INTEGRATION OF GENETIC AND REPRODUCTIVE COUNSELING WITH PSYCHOTHERAPY: CONSIDERATIONS THROUGH A CASE

INTEGRACIÓN DEL ASESORAMIENTO GENÉTICO Y REPRODUCTIVO CON LA PSICOTERAPIA: REFLEXIONES A TRAVÉS DE UN CASO

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Abstract

The main objective of this article is to invite clinical psychologists and psychotherapists to penetrate the world of rare genetic diseases and think over the emotional and psychosocial impact they have on the individual. Beyond the informative act of genetic counseling, both those affected and their families often need a deep psychotherapeutic process to overcome the traumatic aspects and grief which are often associated with the disease. From an integrative look, the process should also include the bio-psycho-social support to promote access to health and associative resources. In short, the patient and/or the family need to be helped to rebuild and re-tell their life in a more autonomous and healthy way. A clinical case is presented to illustrate the need to include psychotherapy into genetic counseling.

Keywords: *Genetic counseling, genetic disease, psychotherapy, trauma, grief.*

Resumen

El objetivo de este artículo es invitar a reflexionar a los profesionales de la psicología clínica y la psicoterapia sobre el impacto emocional y psicosocial que las enfermedades genéticas minoritarias tienen sobre el individuo. Tanto las personas afectadas como sus familiares suelen necesitar de un acompañamiento que, más allá del acto informativo del consejo genético, les ayude a superar los aspectos traumáticos y el duelo asociados a la enfermedad, a través de un proceso psicoterapéutico profundo. Desde una mirada integradora, el proceso debe incluir también información acerca de los recursos bio-psicosociales de apoyo, promoviendo el acceso de los afectados a los movimientos sanitarios y asociativos de soporte. En definitiva, se trata de ayudar al paciente y/o familiares a reconstruir y re-narrar su vida de una manera más autónoma y sana.

Palabras clave: *consejo genético, enfermedad genética, psicoterapia, trauma, duelo.*

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INTRODUCTION

Genetic diseases have a profound bio-psycho-social impact on the affected subject and his family which often is not addressed. The present article aims to sensitize professionals of clinical psychology and psychotherapy about the suffering and difficulties of those affected by rare diseases. We also want to show their need for a comprehensive support that, beyond genetic counseling, helps them both social and psychologically to find out new resources and to overcome the painful and traumatic aspects of the disease, in order to rebuild and focus their life from a greater acceptance and mental health.

Rare diseases

According to the World Health Organization (De Vrueh, Baekelandt & De Haan, 2013) rare, minority, or orphan diseases are characterized by:

- Their low incidence: Below 1/1500 inhabitants in the United States (US), below 1/2000 according to the European Union.
- Their great number: More than 7000 different conditions. Despite their low individual frequency, overall they affect an important fraction of the population: 350 million people worldwide. For this reason, the international portal Orphanet (http://www.orpha.net) says: "Rare diseases are rare, but rare disease patients are numerous".
- They are incurable chronic diseases, most having a genetic origin. The causative injury is intrinsic to the individual, laying in its chromosomes or its DNA. Thus, rare diseases are present throughout a person's life whenever symptoms appear.
- They tend to be severe, degenerative and invalidating, often leading to premature death.
- Due to their genetic basis, minority diseases transcend the individual himself to affect the whole family. Genic disorders are caused by single gene mutations. They can be transmitted from an affected parent to the offspring with a risk of 50% in each pregnancy (dominant inheritance) or they can appear with no previous familial background. In this case, both parents may be healthy carriers (recessive inheritance, 25% recurrence risk) or the disease may have been caused by a spontaneous *de novo* mutation in the DNA of a parental germ cell (Figure 1).

Genic diseases may have a congenital presentation if expressed since birth or may emerge later in life, sometimes when the person has already had children. Chromosomic diseases have different characteristics and will not be analyzed in this paper.

