-esteem, feeling that you are totally insignificant or unloveable.

Sally

Sally is a case in point. She is a 20-year-old secretary in a small, successful company. "I feel nobody is really interested in me, I am not a very nice or interesting person to be with." When Sally came into treatment, she felt so bad about herself that she constantly had to pacify her feelings of guilt, shame, or self-disgust and prove her worth and usefulness by being everything to everybody, looking after others practically or emotionally. "We are four girls in the office. If our boss pops round the corner and says, "who is going to make us a cup of coffee, then?" it's always me who jumps up.

Needless to say, the washing-up is also left to me. The others just won't do it. I often stay behind to clear up when everybody has gone home." Sally also regularly took on twice as much work as everybody else. Once or twice her boss tried to be supportive to her by asking one of the other girls in the office to take some of Sally's load. "I didn't like that at all; I know he was only trying to be helpful, but I felt totally guilty afterwards." Is Sally a masochist or a martyr? Probably neither. However, she had got very used to letting herself be used as a doormat and found it very threatening not to be one. She feared that, if she gave up the role of a doormat, others would reject her.

Sometimes the fear of a lot of pent-up anger or frustration coming out is what stops a person from speaking their mind.

Cindy

Cindy, a 20-year-old student, shared a flat with another girl. "Although we are supposed to be equals in the flat, I don't seem to have the right to say what I think about things. Alison, my flatmate, is very outspoken and often really thoughtless. It's been irritating me for a while. The other day she said in front of a group of people whom she had invited for her birthday dinner that she would not pay for a meal for me, as I would sick it up anyway. I was furious. I would have liked to kick or punch her or shout at her. Instead, I said nothing and just gave her a nervous little smile."

LEARNING TO STAND YOUR GROUND

We can communicate our wants/needs/feelings in three different ways:

1. *Passive*
   Where your own wants/needs/feelings are silenced. This kind of communication may be given with a slumped body, downcast eyes, and a hesitant, giggly, or whining voice. It uses: "maybe", "I wonder if you could, only, just", "It's all right, don't bother".
2. *Assertive*
   Where you express your own wants, needs, and feelings, but also take into account the feelings of the person to whom you are talking.
3. *Aggressive*
   Where you only consider your own wants, needs, and feelings. Inappropriate anger or hostility is loudly or explosively uttered. There is use of threats: "you'd better", or put-downs: "come on, you must be kidding", or evaluative comments: "should", "I thought you would know better".

We all deal with different situations in these three ways. Women with eating difficulties often swing between the passive and aggressive poles and find it difficult to get onto a middle ground.

Think of the last time you behaved passively, suppressing your own feelings. Reconstruct the behaviour chain of this event (see chapter 2).

A. *Where, What, With Whom, and When?*
- What were your thoughts?
- What were the feelings (that you chose to suppress)?
- The thoughts that commonly lead to this pattern are:
  - "If I say something he/she won't like me"
  - "It's silly for me to be upset"

B. *Passive Behaviour*
- How, in what way, did you let someone walk over you?

C. *What Were the Positive and Negative Consequences of this?*

Assertive rather than passive behaviour is a skill you will need to learn and use as a way of finding the middle ground.

ANYTHING FOR A QUIET LIFE?

"Why should I learn to be assertive? Isn't it terribly risky?" you may ask. Whatever your reasons for not voicing your own needs, wants, and feelings, whilst in the short term it may seem easiest, in the long term it can seriously damage your physical and mental health.

- Not being assertive leads to a gradual build-up of frustration, which will keep your bulimia going and can also lead to other health problems like headaches and backaches.
- Others may sympathise with the poor downtrodden you and may seem to "like" your non-assertiveness. However, they'll soon become irritated by you, especially if you moan about how unfair life is or look so unwell with your bulimia and yet don't do anything about it.
- Ignoring conflict might make it go away in the short term, but in the long term tension and frustration increase. It is far healthier to deal with situations as they arise.

You may still say, "This all sounds like a lot of effort to me, and it carries the risk of alienating people around me. I am too frightened even to try." Nobody is saying you should change overnight to being assertive at all times in all situations, but you should at least have the choice as to whether or not you want to behave assertively in specific circumstances.

GROUND-RULES FOR ASSERTIVE BEHAVIOUR

Like everyone else, you have basic human rights: the right to hold and express your own opinions; the right to make mistakes; the right to refuse requests without guilt; the right to change your mind; the right to set your own priorities and goals; and the right to judge your own behaviour, thoughts, and emotions and to take responsibility for the consequences.

- Think ahead—before negotiating, be absolutely clear what you want to achieve and what your rights (and those of other people) are. Anticipate any possible objections, and work out your responses—being prepared will boost your confidence.
- Choose your timing if you can. Asking your boss for a pay rise as she pushes past your desk on the way to a meeting is not the right way to tackle it! Make an appointment with her to discuss the matter privately.
- When you make a request, be specific and direct. Avoid unassertive words like "only", "rather", and "maybe". Don't say, "I wondered whether maybe I could be put forward for promotion." Say, "Could I be put forward for promotion?"
- Criticise behaviour, not the person. Stick to facts and not judgements. Avoid words like "always", "never", and "impossible". Say something positive about the person or situation. After you have said what you had to say, don't hover. Don't undo what you said by apologising.
- When you have to say no, suggest alternatives. "I am afraid I can't help do the baby-sitting for you tonight, but I am free tomorrow if that's any help."
- Use the "broken record" technique on people who try to change the subject or convince you to reverse a decision. Repeat your point calmly, no matter what the other person says.
- Make eye contact. Adopt an upright and relaxed posture—shoulders down and arms by your side, not crossed defensively.

There are other techniques if you are being baited by criticism.

- Calmly accept that there may be some truth in what your critic says, but remain your own judge of what you do.
- Negative assertion: accept your errors or faults without having to apologise.
- Prompt criticism in order to use the information if it is helpful or to exhaust it if it is manipulative.

HOW TO PUT ASSERTIVENESS INTO PRACTICE

You will probably have seen some of the things outlined above in other books or in women's magazines, but you may still be wondering how to put it all into practice.

