

## **Family-Centred Care for Children and Youth with Mental Health Needs: The Case of Anorexia Nervosa\***

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### **Introduction**

It is my great pleasure to be invited to deliver the 13th TP Khoo Memorial Lecture. Mr. Khoo has devoted a long career to developing quality service for people suffering from mental disorders. We admire his work and salute his achievements. I feel honoured to speak in the lecture that bears his name.

Helping children and youth with mental health needs is contextually dependent. Family, peers, school and community are interwoven, forming a social context in which these children and youth must grow and develop. To help them towards this goal, mental health professionals, including psychiatrists, clinical psychologists, social workers and psychiatric nurses, must have a dynamic understanding of the interplay between the symptoms and the immediate social context.

Family-centred care perceives the family as the expert on itself and the patient, and includes families as full partners in all aspects of service delivery and decisions around care (Allen & Petr, 1996). Western countries such as the UK, USA and Canada have adopted family-centred care (Spragins, 2007) as the overall management policy for children and youth with mental-health needs: one cannot

help the child unless one also helps the parents or the caregiver. Even for children placed under institutional care, sooner or later they will reunite with their parents or caregivers.

Although family-centred care is common in Western countries, child and adolescent mental health service in Hong Kong is still predominantly bio-medical oriented and child-focused, characterized by psychiatric diagnosis and medication (Ma, Lai & Pun, 2002). Family-centred care provided is limited and piecemeal. Such practice impacts unfavourably on the child and the parents. In the USA, parental disengagement has been found to associate with early treatment dropout, poorer quality of care and increased out-of-home placements, while family-centred care has accounted for better treatment adherence and compliance, improved quality of care and reduced out-of-home placements for children and youth suffering from serious emotional and behavioural disorders (Lee et al., 2009). In this lecture I argue for the need of adopting family-centred care in helping children and youth with mental health needs in a Chinese context, using anorexia nervosa (AN) as an illustration.

Janet, a 19-year-old adolescent girl, has started dieting and excessive exercising soon

after entering senior secondary school. She has been competing with a classmate academically. One day her classmate suggested that they should compete in dieting. One week later, her classmate admitted defeat and stopped dieting, but Janet continued to skip meals. Before long, her body weight had dropped from 50 kg to 36 kg, with obvious impact on health. She could hardly concentrate on study, had frequent temper tantrums, and suffered from depressive mood and agitation. Alarmed and highly anxious, her parents took her to seek psychiatric consultation. Janet was diagnosed as suffering from AN, an eating disorder that is found especially to affect adolescents. The incidence among adolescents 12 to 18 years old is found to be 0.48% in the USA (Lock, Le Grange, Agars & Dare, 2001); no accurate figures are available for Hong Kong, though anecdotal evidence would suggest that the incidence is broadly similar. The diagnosis of AN is based on the following criteria given in the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) (APA, 1994): (a) refusal to maintain body weight at or above a minimally normal weight for age and height, which is suggested to be less than 85% of the expected weight; (b) a morbid fear of fatness; (c) disturbance in perception of body weight or shape, or denial of the seriousness of the current low body weight, and (d) in females secondary amenorrhoea.

AN has become a rising concern in Chinese societies such as Hong Kong. Males are ten times less likely than females in suffering from the disorder (APA, 1994), and the afflicted young person will be referred to as "she" throughout this lecture.

The aetiology of AN has multiple facets, with interplay among biological, psychological and socio-cultural factors. A child entering adolescence is bound to face stresses from many sources: family, peers, school, and community. For a young person with a strong

sense of personal ineffectiveness (Bruch, 1973), dieting and excessive exercising could become strategies to cope with life stresses (Treasure, Schmidt & Troop, 2000). Her self-starvation would be reinforced at multiple levels. At the individual level, the loss of body weight gives the young person a sense of false control and achievement, which fulfils her unmet sense of mastery and personal effectiveness.