Due to all these particularities, minority diseases often have a devastating impact on both the affected and the extended family: Surprise, uncertainty, frustrated expectations, physical suffering, fear, guilt, disability, the assumption of perhaps a premature death ... Hope and quality of life are threatened. It is a complex

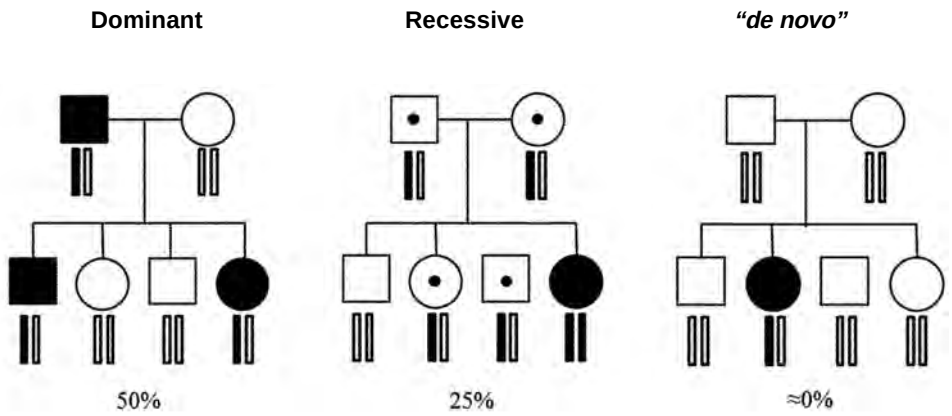

Figure 1. **Inheritance patterns of genic diseases and their associated risk of recurrence**

jolt for the family with profound repercussions on each relative, on the system as a whole, and as a network of interrelations. Feelings of loneliness and lack of protection are common.

This suffering is often accompanied by a long pilgrimage through the health system until a clinical diagnosis is obtained. Giving a name to the pathology is essential to know prognosis and therapeutic options. Rarity complicates the diagnostic task as medical expertise may be scarce. Moreover, the cause and course of the condition may not be known. To ameliorate these limitations, the US National Institutes of Health and the European Commission are fostering international research collaborations to help advance in the understanding of these rare conditions. In spite of that, the average diagnostic time is still several years. It is a long time of uncertainty and impotence that can have serious consequences for the patient. It is also a frustrating time for the healthcare professionals who face their ignorance of the disease. In addition, treatment of genetic diseases is symptomatic, palliative or preventive. Healing is not possible nowadays despite the great efforts of science to develop gene therapy strategies.

However, after the development of the Human Genome Project (Rogers, 2003) understanding of the genetic bases of diseases has grown exponentially. Modern technologies allow an accurate genetic diagnosis for an increasing number of pathologies. All published biomedical information worldwide is daily collected in the free server OMIM (Online Mendelian Inheritance in Man; http://www.ncbi.nlm.nih.gov/) from the National Center for Biotechnology Information (NCBI) where each gene and each disease are unambiguously encoded.

To obtain a genetic diagnosis means to know the concrete gene and mutation underlying the disease. This is an essential step to address prevention, which is based on avoiding the birth of new affected children through the interruption of pregnancy after prenatal diagnosis or by using modern preimplantation diagnostic

techniques. Both are eugenic procedures with serious ethical implications that touch existential basics of intimacy and require a deep revision of values.

Genetic counseling

The preventive reproductive options we have outlined depend on each disease. The gene needs to be previously known and the particular genetic alteration needs to be determined. In the era of Molecular Medicine, this information is offered to the client –patient and/or relatives– in the context of the so-called genetic counseling act, which is described by the National Society of Genetic Counselors (NSGC) Task Force Definition (Resta et al., 2006) as:

> " … the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following:
> - Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
> - Education about inheritance, testing, management, prevention, resources and research.
> - Counseling to promote informed choices and adaptation to the risk or condition." (p. 77).

The term *genetic counseling* was coined by Sheldon Reed in the 1940s (Resta, 1997). In 1969 it was established as a professional discipline in the US. Although the definition does include psychological aspects, there are in fact two models of genetic counseling: The *teaching model*, centered on providing biomedical information, and the *counseling model* based on a therapeutic stance in which the psychological dimensions are considered. In this second model, clinical psychology is included in its curricular subjects, most notably the training skills of the Rogers' humanist model (Rogers, 1981). In Spain, the young Spanish Society of Genetic Counseling (http://www.seagen.es/) takes into account the subjective aspects of the patient. However, the education model is the most frequently used by health professionals without specific psychological training. Nevertheless, it is overall estimated that 50% of families do not receive advice. Even in the US, which was the first country to train professionals, genetic counseling is still a young profession.