For situations where you can plan beforehand:

- Practice what you want to say in front of the mirror.
- Make a tape-recording of what you want to say.
- Role-play the situation with a friend, change roles, take on the person to whom you make the request.

There are, of course, situations where you have to think on your feet. You may have got so used to saying "yes" to other people's requests that you only notice after you have said "yes" that you really didn't want to take on the extra commitment. Remember, you have a right to change your mind. Ring up the person to whom you said "yes" and say, "I am sorry, but I will not be able to do the extra job after all."

You may also find it difficult to come up with an assertive response when someone puts you on the spot. You don't have to. You can tell the person later how you felt about what they said. Say, "I want to talk to you about what you said yesterday. It really hurt me when you said ..."

The first time you assert yourself will be terrifying, but you will improve with practice. You will find that behaving assertively leads to increased self-confidence, and that, in turn, will lead to more assertive behaviour. Gradually your life will become more balanced.

Below we give an example of a tricky situation one of our patients struggled with.

Ursula

Ursula is a well-liked, gentle sort of person, who in her spare time plays in an orchestra. One of the other players, a girl called Lynne, desperately tried to befriend Ursula. Lynne would ring Ursula up daily to tell her for hours about all the problems in her life, but she never seemed keen to listen to Ursula. She would repeatedly ask Ursula to go out with her in a way that was difficult to refuse: "You are not doing anything tonight. That's great. I have got two theatre tickets, would you like to go with me, I will pick you up in the car." Ursula felt overwhelmed at first but then got intensely irritated with Lynne. She avoided her as much as possible. She instructed her parents to tell Lynne she wasn't in when she rang. She thought of not going to the orchestra any more, although she enjoyed it very much. Part of her also felt sorry for Lynne, who seemed to have few other friends. She thought if she refused any of Lynne's approaches, she would hurt her and felt that, by accepting theatre tickets and other small favours, she had lost her right to assert herself and set limits in the relationship. It was obvious that something needed to be done. It was probable that, through partially avoiding Lynne, Ursula fuelled her persistence and that the only way to make herself freer again was to stand up to Lynne. This is how Ursula eventually asserted herself, by using the "broken record" technique:

Telephone Conversation

Ursula: "Hello, Ursula here."

Lynne (slightly reproachfully): "Hi, I've been trying to get hold of you all day, where have you been?"

Ursula (somewhat defensively): "Well, I had to go out and do a few things."

Lynne: "Are you in tonight?"

Ursula: "Yes, I am."

Lynne: "Are you doing anything specific?"

Ursula: "No nothing really, just watching TV."

Lynne (sounding enthusiastic): "Oh good, I thought I might just come over and see you. I'll pick up a pizza on the way. Would 8.00 p.m. be okay?"

Ursula: "Actually, I don't think I feel up to seeing anybody tonight. I just need some time to myself."

Lynne (somewhat surprised): "Oh, don't be such a bore. All that sitting around on your own does you no good whatsoever.

Ursula: "I am sorry you feel I am a bore, but I really don't feel up to seeing you tonight. Perhaps we could meet at the week-end."

Lynne (seductively): "I just thought it would be nice to meet tonight, there are a few new developments with Alan that I want to tell you about."

Ursula: "I'd love to hear about it, but I am just really not up to it tonight."

Lynne (more and more upset): "I don't understand what's going on. You are telling me you are doing nothing, and yet I can't come round. I think that's really selfish of you. You don't do that to an old friend."

Ursula: "I am sorry, but I really want to be on my own tonight."

It was obvious that as the telephone conversation progressed, Lynne was trying to make Ursula feel very uncomfortable and guilty. Ursula coped well by not rising to the bait and by not getting into an argument about whether or not she was acting selfishly.

FURTHER READING

Butler, P.E. (1982). *Self-assertion for women*. New York: Harper and Row.

Dickson, A. (1985). *A Woman in your own right. Assertiveness and you.* London: Quartet Books.

Hare, B. (1988). *Be assertive.* London: Macdonald Optima

Topic : Relationship with self & others
mindfulness Re self : self parenting

Appendix 10

Love, Trust, and Commitment

Robert R. Perkinson, Ph.D.

It seems that going through life we should be taught a few simple things about relationships. After all, we have a relationship first with ourselves, and then, if we so choose, with others. How can we trust ourselves? How can we trust others? When are we committed? When do we love? This exercise will start you thinking about these essential parts of a relationship. Use this exercise to ask yourself some important questions.

THE FIRST RELATIONSHIP

Infants learn about love, trust, and commitment from their primary caregiver; this is usually the mother. When the infant cries out, someone comes and addresses its needs. The baby can't see very well, so this something comes out of a haze, seemingly out of nowhere. Whenever the baby cries, this something comes. It comes every time, and a great trust develops between infant and mother. As the child grows older, it becomes aware that this something has a particular sight, smell, sound, taste, and feel; soon it has a name, Mother.

Somewhere in childhood, the child learns that mother doesn't have to come, she chooses to come. Why does she come? Why, at all hours of the day or night, does she choose to come? She comes because she is bonded with her child. Her child's pain is her pain, her child's joy is her joy. She cannot ignore her child's pain because when her child hurts she hurts. In this bonding or joining of mother and child, there is love, trust, and commitment. "Mother will always be there for me." The child knows this. Their very life depends on it.

It is from this first relationship that we learn what to expect from all of our other relationships. We expect relationships to have certain core characteristics. If the relationships are healthy, they will have as essential building blocks love, trust, and commitment.

TRUST

How do you know that you can trust yourself? What are you going to do to prove to yourself that you are trustworthy? First, you will need to develop consistency of action in your own behalf. If you act consistently in a manner that is in your best interest, you have gone a long way in learning how to trust yourself. You must be consistent even when times get rough. You need to learn that no matter what, you are going to do things that are good for yourself. You are trustworthy to someone else when you consistently act in that person's interest.

COMMITMENT

Commitment means you are faithful and loyal for an extended period of time. It means that on a daily basis, you can count on yourself to follow through. You have plans to be good to yourself, and you are going to stick with these plans. You are going to, day by day, hammer away at the things you want. You are not going to give up. These same elements apply when you commit yourself to someone else.