At the familial level, a different drama plays out. Typically ill-informed about the disorder, fearful and desperate, parents would keep pressing the young person to eat; the young person then perceives the parental effort as a means of control, rather than as an expression of love. She would fight back and be obstinate in her self-starvation. The parent-child conflicts are self-defeating, and often contribute to developing and even aggravating the symptomatic cycle of AN (Micucci, 1998). The literature shows that the psychosomatic families including families with AN manifest four characteristics: enmeshment, over-protectiveness, cross-generational collusion and conflict avoidance (Minuchin, Rosman & Baker, 1978). The stifling family context prevents the parents and the child from joining hands to drive away the disorder. However, Eisler (2005) has cautioned that the family features observed in treatment can be perceived as the consequence of the onset of the disorder, rather than as its aetiology. Mental health professionals have to be vigilant in not blaming the parents in assessment and treatment, which would be theoretically flawed and clinically anti-therapeutic.

At the socio-cultural level, the young person's emaciation is reinforced by the standard of beauty in modern society, being thin and slim. Based on the results of the study of the three Chinese communities in Hong Kong, Shenzhen and rural Hunan, Lee and Lee (2000) postulated that the disorder is the result

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of westernization and urbanization. Leung, Lam and Sze (2001) hold a different view; they argued that slimness and thinness are part of the traditional standard of beauty in Chinese culture and society. In any event, both sets of authors stress the importance of the larger socio-cultural context in shaping disordered eating in general and reinforcing the young person's self-starvation in particular.

In helping the youth with AN, one needs to go beyond the symptoms of the disorder to understanding her stress and tensions in life as well as the social context that may have contributed to developing and maintaining the disorder.

#### Family Therapy and Anorexia Nervosa

Family therapy is an approach in treating human problems by bringing family members together to transform the structure of the family, their interactions and the entire family (Nichols, 2009; p. 5-6), in the belief that change of the social context will bring about change of individual behaviour. Family therapy is not unitary, and there are different intervention approaches (e.g., cognitive behavioural family therapy, experiential family therapy, structural family therapy) with different treatment emphasis. Since the 1980s, its treatment focus has shifted from family pathology to family resources, strengths and resilience. Family therapy is employed in helping children and adolescents with AN for two reasons. First, the disorder is both an individual experience as well as a family experience. If untreated, it has devastating effects on the young person's physical, psychological and social well-being, and has spill-over effects on well-being of family members and on the healthy functioning of the family (Ma, 2011; Treasure, Murphy, Szmukler, Todd, Gavan & Joyce, 2001). Second, family therapy has demonstrated its treatment efficacy in Western countries such

as the UK (Russell, Dare, Eisler & Le Grange, 1992), the USA (Minuchin, Rosman & Baker, 1978) and also in a Chinese context such as Hong Kong (Ma & Lai, 2006; Ma & Lai, 2009).

If not properly treated, two-thirds of AN patients would have persistent morbid food and weight preoccupation, while 40% have bulimic and social phobia; the most serious 20% would die from suicide or cardiac failure (APA, 1994). Our study (Ma & Lai, 2009) has shown that Chinese youths with AN, measured by the Chinese version of the Eating Disorder Inventory (EDI) (Garner, 1991; Lee, Lee, Leung & Yu, 1997), reported higher scores at the 0-3 scoring system with higher score denoting more symptomatic of the psychological theme, in descending order, on Body Dissatisfaction, BD (mean = 10.00), Maturity Fear, MF (mean = 7.83), Ineffectiveness, IEF (mean = 6.90), and Interpersonal Distrust, ID (mean = 6.04), indicating that these youths were more symptomatic on these four areas. However, the scores of the six subscales of the EDI in our clinical sample were lower than the scores reported by Chinese girls age 14-18 (n=1691) in Leung, Wang and Tang's study (2004), which might be attributed to underreporting of our clinical sample. The scores of two subscales, namely Ineffectiveness and Interpersonal Distrust, were higher than the scores obtained from Leung et al's study (2004). The Chinese youth of our study (Ma & Lai, 2009) rated themselves as moderately symptomatic on their psychological distress, measured by the SCL-90-R (Derogatis, 1992), in descending order, of Obsessive Compulsion (mean = 1.00), Depression (mean = .98), Interpersonal Sensitivity (mean = .96), and of Paranoid Ideation (mean = .88). The mean scores of the mothers and the fathers along the nine dimensions of the SCL-90-R were lower than the afflicted youths, but their scores indicated that their psychological distress