Genomics Medicine is evolving fast and there is a need for professionals who translate genetics into clinical practice, including the psychological and ethical aspects of rare diseases. It is necessary to reflect on their bio-psycho-social and existential impact and to adapt academic contents to the patients reality. In this sense, genetic counseling has always had a difficult relationship with psychotherapy. The question "How psychotherapeutic should genetic counseling be?" (Fraser, 1982, as cited in Austin, Semaka, & Hadjipavlou 2014, p. 904) has not been solved yet. A NSGC study showed that only 5.9% of its members are in fact interested in psychotherapy (Eunpu, 1997). The objective position of the educational model forgets the important vital, reproductive and social repercussions of genetic

diseases on both the affected and relatives. Counselors must be sensitive to the complexity of this suffering to help alleviate the pain and assimilate the situation. Through this experience the client may obtain a greater psychological maturity, not only to make decisions but to live in a healthier and adaptive way. This approach coincides with the American Psychological Association's definition of psychotherapy (APA, 2013).

Kessler, in his book *Psyche and Helix: Psychological Aspects of Genetic Counseling* (as cited in Kessler, 1997) described genetic counseling as "a type of psychotherapeutic encounter" that can not be reduced to a mere informational act. Heirs of this approach, Austin and colleagues (2014) suggested conceptualizing it as a form of psychotherapy in which the communication of genetic information is the central objective of the process. Accordingly, the Accreditation Council for Genetic Counseling (ACGC) currently requires advisors to be trained in Rogerian listening and intervention tools, coping mechanisms, family systemic dynamics and grieving processing. The aim is to facilitate a duly informed decision-making but also a better adaptation to the disease by reducing anxiety and increasing well-being (Meiser, Irle, Lobb & Barlow-Stewart, 2008; ACGC, 2015). As mentioned, the process of reporting on diagnosis, prognosis, and reproductive options raises serious existential questions that increase client's anguish. It is therefore necessary to be sensitive to the deep psychological aspects of genetic counseling. In this sense, the psychologist and clinical advisor Yager concluded that the change in the genetic patient mainly depends on counsellor's empathy and countertransference, which transform an arid information session into a therapeutic encounter (Yager, 2014). This is the approach we share. We consider the counselor should have the capacity to deepen and reflect with the affected person on essential aspects of life and death, to offer a real accompaniment to his fears and needs.

The present article seeks to delve into this theoretical framework in which the genetic counselor is fitted into the clients' shoes to promote autonomy, through not only the transmission of information but also the quality of the therapeutic alliance (Safran & Muran, 2005). Moreover, we consider the need for many patients and relatives to address a profound psychotherapeutic process to review the suffering, grief, trauma, guilt, and depression often associated with the presence of a serious hereditary disease within the family. In this process, the therapeutic bond and relationship are especially important (Geller & Porges, 2014). Providing the client a secure basis of trust will enable him to delve into the most difficult or forbidden aspects of life to integrate them into a healthier personality. A humanistic, relational and integrative model of genetic counseling and psychotherapy is proposed to address the multiple dimensions of this complex problem.

Beyond genetic counseling: Reproductive advice

Within this context, assessment of the reproductive choices of each family member becomes crucial. In the absence of cure, prevention of rare diseases is based

on eugenic procedures that preclude birth of new affected subjects. Until a few years ago, the only option was prenatal diagnosis and legal termination of pregnancy through therapeutic abortion. Today, technological advances allow preimplantation diagnosis by which gestation of affected embryos is avoided. This requires assisted reproduction which, in addition to a high economic cost, has an impact on the couple and, more specifically, on the women's physical and emotional health. The potential psychological impact on the artificially gestated baby (Winter, Van Acker, Bonduelle, Desmyttere & Nekkebroeck, 2015) also needs to be investigated.