LOVE

A good definition of *love* is that love is the interest in, and the active involvement in, a person's individual growth. Love for someone else needs trust and commitment, but it needs something more—it needs empathy. You must feel the other person's feelings as if they are your own. Empathy is the feeling you share with another. It is being on the same

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from: Perkinson RR (1997)
Chemical Dependency Counselling
California: Sage Publications

wavelength. I feel your feelings. When you feel sad, I feel sad. When you feel joy, I feel joy. To help you is to help myself. To love you is to love myself.

Perhaps somewhere along the way you have lost the ability to experience normal relationships. Maybe you never developed a trustworthy, committed, loving relationship with your primary caregiver. It could be that you never really felt accepted the way you needed to be. Children need a lot of encouragement when they try things, and a lot of praise. This makes them feel accepted, cherished, and loved. If you take a child and sit on her or his bed every day of their life, and tell him or her how wonderful they are, maybe by the time the child is 6 years old, he or she will be ready for school. Children need a lot of encouragement to develop a sense of self-worth.

HOW TO BE LOVING TO YOURSELF

To be loving to yourself, you must give yourself a lot of encouragement and a lot of praise. If you missed this as a child, your challenge is to reinforce yourself. Treat yourself the way you wanted to be treated. Be your own mother and your own father. Give yourself all the love you wanted.

Imagine for a moment that you are a very young child with a fragile, impressionable mind. Write down 10 things you would need to see from your parents.

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________
6. ______________________________
7. ______________________________
8. ______________________________
9. ______________________________
10. ______________________________

Only you know what you need. It is up to you to give to yourself everything you wanted. Give to yourself all of the love you need.

RELATIONSHIP WITH SELF

List the things you need to see from yourself that will prove that you can be trusted to act in your own best interests.

____

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____

List the things you need to see from yourself that will show that you are committed to your own growth. This is a day-by-day commitment.

____

____

____

____

List the things you will need to see from yourself that will show you that you love yourself.

____

____

____

____

How to Find Out the Good Things About Yourself

List the things about yourself that you feel good about or are proud of. Start with physical appearance. What are some of your good physical qualities? List as many as you can think of. Start with your hair, and move downward to the tips of your toes. Admire the color, size, shape, feel, smell, sound, whatever you can think of. Don't let the old stinking thinking keep you feeling bad about yourself. Get accurate.

Physical Appearance: What do you like about how you look?

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____

Personality: List all of the personality characteristics that you like and admire about yourself. What do people seem to like about you? What do you like about yourself?

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____

You need a lot of encouragement and praise. Now you have a lot of accurate things to say to yourself that make you feel good about yourself.

Things you enjoy: List the things you enjoy doing. How do you play? What do you do for fun or entertainment? What would you like to start doing?

1. ______
2. ______
3. ______
4. ______
5. ______
6. ______
7. ______
8. ______
9. ______
10. ______

People you enjoy: List some of the people you enjoy being around. Write down what makes them feel special to you.

1. ______
2. ______
3. ______
4. ______
5. ______
6. ______
7. ______
8. ______
9. ______
10. ______

Take a long look at what you have written. See how wonderful you really are.

Say Good Things to Yourself

Now you have all these good things to say to yourself. Start with 10 things and write them down on note cards. Carry these cards with you and read them to yourself periodically through the day. Look at yourself in the mirror and say these things to yourself. Practice until you have these 10 memorized, then take 10 more. Constantly bombard yourself with positive self-talk. When you find yourself speaking harshly to yourself, stop and self-correct, get out the cards if you have to, but don't continue to treat yourself poorly.

Do Good Things for Yourself

You are saying good things to yourself. That's healing and treating yourself well. Now what can you do for yourself today that's really special? Maybe take a long hot bath, or go for a relaxing walk. Could you spend some time with a friend you enjoy? How about getting some ice cream, or just reading and taking a nap? Come up with a few special things to do for yourself today. Write each of these things down and do them. When you are doing these things, think of why you are doing them, because you are a person of great worth. Do this every day. Before you get up in the morning, commit yourself to treating yourself well, then get up and get busy, enjoy life, feel the pleasure of being alive. You deserve it!

RELATIONSHIPS WITH OTHERS

You have some things that you want from a partner, a friend, a lover. It is your responsibility to ask for what you want. Be specific, and give them a lot of encouragement when they try to give these things to you. You know the secret: Be reinforcing, give encouragement, shower people with praise—it's contagious. If you give more often, you will get more often. Happiness is created when we unselfishly give to others.

How to Find Out If a Relationship Is Good for You

What are the things you need to see from someone that will show you that they are trustworthy, committed, and loving to you?

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____

How to Get What You Want in a Relationship

If you have a friend or partner, you must ask them for what you want. They can't guess what you want or need, you must tell them. Remember, give them a lot back when they give you something. Ask them what they want, and do your best to give it to them. As you give to this other person, you will feel good about yourself and you will get more of your needs met in return. The more you give, the more you will get.

After completing this exercise, you should be treating yourself well. You should know what you need to see from yourself, and from others, to make you feel good. You have learned that you directly influence how you feel. You are not helpless before others or before your environment. You can love yourself. You are special. You are worth it. Others can love you. You can love others. You can feel whole, healthy, and complete. You have all the skills you need.

Programme: Group Therapy for Women with MRKH Study (latest version)

Session 1: Ones' experiences of groups, this group and it's "ground rules" such as issues of confidentiality (and limitations of this re self harm & therapist's supervision), GP letter consent, overview of the programme & model used, getting acquainted & life before the diagnosis (collection of questionnaires). Homework: writing exercise 1 (we will make a start at this together towards the end of the session, whilst looking at initial distress tolerance skills in relation to this - handouts).

Session 2: Becoming aware that something might be wrong, seeking help, investigations, expectations, experiences, diagnosis, own/other's reactions, understanding of MRKH, who/what told/to tell, what support (to) asked/(ask) for. - Discussion of writing exercise (homework s.1): Your deepest thoughts/emotions about the above event (all characters in story, zooming into you). Homework: writing exercise 2, reading: assertiveness handout.