warranted clinical attention and care. The marital lives of the parents had not been negatively affected: their mean scores in the four subscales of Dyadic Adjustment Scale (DAS) were not significantly different from those of the adjusted Chinese couples in Shek's study (1995), except for the subscale of dyadic satisfaction. The disorder had negatively affected the functioning of these families as measured by FAD, a scale developed from the McMaster Model of family functioning (Epstein, Baldwin, & Bishop, 1983). The mean scores of the youths, the mothers and the fathers on the seven dimensions of perceived family functioning, including problem-solving, communication, roles, affective responsiveness, affective involvement, behaviour control, and general functioning, exceeded 2.0, a threshold adopted by the Canadian respondents (Miller, Epstein, Bishop & Keitner, 1985) to differentiate "healthy" from "unhealthy" families. The results indicated that from the perspectives of the youth and the parents, their family functioning was in general unhealthy and particularly problematic in roles, behavioural control and problem-solving (Ma & Lai, 2009). Our data have confirmed the negative impact of the disorder on the psychological well-being of the youths and the parents, and on their perceived family functioning. What remains uncertain is the differential effect of the disorder on each of the family members and on different families. The differential effects should be carefully assessed in the initial phase of clinical contact.

Medication is generally ineffective in treating AN. Psychotherapy has been shown to work effectively together with conventional psychiatric treatment in helping the patient; its success rate ranges from 39% to 63% (Lock, Le Grange, Agras & Dare, 2001). The research team of Maudsley Hospital, London, has carried out three clinical trials of family therapy versus individual therapy and drug treatment; the results show the treatment

efficacy of family therapy in helping children and youths aged 18 or below with the history of illness shorter than three years (Russell, Dare, Eisler & Le Grange, 1992). The treatment effect remained unchanged in the 5-year follow-up study (Eisler et al, 1997).

In Hong Kong, our study (Ma & Lai, 2009) has shown that out of 27 patients referred for family therapy, 22 patients and families completed the family treatment (81.46%), which was offered with one session (approximately 1.5 hours) fortnightly. Treatment outcome was measured by the change in the body mass index (BMI), the symptomatology associated with the disorder (EDI), the psychological distress (SCL-90-R) and the perceived family functioning (FAD). The BMI of the Chinese youths in our study had increased from 15.48 in the pre-treatment stage, which was lower than the average BMI 17 of the same age cohort in Hong Kong (Leung, Cole, Tse, & Lau, 1998), to 18.46 in the treatment phase; it was maintained at 18.36 six months after treatment. There was change in the symptomatology associated with the disorder. Immediately upon completion of treatment, scores on DT and IA had improved but there was not much change of the other subscales. Six months post-treatment, decreased scores of DT, BUL, BD, PF, IA, and MF were observed but the change was statistically insignificant except for the PF score (Ma & Lai, 2009). Change in the level of psychological distress was slight but the decrease was statistically insignificant. Six months post-treatment, the mean scores in all the nine dimensions of SCL-90-R had decreased, with the six symptoms moving out from the moderately symptomatic range to the functional range. The same was true for the change in psychological distress of the parents. From the perspective of the fathers, there was higher dyadic consensus six months post-treatment whilst the mothers perceived increased dyadic satisfaction and dyadic

cohesion six months post-treatment. Contrary to our prediction, perceived family functioning of the Chinese youths and their parents did not show any change immediately upon the completion of treatment and six months post-treatment. Nevertheless, the results obtained from our outcome study were incompatible with the subjective experience reported by the youths and families from an in-depth post-treatment interview. Both the youths and their parents perceived changes in their family with decreased family conflicts and increased understanding with one another (Ma & Lai, 2006). The inconsistent results might be accounted for by the insensitivity of the measure to capture changes of the family.

In reading our study, one has to be cautious of its limitations, which includes low generalizability due to a small sample, lack of a control group and use of self-reported measures. Despite these limitations, our study has provided evidence to support the applicability of family therapy in helping Chinese youths with AN. We have elicited clinical themes, such as control and power struggle during the mealtimes and maturity fear of the young persons, in treatment (Ma, 2007a), which are in line with themes reported in the Western contexts (e.g., Minuchin, Rosman & Baker, 1978). Besides, we have identified issues particular to our cultural context; for instance, the onset of seven of the youths' disorder in our study was related to poverty (Ma, 2007b); Chinese youths and their families were motivated in seeking family treatment, probably due to the life-threatening nature of the disorder and emphasis on family care and support in the face of hardship and adversity. With the support of the family therapist, they were ready to deal with their family conflicts, rather than sweeping them under the carpet.