In vitro fertilization (IVF) is the technique of choice for preimplantation diagnosis of hereditary diseases. This process requires hormonal stimulation of women to maximize fertility, egg retrieval and fertilization in the laboratory with sperm from the man. After three days of *in vitro* culture, one of the 4-8 embryo's cells is removed by micromanipulation and further analyzed by the specific family mutation. Mutation free embryos are implanted in the mother's uterus. The process is costly, not risk free and its success is usually less than the estimated 20% of conventional IVF processes. It often takes several cycles of treatment to achieve pregnancy. The psychological effects on women are evident. Besides the anxiety of waiting for a positive result after each step, there are the side effects of hormonal treatments and the stress to which the body is subjected. These aspects are often not informed nor accompanied. Detailed information on all the pros and cons followed by a careful period of reflection is, in our view, essential. It is concluded that both prenatal and preimplantation diagnoses involve additional distress for the couple which is added to the previous suffering for the disease.

For all these reasons, the development of nascent Molecular Medicine requires a cross-link between two disciplines: Psychotherapists might learn about hereditary diseases and assisted reproduction, and genetic counselors might have notions of psychology and psychotherapy.

CASE PRESENTATION

With this objective in mind, the case of a female patient of reproductive age affected by an inherited disease is presented. Informed consent was obtained to report and publish her process. She requested genetic counseling and, at the same time, she made a psychotherapeutic demand to elaborate her vital fears. The parallel processing of genetic and reproductive information relative to the disease and the deep psychological conflicts that emerged is displayed. Through an indivisible process of integration, she was at last able to make a reproductive decision from emotional health and contact with life. For this reason we have called her Liang, "the bright one". The psychotherapeutic process was developed on the basis of a personal combination of humanist, relational and integrative models (Coderch, 2010; Gimeno-Bayón & Rosal, 2003; Erskine, Mouesund & Trautmann, 1999; Payás, 2010; Wallin, 2012).

Liang was a 31-year-old woman who was referred to one of the authors for her

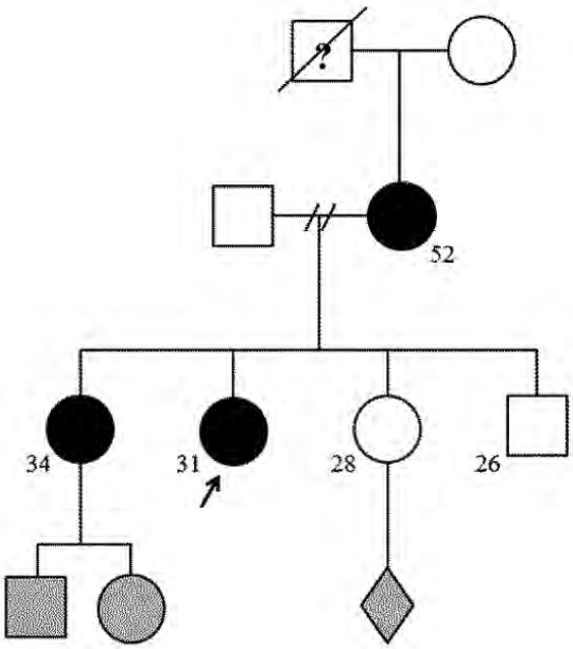

Figure 2. **Family tree. Affected subjects are shown in black; healthy individuals are shown in white; children without diagnosis are in gray. Numbers indicate the age of each individual. The arrow points to Liang.**

double training in human genetics (Monros, Smeyers, Ramos, Prieto & Palau, 1995; Monros et al., 1997) and adult psychotherapy. As shown in Figure 2, the patient was the second of four siblings. She was a teacher and psych pedagogue, and had finished training in Gestalt psychotherapy. She lived with her couple in a small town where she worked in a school. She was an expressive, attractive, intelligent woman. She had been recently diagnosed from a rare hereditary disease, a Rendu-Osler-Weber Syndrome, and she came up with a double demand:

- Genetics demand:
  - Assessment of the disease and its consequences.
  - Genetic and reproductive counseling: She wanted to have children.
- Psychologic demand:
  - To assume sickness and fear: Fear to live and fear to die.
  - To perform, maybe, a grief work: Grief form health, from her frustrated life expectations, from the children she may not have.

The complexity of the demand required a profound integrative therapeutic approach which could not be achieved by a symptom-oriented model of psychotherapy nor through a cognitive-behavioral model.