Session 3: Discussion of writing exercise (homework s.2): How experience/MRKH is effecting your life in its varied aspects and how you are coping. Developing further coping/distress tolerance strategies (relaxation tape 1, talking, discerning what is what etc.) & looking after oneself (love, commitment & trust), allowing space to acknowledge what is happening following diagnosis. Homework: writing exercise 3, completion 1st half of love commitment & trust handout, trying tape 1 at home.

Session 4: Discussion of writing exercise (homework s.3): Meaning of diagnosis, conclusions drawn re self, others, the world. Challenging misconstruing, addressing possible feelings of guilt and shame. Perspective from self then; from vantage point of self when you have grown mature & wise - looking back at the experience; from the perspective where you look at experiences that tell you a different story about yourself. Societal scrips re female roles, femininity. Acknowledging similarities, differences, a variety roles/bodies/qualities/equality/value/uniqueness. Homework: writing exercise 4.

Session 5: Discussion of writing exercise (homework s.4): What lost as result of experience, mourning losses, pursuing alternative avenues, old/new life goals, the role of time, adjustment over the lifespan;

crossing bridges when you get there/one step at a time. What learned/gained re self, others, life, from your experiences. Responses to pregnancy in siblings/mother/friends & own needs etc. Homework: time to reflect on what looked at in this session, what will look at in session 6 & 7, advance homework exercise 5 for session 7, collect thoughts. Complete 2nd half love/commitment/trust handout.

Session 6: Creating a new vagina, natural stretching/dilator therapy & concerns/experiences of these. Relationships, when/what to tell, love languages, love/commitment/trust for/to self & others (- 2nd half love/commitment trust handout), standing up for your needs, sexual intimacy. Homework: writing exercise 5.

Session 7: Discussion of writing exercise (homework s. 6): Deepest thoughts/feelings now, how affecting life now & coping. Putting it all together in goodbye letters (writing to the group and reflecting on what you found helpful participating, what you learned and like to keep doing, what you found difficult, how you see yourself now, the future and you might deal with any issues arising, role of time etc.): review & looking ahead. Tape 2 from negative to positive thoughts/feelings/images. Homework: completion of questionnaires, to return by SSAE, trying tape 2 at home. Look for, buy and bring a card you like to receive yourself, to follow-up, session 8.

(Follow-up) session 8: How did you get on, any issues arising, further consolidation of experiences/insight's/reflections, going from here. Writing on each others cards. Opportunity for exchange of details amongst those who would like to keep in touch with each other on a self organised basis. Completion of questionnaires in session.

Kindly note that material in terms of handouts and instructions for the varied writing exercises, will be given to you at the appropriate session.

The "Queen Charlotte's" model of Cognitive* Behavioural Therapy for processing (adjusting to) the negative life event of being diagnosed with MRKH

Early experiences --> interactions with carers, teachers/peers --> beliefs developed about self/others the world

- possibly already including beliefs about difference re absence of periods, due to possible multiple congenital abnormality, or a subconscious "knowing" for some/a long time that something is not right; that they will never have periods/carry children.

Critical Incident(s): experience of negative life event/trauma of being diagnosed with MRKH - (alongside, possibly, other difficult events, prior to diagnosis and following it, with similar/different responses):

- World upside down, shock --> shattering of sense of self, losing all sense of self, at a time when identity is fragile and still needs to be further formed/developed and is often construed in terms of "being like others", wishing to be like ones' peers.
- The negative life event may reinforce previously held beliefs in terms of difference.

Negative conclusions drawn from the experience re self, self to others, the world; leading to core beliefs about self, others, the world & future (I am..., others are..., the world is ..., the future is ...):

- I am different (no periods, not like peers)
- I am inadequate (no vagina, no sexual intimacy possible as peers can)
- I am useless (no womb, not able to conceive/carry a child), even worthless

--> An overarching conclusions is drawn:

- I am part female/incomplete (my body is letting me down, doubting their femininity)/a freak

- If I am this way, I am 2nd best, no one would want me, I will never find a soul-mate, the future is bleak
- If this can happen anything can happen, the world is an unpredictable scary place

Leading to Rules for living/for self (yardstick of worth; unless I am..., if... then....):

- Counteracting feelings of defectiveness by proving to be as good as everyone, possibly with an overfocus on things you can change, such as weight/food intake and excelling in this, leading to Bulimia Nervosa, or freezing feelings of defectiveness turning to Anorexia Nervosa, Binge Eating not wanting to look feminine either and "minimising" the pain, or turning to drink/drugs, sleeping around to proof/check self once vagina been formed with s/t gain & l/t loss.

Reactivation in every day life situations of those beliefs and a filtering of incoming info.

- Leading to critical thoughts/images about self/others/world with negative predictions about the future I will never.... and
- feelings of hopelessness, anger and sadness and
- further behaviours of avoidance/overcompensation etc.

---> Reinforcing the above in an ongoing cycle.....

Therapy: reorganise the oftenwise "muddled/frayed" memories around diagnosis, parts heard/understood, not heard/remembered, allaying misunderstandings, challenging negative conclusions drawn (all or nothing thinking/catastrophising/overgeneralizing/misinterpreting); filling in the "dotted lines". Look at who you really are, rebuilt and further develop a sense of self, self vis a vis others, the world, integrating the writing exercises - as a "spring board" for doing this and engaging in our discussions, to come to a more or less coherent schema (picture/set of beliefs) of these, also using "guided imagery" to reinforce this new schema. It involves in its most simple, "skimming the surface"/addressing the symptoms - of low mood, self-esteem etc - format, an addressing of the dyad of cognitions (thoughts), feelings & behaviour; changing the way you feel by changing the way you think about the event and/or respond to it. It involves in its "going below the surface" form, a systematic self confrontation and cognitive reappraisal of the event and expectations for the future; developing a more or less coherent schema of the event and of self in relation to it (which then will be reflected in a change in feelings, ways of being behaving at symptom/surface level).