#### Our Model of Family Treatment

In helping the Chinese youth and families with AN, we have adapted Micucci's (1998)'s

family treatment model (the model) because of its strengths: (a) the model directly addresses the family politics and intense family conflicts that arise from the disorder; (b) its view of the disorder and its effects on the family context is complex and multiple layered; and (c) the model has taken care of the suffering of the young person with AN and of the importance in developing strong therapeutic alliance with her at the start of treatment; and (d) most importantly, the model is an expansion of the structural family therapy school (Minuchin & Nichols, 1993; Minuchin, Nichols & Lee, 2007), from which I received my clinical training and supervision.

The model of family therapy is an integrative approach, which comprises three major theoretical perspectives: family systems perspectives, feminist psychodynamic perspectives, and socio-cultural perspectives. Family assessment would be placed on family process, rather than on the symptoms per se. Three major family processes are fundamental to assessment and treatment: (a) isolation and conditional acceptance; (b) control versus genuine connection; and (c) the symptomatic cycle (Micucci, 1998).

Families with AN appeared to be overtly close and cohesive with diffuse boundaries. But an exploration of the youth's inner world revealed a profound sense of disconnection and isolation felt by the youth in the family. She perceived the parental love as conditional on her performance and achievement, and parents are often not aware of this. In facing the deteriorating health of their emaciated child, the parents would force her harder and harder to eat, which in turn deepens the sense of isolation of the youth and results in her resistance and rebellion against the controlling parents. The youth and the parents are entangled in a losing battle—the youth insisting on continued self-starvation and the parents becoming more desperate, helpless and hopeless. The symptomatic cycle of family

interactions that emerged drained the energy of the family and maintained the symptoms of AN.

The crucial task of the family therapist is to help the youth and her family to contextualize the meaning of the disorder within its immediate socio-cultural milieu, and to shift their focus of attention from the symptoms to the symptomatic cycle of family interactions that had maintained the symptoms. Once this therapeutic task was achieved, an effort should be made to activate the youth and the family to disrupt the symptomatic cycle of family interactions and identify alternative ways of relating to one another, which would offer options and possibilities for them to join hands in driving away the disorder.

I have modified the model by incorporating the cultural lens of family, *jia* (家), in assessment and treatment. The concept of family, *jia*, in traditional Chinese culture, refers to extended family or kinship, *jia zhu* (家族), rather than as the nuclear household as customarily conceived by Western sociologists (Wen, Chang, Chang, & Chu, 1989). Besides, the concept of family is subjectively defined and fluid in nature. Chinese people are flexible in applying the concept of family in different contexts; for instance, the concept of family would be broadly defined in funeral or wedding ceremonies and may be narrowly circumscribed in a family business. By adopting a cultural lens in conceptualizing family, the therapist would be curious to explore and understand the role (if any) of the parents' family-of-origin in assisting the youth and the parents, the extent to which their help is facilitative or hindering the process of dealing with the disorder, and the possibilities provided by the extended family in offering help should therapeutic impasse occurs in treatment.

Besides, I began to realise soon after the start of this clinical research the importance of motivating the youth to take charge of

her own health and be responsible for her recovery. Engaging the youth in treatment and winning their trust are as important as effecting contextual change in the family. The former treatment goal can be achieved through the skilful use of motivational interviewing (Vitousek, Watson & Wilson, 1998) whilst the latter can be accomplished when the therapist is caring, warm and firm, who acts like an authoritarian parent (Miller, 1991) in a persistent manner to demand change in behaviour and be permissive of her to remain ill, if wished.