Rendu-Osler-Weber disease

Already known as Hemorrhagic Hereditary Telangiectasia (HTT), it is a rare disease caused by malformations in the blood vessels of skin, mucous membranes and viscera. Symptoms can be summarized as nasal, gastrointestinal and respiratory hemorrhage, respiratory and cardiac insufficiency, stroke, convulsions, hypertension, hepatomegaly, cirrhosis, telangiectasia, hemangioma and anemia. The disease has an evident risk for life.

Specific treatment does not exist and patient's quality of life is based on prevention through periodic medical reviews. Cauterization, surgery and endovascular embolization are usually needed. Prognosis is largely variable, from severe forms with premature death to milder forms that allow a normal period of life.

The disease has an autosomal dominant inheritance pattern with a 50% recurrence risk. Two variants are distinguished, according to the gene involved:

- HTT1 (OMIM 187300): Type 1 variant is caused by mutations at the Endoglin gene, on chromosome 9. It is characterized by an earlier onset of nasal bleeding and a greater involvement of lung and brain.
- HTT2 (OMIM 600376): Type 2 variant, caused by mutations at the ALK1 gene on chromosome 12, has a greater hepatic involvement.

Liang: Medical Record

Liang was clinically diagnosed a few months ago. She inherited the disease from her mother, who was diagnosed at 50 years of age. The mother suffered daily from nasal bleeding, had affected lungs and heart, and had suffered the embolization of five pulmonary fistulas. As shown in Figure 2, Liang older sister was also affected while the two younger had no symptoms. The causing mutation probably came from the maternal grandfather, already deceased. Liang had been recently submitted to a pulmonary embolization in which she had complications. As soon as in the first session she said: "*I saw death in front of me*". In two months she will have a brain scanner that caused her significant distress. With this background, her double demand for genetic counseling and psychotherapeutic work on her fear of illness and death made great sense.

Other manifested problems

In the course of the first two sessions, other relevant biographical antecedents emerged. For a closer approach to the patient's subjectivity, maximum fidelity to dialogues and internal verbalized processes has been maintained in the description.

> **Liang's father**: Parents divorced when Liang was 14. The father was alcoholic and a womanizer. However, when talking about him she smiled and said: "*I no longer victimize. On the contrary, I've taken responsibility for myself and I've chosen a good partner*. "
>
> **Liang's mother**: The mother had a labile personality due to a difficult childhood. From the first session the conflict with her emerged: "*My*

mother overwhelms me. She's manipulative and victimizer. She always wants to be the protagonist, always complaining ... I can't stand her. "
"She made several suicide attempts… when I was three she slit her veins ... Sometimes she packed her bags to leave home ... I was so scared! When I was 10 she told me about her suffering, her autolytic attempts… she explained to me that my father besides drinking went off with other women ..."
"When I was a child I was very afraid she would die. I invented magic games to save her, like thinking: 'If it's yes, she'll die; if not, she won't die.'"
Resentfully, she said: "*With this disease she finally has what she always wanted, a reason to really complain! It makes me very angry! I worked it a lot in Gestalt therapy but I don't get over it ...* "
At the end, from the emotional connection, she added: "*I'm like my mother, I even have her illness*!"

It will be seen throughout the presentation that Liang was a person who had worked on her personal development, with a high insight capacity that favored her rapid psychotherapeutic advance. She displayed important intrasession and intersession changes. Therefore, despite the complexity of the case, it will be faithfully described in an agile way through the intervention processes. These were based on the great technical diversity of humanistic psychotherapies, with whom she felt comfortable. Special care was taken to ensure closure of all contents at the end of each session. A person with her highly emotional doorway (Ware, 1983) but psychologically less mature, would have required a different approach and undoubtedly a longer process, more focused on emotional restraint and on fostering metacognition and mentalization (Main, 1991, as cited in Fonagy 2000; Wallin, 2012).

Liang's partner: Liang had been in a couple relationship for four years. She wanted to have children but he did not want to. She said: "*I told him I could do without a partner but not without children, so he accepted. This was before I was diagnosed with the disease. Now he's also afraid: Afraid that I die, afraid that I die of hemorrhage during childbirth, afraid to have sick children ... We talk a lot ... I don't want to take it alone*". In this last sentence, an implicit demand for accompaniment was intuited, probably due to a healthy need for change. It reflected her previous experience of solitude, as it might be inferred from her childhood experiences. The partner emerged as a solid place, a secure bond.