* cognitions are thoughts/beliefs/ways of thinking, that lead to feelings

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THE NATIONAL CENTRE FOR ADOLESCENT AND ADULT WOMEN WITH CONGENITAL ABNORMALITIES OF THE GENITAL TRACT

October, 2005

Dear Potential Participant,

I have been doing a study which tries to test a theory and group therapy treatment that I have developed, for its accuracy & effectiveness. It concerns here a theory of what happens when women are diagnosed with the Mayer-Rokitansky-Kuster-Hauser (MRKH) Syndrome and a therapy (which flows from this theory), to navigate this so difficult life event.

MRKH is a Syndrome where women have been born without a vagina and womb, which mostly does not get discovered until they reach puberty and fail to menstruate. These women have the normal female chromosomal pattern and are born with normal ovaries and external genitalia. Due to the presence of ovaries, these women have normal levels of progesterone and oestrogen coming "on line" at puberty. As a result of which they develop the classically rounded female shape, as well as the normal female sexual secondary characteristics of pubic hair and breasts. As these women have developed physically and emotionally in every sense as any other woman may have, but for their lack of periods, diagnosis comes as a terrible shock to them. It turns these women's world upside down and makes them question everything they have ever known about themselves, others, the world. It makes them question their core gender identity, something which previously, might never have had a question mark hanging over it. They often come to conclude from the experience that they are different, not normal, a freak. That they are defective, incomplete, worth/useless as a woman, outside of female experiences/roles, and that they have no place in society. That they are unacceptable, unloveable to the other sex, that no one would want them. That if this happens, anything can happen, and that any agency they previously might have felt they had in their lifes has dissipated with the event. As a result they think that the world is a scary place, and that the future is bleak. Medically, the absence of the vagina can be corrected in a non-surgical, but very painful fashion. However, we can not grow them a womb, and the few avenues open to them to having children in later life, are often invasive and fraud with difficulties.

In this study I have given women who took part in the group therapy treatments a set of questionnaires, before they started their groups, when they finished their groups and at 3 month follow-up. This is to see how their feelings change over time, as well as the thoughts underlying these (via other exercises) as a result of doing the groups. The women who took part in the group are compared to women who were put on a waiting list. This serves the purpose of "whittling out" the difference it makes doing the group, as compared to not doing a group. This is a bit like how in medicine, medication is tested by giving patients a real pill and comparing the findings of this with people who are being given a sugar pill.

One of the suggestions in the little research that does exist about the above condition is, that women who are diagnosed are more depressed than the general population of women out there and have more difficulties inter-relating etc as a result of their predicament. However, in order to be really sure about that, I need a comparable group of women, who do not have the condition, to fill in the set of questionnaires that the women with the condition are filling in, to be able to compare the two groups, and work out whether this is really so.

This letter comes to ask you whether you would be willing to complete the enclosed questionnaires, to help me find this out. The questionnaires are totally anonymous, you only need to complete your age, your profession/job status (ie. what you do with your days, ie. whether you are working, studying, being a mum etc), what your relational status is (ie. single/married etc), and the number of children you may have, in the spaces provided on the top of the first questionnaire, as well as complete the 4 questionnaires themselves.

If you would like to take part in being a control group to the women with MRKH, your consent to doing so, forms the actual completion of the questionnaires (if I made you sign this sheet I would still know who has completed the set). Once completed, just post the enclosed back to me, in the envelope provided.

The women who have taken part in the groups have been telling me that the therapy groups have been making a tremendous difference to their lifes and experience of self in relation to others. Between November 05 and April 06, I will be disseminating the findings further. The theory and therapy model developed, can in future, be possibly cross-applied, in a tailored format, to women with related congenital conditions, or non-congenital conditions, such as premature ovarian failure or women who have had their womb/ovaries removed due to endometrial cancer. It is much needed to help us understand what really happens to these women and how we can help them help themselves find a way of reframing the experience and not be defined/crushed by it.

Thank you in anticipation of your attention.

With very best wishes,

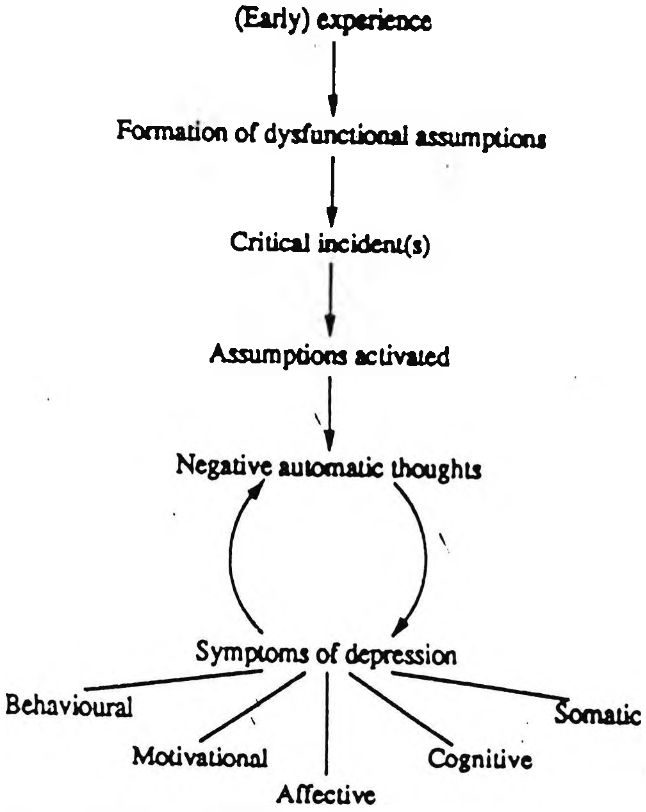
G Heller - B

Jacoline G. Heller-Boersma
Chartered Counselling Psychologist

Enclosures./.

Appendix 11.1

Depression



The cognitive model of depression

Taken from Hawton, K. & Salkovskis, P.M. & Kirk, J. & Clark, D.M. (2000) Cognitive Behaviour Therapy for Psychiatric Problems - a Practical Guide. Oxford: Oxford University Press.