The process of change comprises six steps: (a) negotiating a treatment contract by shifting the family's focus from the symptoms to the symptomatic cycle or the constricting the family process that has maintained the symptoms of AN; (b) encouraging parental collaboration by supporting them to help the starving daughter gain weight rather than to control her; (c) addressing unresolved conflicts and improving the family relationship; (d) handling relapses by preventing the re-emergence of the symptomatic cycle and further enhancing family relationship; (e) supporting individual development and (f) supporting transformation (Ma, 2011; p. 45). These steps are by no means discrete and separate from one another; they overlap and are cyclic in the process of helping. Family therapists must be mindful of the changing therapeutic context, which in some circumstance would indicate the need to recycle to the previous step in order to gain a better understanding of the situation, rather than prematurely pushing for change.

Take Janet as an example. After assessing the effects of AN on her, her parents and the family, the therapist explored the symptomatic cycle of family interactions that have tied down the family from opening up viable options and the possibilities of coping. Our exploration shed light on the fact that Janet's father had kept blaming his wife for being too soft and

lenient in handling Janet's self-starvation. Feeling angry and culpable, Janet's mother kept all difficulties to herself until the distress had reached a point that she could no longer bear. She blew up and withdrew to the bedroom, leaving the mess to her husband. In so doing, the parents had been undermining each other's effort. They became more powerless, helpless and hopeless. While appreciating the need of engaging Janet in treatment and of motivating her to be responsible for her recovery, the therapist should make use of every opportunity to transform the presenting problem from an individual pathology to a family issue, which calls for the contribution of each of the family members as well as their collective effort to break their vicious cycle of family interactions and to find better ways of relating to one another. With the change of family context, so that the parents no longer blame each other but collaborate as a team in helping, Janet would be more willing to let her parents assist her in navigating the journey of recovery.

For family therapists like myself who have no medical training, two points are of vital importance in caring for the youth with AN. First, the therapist has to collaborate with a medical practitioner (a family physician, a psychiatrist or a paediatrician) who has clinical experience in managing AN. Second, the therapist has to weigh the youth every time before family treatment. The body weight indicates whether the youth and her parents are responsive to family treatment and whether the youth's health condition is at risk. If weight loss indicates an imminent risk, the therapist has to persuade the parents to seek urgent medical care or hospitalisation, if needed.

#### Family Therapy and Family Centred Care

Larger system collaboration (Lee et al., 2009) is part and parcel of the family-centred care for Chinese youths with AN. The power of family therapy would be weakened if the

therapist did not collaborate with helping professionals from school, mental health service and social service in achieving the goal of helping. For instance, Janet has problems in relating to her classmates and peers. She felt socially rejected and isolated at school. The disorder can be perceived as the shield for her to avoid facing the distress at school. A sympathetic teacher, a school social worker or a counsellor who can create more opportunities for Janet to develop new friendships would be of tremendous help to her recovery. Should the young person have drastic drop in body weight or health crisis, an easily accessible medical care and psychiatric service is vital.

Management of the Chinese youths with AN is complicated by the fact that a few families under our care have been struggling with other problems such as financial difficulties, unemployment, poor physical health or mental well-being of one or both parents before the onset of the youth's disorder. Family therapy alone is insufficient in meeting the service needs of these families facing multiple problems. Their needs can be better fulfilled through provision of tangible services (e.g., welfare subsidy), referral to medical or mental health service, career counselling or employment assistance, and resource mobilization from the formal and informal social network; all these require the interface of the mental health service with the education system and social welfare services.

My dual professional qualifications as a social worker and a family therapist have equipped me with the knowledge in both fields in helping. Family therapists or mental health professionals with no training in social work should collaborate with a social worker in the community in providing holistic care to families with multiple problems.

Prevention is better than cure. Mental health professionals should join hands to

challenge the socially defined norm of beauty – thinness and slimness. It is time for teachers, parents and mental health professionals to educate the younger generation in school, in the family and through the mass media to embrace diversity and plurality in body shape, and to accept, even to celebrate a variety of body images in society. Effort should be made to curb the stigmatization effect of the disorder, which may have hindered the youth and her family from seeking help.

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#### 摘要

以患厭食症的青少年為例，介紹為需要接受心理健康服務的兒童及青少年提供的「家庭為本的照顧」

「家庭為本的照顧」對需要接受心理健康服務的兒童及青少年是非常重要的，講者以患厭食症的青少年為例，分享其臨床研究結果，描述家庭治療及家庭為本的照顧在協助她們康復的評估、介入理念、原則、和其臨床效果。

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