Diagnostic hypotheses

1. Genetic hypothesis. After an in-depth documentation on the clinical and genetic bases of the disease through the literature and data collected in the OMIM, it was assumed that the family mutation was probably located at the Endoglin gene. Molecular analyses were necessary to confirm the diagnostic suspicion.

2. DSM-5 diagnosis. Liang met criteria for the following diagnosis:

309.24 Adjustment Disorder with Anxiety (principal diagnosis)
V62.89 Phase of life problem
EI78.0 Rendu-Osler-Weber disease

Liang had a high degree of functionality in all aspects of her life. Her anxiety and mood related symptoms meet criteria for an Adaptive Disorder in response to the recent diagnosis of her illness and her desire to be a mother. She did not meet criteria for any personality disorder. Nevertheless, some histrionic traits may be highlighted, as well as her well-kept and seductive appearance and her high and changeable emotionality, together with a slide obsessive tendency stemming from her need for emotional, mental and interpersonal control as a child to cope with family conflicts and her mother's threats.

Her healthy personality style according to Millon and Everly (1994) fit into the sociable pattern (lively, expressive, dramatic, charming) and to a lesser extent, to the cooperative complacent pattern.

3. Diagnostics according to Transactional Analysis. Transactional Analysis was chosen as an alternative diagnostic model for its explanatory capacity of the different dimensions of personality which facilitates identification and integration of the different phenomenological parts.

Ego states

- *Child state*: At the beginning, a frightened Child (Natural Child and Adapted Compliant Child) predominated. Current healthy aspects coexisted with historic unresolved emotional aspects that confused her.
- *Adult state*: Structured Adult, present when required.
- *Parent state*:
  - Persecutor internal Controlling Parent that frightened and blamed her.
  - Great external Nurturing Parent, as derived from her profession and her role of caring for her mother since childhood. Identification and symbiosis with the mother were still maintained.
  - Deficit of internal Nurturing Parent.

Emotional subsystem. Through observation and through what she expressed in her demand, her frightened Child was afraid of illness, suffering, living, and dying. Her fear was understandable but had a great deal of anguish. It could be considered a parasite fear caused by the cumulative trauma of her childhood experiences.

She easily connected with rage and shame. These emotions were also the product of trauma and she was not able to mentalize them.

Liang also felt frustration because the diagnosis of her disease forced her to reconsider her life expectations. Her plans and illusions threatened to be thwarted.

Guilt appeared as a parasitic emotion. She felt guilty about her desire to have children in case they inherit her disease, guilty to give them a sick mother, guilty in case she died, guilty for her partner.

Finally, sadness emerged as a forbidden emotion. In her own words: "*I want to be calm and present but when I stop it always appears this bitterness ...*"

Cognitive subsystem. As mentioned above, the patient had a highly functioning and structured Adult. She was intelligent and alive, interested in self-improvement, and had a high capacity for insight.

Her apparent existential position was (+ / +) with a slight tendency to mania. Internally, the trend was depressive / nihilistic (- / -).

Behavioral subsystem

- *Defense mechanisms*: The most outstanding were introjection and denial. She disconnected from emotions through control and doing, since "*connecting is threatening*".
- *Unproductive behavior*: Agitation.
- *Stroke system*: Deficit of unconditional positive strokes and self-strokes.
- *Favorite role*: Rescuer. She was a supporting daughter, a caretaker of her mother.
- *Drivers*: "Be strong!" and "Please others!" were the most salient.

4. Attachment style. Liang displayed an insecure attachment with disorganized style (Main, 1970, as cited in Wallin, 2012). This term defines the person who develops a controlling conduct with role reversal to try to solve an irresolvable contradiction: The need to resort to parents for safety and, in turn, the fear and desire to flee which they produce. It is typical of families where parents hurt, which causes a deep distrust of "the other" being available. Therefore, in threatening or stressful situations the person can move from the anxious-ambivalent style to the avoidant style. This aspect was hardly active in Liang's present life thanks to her personal work and the security bond she had established with her partner.Attachment style categorization was based on the Adult Attachment Interview criteria (Hesse, 1999).