Appendix 10.1

South London and Maudsley NHS
NHS Trust

Consultant Psychiatrists:
Professor Janet Treasure
Dr Ulrike Schmidt

Consultant Psychologist:
Mr Padmal de Silva

Clinical Nurse Leader:
Gill Todd

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13th June, 2001

Dear Holly,

I am writing to you to say good bye, having reached the end of the intensive part of treatment at the Maudsley Outpatient Eating Disorder Unit. I will miss our weekly meetings and our time of working together. This letter serves to allow us to not only say farewell, but also for us to have a bird's eye view of the experience of therapy. It seeks to be a testimony of the very difficult losses that you suffered over the course of treatment. This letter hopes to bear witness to the great personal suffering that you have endured and that lays behind your eating disorder. It describes the process of moving from the shadow of being a victim of childhood sexual abuse to being a survivor and moving into the light of starting to claim life for yourself again. This letter wishes to applaud the tremendous hard work you put into therapy, whilst expressing how much I loved working with you and how much I really do value you as a person, Holly!

We started therapy, looking at how your Eating Disorder helps you short-term, yet not in the long-run, to deal with the predicament you find yourself in. You explained that starving yourself, "binging", vomiting, using laxatives and painkillers has aided you through very difficult times, where it allows you to numb painful feelings, thoughts and memories. You also feel this is a very slow way to die, which never sufficiently cuts out the agony of carrying the feelings of guilt, shame & worthlessness, that you carry about with you. The laxatives, particularly, can never quite flush away the awful memories of what you experienced at the hands of your grandfather and his brother. They give you stomach cramps, diarrhoea, headaches, swollen ankles, and have made you end up in hospital with a twisted gut. You feel so exhausted, so wretched and weak, that you go back to bed and stay at home, whilst sleeping a lot. This makes you feel safe from the world out there, protecting you from further hurt, yet leaving you isolated from potential support. You have been experiencing a lot of colds and boils with a lowered immune system. Your eating disorder, as a coping strategy for the pain that underlies it, is standing in the way of getting physically and emotionally well. To get well enough to realise the dreams that you have of a better life, of working with animals, of doing a course, of finding a soulmate and having a family. Being rather underweight at times, makes your periods irregular, where they stop for long periods of time, which jeopardises your fertility.

The next step we engaged in was looking at your patterns of eating and how we could change some of your food/starving/"binging"/vomiting/laxative/painkiller regimen. We looked at your sleep hygiene and your relationship with T and creating some space for yourself in this to look at your own issues, rather than being pulled down by T 's' issues, any spitefulness, possessiveness. Engaging in the above, in problem solving and developing alternative coping & assertiveness skills, we laid the groundwork for working directly with the incest. The latter you expressed to be ready for, particularly as making some changes had you to engage in other destructive behaviours. This made a lot of sense, as you still needed relief from the emotional pain that lies at the root of your problem and that had not gone away, all of a sudden. You had started drinking to blank these out, yet hated doing so.

Discussing strategies to comfort yourself and keep yourself safe from drinking, we started the so difficult process of working through the wounds of childhood that you carry, by means of writing exercises at home and talking in our weekly sessions. You told me that you are from a family with six girls, yourself inclusive. Your dad was a very selfish and insecure man, who was there for his friends, but never for his family. With your mum as the breadwinner, he would gamble and engage in affairs and be generous to others. He believed that women amounted to nothing and treated his wife and his daughters accordingly, beating you, burning you and putting you down. Mum for long felt that not separating from dad was doing you girls a service. Mum, really, kept hoping that the provision of a son to the family would turn your fathers heart. However, she was left to fend for herself, with her own family having withdrawn their support when she married your dad, and only having your dad's parents to help her out. These grandparents provided a place for you to go to during weekdays when she had gone out to work and you would come from school and during school holidays. Whenever, dad did come home, there would be fights and violence and mum, as you remember, every so often could not cope any longer, where she had to go into hospital to have a "rest". This made you feel that you girls were too much of a handful. With her away in hospital or at work, you as the third oldest, had to look after your younger sisters. Doing this you found yourself often ending up carrying the responsibility for mischief they got themselves into and being made to carrying the blame (something you still feel happens a lot in various ways). You often felt very lonely with M having the support of your cousin Ja with Ju being quite independent and seemingly self-sufficient, and D and A , your younger sisters, having each other. Oh, how you longed for someone to care, to give you a nice clean frock, lay their hands on your head and give you a hug. You remember that Aunt R , your mother's sister was a support to your mother and was of a corrective influence to your father. Life you feel would have been quite different if she had not died an untimely death, when you were only seven. Notwithstanding this you feel that you carry her essence wherever you go and that she is there for you, giving you this assurance when she gave you a "wink" from her coffin. And looking for the affection you so needed, like any child would, you were driven into your grandfather's and his brother's hands. Feeling utterly deserted and being driven to spend so much time with grandma and grandpa. You somehow hoped that grandpa, particularly, would care, as he said he did. This did at first appear so as he was nice and would sit you on his lap, whilst reading Bible stories to you and letting you get away with "blue murder". However, this so outwardly religious man, who had had "demons" cast out of you when you were only small and suffered from epilepsy, appeared to be two faced and a source of evil, rather than that you were. Your granddad, who always hammered away that you ask forgiveness for your every move so you wouldn't be damned and cast into hell, had a very very dark side himself. He made you experience something which could be described as darkest hell, rather than seeking your wellbeing away from such trauma. You still find it hard to erase the memory of his wicked grin from your mind and all the things that he did to you, which words can't quite describe. Fulfilling his own wicked desires, he tried to "buy you off" with sweets, and as a young girl, this is how you thought one would get sweets. You were very confused as to whether what you were experiencing was "normal". How was it that the man in church was told off when he put you on his lap, and you were told that strangers could not be trusted, whilst the person you trusted most never "just" put you on his lap but used you in every way. You told me that it felt more unsafe to be with him, than to be with a stranger. How was it that when you did drop hints to your mum, she could not hear. How was it that nobody saw, nobody reacted, was it then after all not wrong? And you kept going to your grandparents house, as there was no other place to go with mum out at work, whilst you kept hoping that you one day you would get what you were really looking for. The affection that you were looking for, as any child does, as your niece and nephews do. The affection that we all need to flourish and grow and feel that we are special, that we are valued. However, time and again you were disappointed and more and more you came to see that this was not right. The sweety money that you got post-event burned in your hands, and sweets did never mean to you what they mean to the unabused child. They made you feel worthless, they did not taste, and smell and look the way they were meant to be. They tasted so bitter, so salty, they encapsulated the tears you could not cry and the sense of guilt that you carried. Those days were such dark days, you told me and in those days you even felt that the bear family that you had created in your mind to take you away from the distress, that would care for you and sit at the end of the bed, had turned against you. You started jay walking and really wishing that you could be taken away. As you turned fifteen your mum and dad where in the process of a divorce, whilst you moved house. You then could not cope any longer with the secret you had been carrying. You stopped going to school and fell ill, and this is how a social worker came to visit you. To her you confided and she listened to you and believed you, the first person who ever did. With the truth having come out and having "told" on grandpa, you hoped that things would get better. However, grandpa could not own up to the responsibility laid on him and the fact that he had been sexually abusing his granddaughter. Grandma, who always said she would stand up for you, could simply not carry the burden of what this meant for you, for her, for grandpa, for all of the family. The only way she coped was to cut you off and deny it. For so long you were at the receiving end of the anger grandma carried towards grandpa, the pain he caused to her, to you. The best way she dealt with it was to ignore that it had ever happened. Her bitterness about it all has at times given you the sensation that she has been pulling your hair, even now she is long dead. And your own mum and dad were too busy with their own divorce and could not carry the price of their neglect of you. They could not support you and you felt blamed for tearing the family apart and even complicating matters further. When you were taken to the police, you tried to get it over and done with, even without understanding the language they were using, just to reduce your mother's distress, whilst having to deny your own. You grandpa got away with it and the terminology used was more along the lines of child molesting rather than the severe sexual abuse and rape that you actually experienced, ever since you can remember. In the end it felt like the whole thing was denied, that nobody cared, that everybody blamed you and that even your godfather had turned against you. And those days saw you eating less and less and using more and more the strategies that you are using unto this day, to cope with those feelings of aloneness, of being deserted, of being worthless, of having no needs and using starvation and flushing away with laxatives the dirt you felt that clung to you. And sweets became more and more troublesome to you, you just had to bring them up, you could not keep them inside of you, they burned inside your stomach. Even though one of mum's partners (from after the separation and before she remarried) stood up for you, she finds it hard to acknowledge what has happened. Your dad, who remarried and moved to Canada has tried to make up. However, you do not wish to see him, as making good for his violence to you and his part in the family dynamic that resulted in granddad's abuse, is no easy feat.