Case formulation

Given her explicit demand and previous experience in Gestalt Psychotherapy, in the first session a weekly frame of one hour was scheduled to perform the genetic counseling in parallel with a work on elaboration of her fear of contact. A final grief work could be done, if necessary, to help her to come off the life expectations which she had to give up.

However, after the family's information obtained in the second session and the observation of her emotional response and defensive mechanisms –trying not to enter into the feeling but overflowing in anguish– the process was rethought and the following three main objectives were formulated:

1. Intrapsychic and relational elaboration of childhood conflicts:
   a. Introspective work of experiential contact with the Child's fear.
   b. To differentiate Child's fear from the present adaptive Adult's fear.
   c. Elaboration of traumatic memories.

2. Decontamination of parental charges and Self-parenting.
3. Genetic and reproductive counseling.

Final objective: To achieve a balance between the reality she lived and her confidence in life and, from there, to be able to make healthy reproductive decisions.

It has to be mentioned, however, that some sessions were 90 minutes long, given the need to elaborate and close the abundant and complex emerging material. This was agreed upon with her to ensure contents integration.

Procedures of Intervention and Therapeutic Process

Empathic listening, inquiry, emotional restraint, and information were used from the beginning to generate a safe space in which Liang could feel in good hands and establish a therapeutic bond (Erskine et al., 1999; Safran & Muran, 2005; Wallin, 2012). Already from the first session she felt understanding and help. She quickly got into confidence, showing her need for affection and for a maternal figure to trust.

During the first few months, sessions' contents danced between cognition and emotion, between the biomedical information the therapist was offering and her emotional reactions. These were used to enter into experiential contact and, through relation and different intervention tools, to observe, process, and integrate her intrapsychic and relational conflicting aspects.

1. Genetic counseling

Liang showed a great ambivalence between her desire to have children and her fears. Her initial demand was: "*I want to have a healthy baby*." The tasks of the therapist as a genetic counselor focused on:

- Clinical aspects: In order to frame the demand within a realistic context, the clinic of the disease was studied throughout the international bibliographic funds: Symptoms, risks, variability of intra and inter-family gravity, and prognosis.

- Genetic aspects: Precise genetic diagnosis –which means determining both gene and mutation– was the first essential step for drawing reproductive possibilities. A laboratory was searched in which both genes that caused the syndrome could be analyzed and sample's delivery was facilitated.

- Patient Association: Contact with the Spanish Association of Rendu-Osler-Weber Syndrome was located (http://www.asociacionhht.org/) was supplied to the patient. As discussed above, sharing information and experiences with other people, families and groups has, in general, a psychosocial beneficial effect. Associations also bring medical, social and institutional resources.

2. Reproductive counseling

Only after knowing the specific patient mutation can the reproductive approach be followed, so the person has time to reflect before making a definitive decision.

It is important to mention, as Liang was informed, that current diagnostic techniques do not allow "*to secure a healthy child*". The use of donor eggs was ruled out as a reproductive option since she wanted a biological child of her own. Therefore, two alternatives were drawn: (a) natural pregnancy and prenatal diagnosis; (b) IVF and preimplantation diagnosis. Liang was clear she did not want to undergo an abortion. Therefore, this second option was the only viable one and we proceeded to look for a center where to do it. However, as will be seen below, the thought of "*having a lab child, not conceived through the act of love*" also distressed her.

3. Psychological aspects and psychotherapeutic process

Liang process was unusually intense and fast. After two visits of inquiry, goals were reoriented and already from the third session a deep psychotherapeutic work began. This was facilitated by her previous therapy and training, her capacity for insight and the attunement that was established with the psychotherapist, as discussed above. Throughout the process it was important to keep in mind her bonding style, since idealization –natural at the beginning– could be polarized into intense frustration if archaic relational schemes were activated. Our relational integrative model takes special care of the therapeutic presence and bond to promote client's safety and overcome transference conflicts (Geller & Porges, 2014).