The feelings of guilt and of shame we started relieving somewhat, when we looked at your story from your nephew's perspective and what his needs are now, as your's were then. Having such a love for children and being very gifted with them (as they have fun with you and tell you their stories and worries), you could relate to yourself then, and see what happened through the eyes of young Holly. You could start feeling how things were for you then, and what you now feel as an adult about it. You now know that what you asked for wasn't much, to be loved, to be appreciated, and for that you do not feel any guilt. You know that the responsibility for the abuse is squarely laid with your grandfather and his brother and that they have taken that into their graves with them. You realise that your parents are responsible for the pattern of interaction within their own family of what were five girls and themselves then. You could express some of the anger and disappointment at not having any of your needs met. The guilt and shame associated with taking the sweety money we could only start to reframe, when Suzie your dog finished a sweet bag for you and you could see through her eyes that it is no sin to like sweets. However, most of us do not need to pay such an awful price for liking something which is perfectly legitimate and that taking them does not make you worthless, though grandpa made you feel that way. You know that sweets are not a currency and that what happened to you cannot be bought free with any price. Your animals are showing you as well that you need to be fed and that you are worthy and deserving of food, as they are, and that you do have needs for comfort as they have.

Having experienced such trauma in your life, it is remarkable how resilient you have been Holly. How, you did so well learning yourself to read, how when you came out of school early, you learned sewing, jewellery making, doing admin. for Mind, and giving yourself to a friendship with T. Through this relationship (for which you had high hopes but which often involves more giving than taking and which does not meet your need for a partner), you overcame your fear of dogs, as T.'s brother had a dog. This has lead you to adopt a menagerie of happy and tremendously well cared for animals yourself. And your pets, whose language you speak, need very much mentioning. Because animals are you Holly and the comfort you give them and they give you is truly fantastic. Bearing witness of the process of therapy, I must describe your strength in coping with the tragic losses of Moggie and Tiggy so shortly after each other, whilst already engaging in such a difficult piece of work around the abuse. Losing Moggie, one of your cats and dearest friends around session 20, in a fatal road traffic accident, caused you much agony. With the caretaker of the school having found her dead and having buried her before he was able to speak to you, you were experiencing shock and disbelief as to what had happened. You kept thinking that she would walk in again and it had all been as if in a bad dream. You kept wondering, what if I had not let her out, what if I had not let her engage in her love of the outdoors. However, visiting her little grave in the school yard, you came to realise that it was true and with it came a realisation of the loss of a loved one and the pain of facing goodbyes and death. You then started questioning whether Moggie's accident was God's punishment for your jay walking as a child. However, we discussed that you always seem to take responsibility for whatever happens. We pondered that God knew your distress then and now and would not punish distress with further distress. This was also a time that you were able to speak to Jenny Dexter, the hospital chaplain, who shared with you something of a kind God, rather than a God who constantly needed to be feared or whom you were a slave of. Losing Moggie allowed you for the first time, Holly, to express your tears. Working through the horrific memories of the abuse you had found it so hard to express tears at the loss of what you never had as a child. However, now you cried, whilst getting in touch with your emotions. The loss of Moggie threw up a host of further questions as to where we do go when we die (something you also discussed with Jenny) and whether grandpa and grandma, where they were now, somehow could inflict hurt on her, as they have on you, and you wishing that you could protect her from that. It was difficult to not see your dreams for yourself of a normal life, which so very much had Moggie in it, shattered. However, you came slowly to realise that though Moggie had gone, your dreams for yourself would not have to die. And that actually that part of her that was so very special, you would always carry with you together with your dreams. That you would respect her and carry the happy memories you have of her and the love you have for her and she has for you. Then suddenly Tiggy, one of two of Moggie's son's, died. This time you were the one who found the pet. Tiggy had died eating a plant, you at the time did not know was poisonous. You had had so much fun with Tiggy that morning with her clambering up to things and about. And it was agony to find her this way, with the loss of Moggie still so fresh. However, you were able to say goodbye to her and give her a good send off. You take comfort in knowing that Moggie and Tiggy can look after each other now, there where you cannot go. And as you and your little menagerie of pets are adjusting together to the losses that you have experienced so recently, with two dogs and two cats left, you really treasure the time you have together. You now fit all into one chair together and you cherish the memories of Moggie and Tiggy who live on in your hearts. You embrace the reality that without commitment and love their is no loss felt at death. However, mourning your pets you have been able to be true to what they meant and mean to you. You have been able to join the great human life cycle of birth and death, where you grow through loss and move on.

This process of dealing with the abuse has allowed you to no longer feel a victim of the past but be a survivor of it and claim your life for you. Working through this and the grieving of your dearly beloved pets, you wish to move on and go on to realise the many dreams you have for yourself.

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Your wish is to get involved with animals professionally, be it working voluntarily with the RSPCA, your local Vet, the Battersea Dogs Home, the Animal Sanctuary or Animal hospital. You are considering taking a Vet nurse or computer course. You are good with children and tried nursery nursing in the past, however, kept worrying about their welfare at home, having experienced the neglect and abuse that you have. Your sister M has valued your friendship with herself, her husband and her children so much, that she has made you godmother to Jade her daughter. You very much appreciate being part of her family and what she has, whilst M appreciates your support. To see her in a loving relationship, happy with the gorgeous kids she has, you learn something of a world you never saw as a child or knew existed. It gives you hope as you would love to meet a man, who would value you, who would enjoy having pets, as well as, starting a family with you one day. You have started going to a group of survivors of sexual abuse to find mutual support, as well as reading survivor's accounts. You are considering getting involved with people more, though it is hard to not let the old mistrust of the world, due to your experiences, get in the way. Popping into the Cafe Forever for a coffee at the the LCM Gengall Centre, near where you live, might be an option. You find it hard to fully stop your patterns of food, laxative and painkillers use, however, are slowly seeing that telling yourself that you are worth it, needs to involve a change in this behaviour as well. Trying to start to eat regularly, weaning yourself of laxatives and painkillers, putting on some weight so your periods return and become regular, whilst caring for yourself, your pets, reading books, planning various activities, writing your own endings to bad dreams when they still crop up etc..., are all goals that help you move from the shadow into the light.

Finishing therapy, I imagine, you may be experiencing a sense of sadness and maybe even desertion, as the intensive part has been completed. However, endings always mean new beginnings. Only us separating allow you to start the process of going by your own strength. As you have allowed yourself to exist in therapy, I am positive you will be able to allow yourself to exist outside of it as well. Though at times you may feel nothing much has changed, you now understand why you resorted to your eating behaviour in the first place. There will be days Holly that you will find things are very hard and you wonder will things ever change. Like you did the other day when you didn't get your medication represcribed straight away and you fell in a gap and felt so weird you wished you were not there. But I trust Holly, that on those days, when the pangs are still so very much felt, that you will know how to keep yourself safe and recruit help via A&E, your sister, T the Samaritans and any friends that you will be making in these coming days, weeks, months and years. As you deserve life Holly, your pets need you, Jade and others need you and you need them. But I pray that the days that you feel very alive and are fighting, where you do not need to hide yourself, will become more and more. You told me that your guardian angel, Aunt R is encouraging you to move on, rather than join her, and begs you to start afresh. Because surviving means moving on and claiming your dreams and living in hope. Your great ability to introspect, to self reflect, to describe you own experiences, however, traumatic and painful and defining personal outcome, has been such a great gift, a gift that will help you further along the way, as it has done all along.

I look forward to working with you in follow-up, when you are consolidating on the above, when you are taking time to get to know further what all this means to you and what difference it will make.

Lots of Love & With Best Wishes,

Jacolina

Jacoline G. Boersma-Heller
Outpatient Therapist

Appendix 11.2

Both DSM-IV-R (APA, 1994) and ICD-10 (WHO, 1992) classify non-bipolar/non-psychotic depressive disorder as a syndrome that consists of a group of signs and symptoms, rather than providing a description of the phenomenon. The group of signs and symptoms that make up the syndrome relate to both an inhibition of mental life in the shape of flat affect, apathy, loss of confidence/self-esteem, self-reproach/guilt, as well as a slowing up physically in terms of fatigue, insomnia/hypersomnia, appetite/weight in/decrease. Though in a small proportion it may be characterised by a constant state of restlessness, due to feelings of guilt etc. Non-bipolar/non-psychotic depressive disorder (here called depression) is a diagnosis that is only applicable when no manic symptoms (ie. elevated/expansive mood, increased self-esteem/grandiosity, decreased need for sleep, flight of ideas, reckless behaviour etc.) are present and the syndrome is not a result of other (non-affective) conditions. Ie. the result of alcohol/drug abuse, medical illness, schizophrenia, personality disorder etc. Only when mood disorder occurs first can it be classified as "primary", whilst depression following alcohol/drug abuse etc. is classified as "secondary". The former is somewhile called "neurotic" depression and the latter "psychotic" depression (Robins & Guze, 1972). Depression, as classified by DSM-IV-R and ICD-10, is quite different from the transient fluctuations in mood that most people experience at one time or another, since symptoms cause quite considerable impairment of functioning. Depressive disorder lays on a continuum of severity. This is reflected in the three categories of mild, moderate and major depression that ICD-10 outlines. Depending on the amount of symptoms present, mild depression is regarded when more than four symptoms are observed, moderate when more than six symptoms are reported and major when more than eight symptoms are present. Mild, moderate and major depression all include the symptoms of flat affect, apathy & fatigue.