Session 3. While she was being informed about (1) a doctor in Spain who was a specialist in her illness; (2) the existence of the association of patients and (3) the finding of a molecular genetics center where studies could be performed, Liang got into an intense anguish. At the same time she realized she was denying her feelings and getting blocked. As it was previously agreed, she was asked to make contact with this anguish in the body and to elaborate it through the Brainspotting approach (Corrigan & Grand, 2013). Although at the beginning it was difficult for her to maintain the gaze, she intensely connected with a great weight on her back: The burden of her mother and grandmother as a hump. Her body curved forward and she began to verbalize her feelings and experiences:

> "*It drowns me ... I get a lump in my throat ... I can't breathe ... Not to breathe, not to live ... I take it for love ... Without this I lose my identity*."
> Therapist: "Close your eyes … get it out ... just for a while "
> Liang made the gesture of removing the weight of the back with her hands. Her body bent forward. She connected with a new sensation of great fatigue. She felt down.
> Therapist: "Liang, sit back upright ... Well ... feel your body like this."
> She then experienced a profound change in her body. She leaved exhausted but with a great sense of lightness.

Session 4. During the week Liang got in touch with the patient association. The therapist informed her there was a center in the same city where IVF and preimplantation diagnosis could be performed once the mutation was detected. She entered anguish again, living it as a medicalized and unnatural act. She broke into

tears and screamed: "*I feel the animal instinct of a female who wants to be fertilized by her male*!" Her inner contradiction was evident, an impasse between her Nurturing Parent who did not want to abort and her Natural Child who desired a natural pregnancy.

The spontaneous direction of her gaze allowed beginning a Brainspotting process with this body experience. Liang had an insight and realized she was in a great hurry to decide, as a result of her need to escape the discomfort. There was a major intersession change that week.

Session 5. The following days Liang spontaneously disconnected from the "children theme" and decided to give herself time. Recalling the previous session, she commented:

> "*I don't want my life to be this way ... I'm always accelerated. I'd like to live more calmly but when I stop I always find this underlying bitterness ... and then I go back to activity so that I don't feel it."*
> The therapist invited her to close her eyes and stay with the feeling. She first connected with her 13, when she realized that one day she would die and everything would end. She then connected with her father: "*He's the bitterness of life ... all gray, all bad humor ... he embitters me…"* She cried and begun to regress: *"As soon as he opens the door there's tension, shouting, scolding ... He drinks to forget but it's still worse ... He's a bitter and is bitter to others... ... It was at eight or nine when I knew he was drinking. I remember well the night they brought him home drunk ... I was in bed with my sisters ... So scared! I vomited in silence, alone ... Let no one hear me ... Don't disturb ... So much fear! And now what will become of us?* "
> Liang tried to contain her tears by squeezing her eyes with her fingers as she relived the scene. The therapist pointed it out.
> Liang: "*That day I was so scared!!!"*
> Therapist: "Where was your mother?"
> Liang: "*My mother, when she couldn't stand it, she said she was leaving and packed up ... I didn't want to ... Not to make noise ... Don't disturb ... and take care of her*."
> Therapist: "When did that child learn to be silent and stand it alone?"
> Liang: "*I learned early not to make noise, to hold back the tears although then they come out for anything ... and pray ... I've always slept with my older sister, in times with both. We went to bed alone and prayed ... Lucky sleeping with them! But that night they were sleeping, I didn't say anything ... it was my secret ... I vomited in silence ... Homelessness ... Shame ... Fear ... And now what will happen? My head was spinning ... How much I'd have needed my mother...!*"

In this regression state the therapist performed a Parenting work so that Liang could live the experience of being accompanied and receive the warmth which that day did not have at all. Although her experience was of deep solitude, when drawing

up the session the company of her sisters and the resource of praying were rescued.

Session 7. This week Liang turned 32. She said: "*I want to live in health but I have lots of resistance. I'm very attached to my illness*." The therapist proposed to do Brainspotting again.

> During the session, Liang connected with different experiences and beliefs: Fear ... death ... the father ... "*I'm like mom … ... Not to live ... Not to laugh ... Not to make noise ... ... So alone!"*
>
> In this session she realized her script beliefs: "I take it alone" (implicitly "I can't trust anyone") and "I must take care of my mother".

With the therapist interventions, she was able to decontaminate her Adult part from the Child, the present from the past, to differentiate the current woman who faces that one day will die from the scared lonely Girl. She also realized she is not alone now: She has her partner, growing up together in the relationship.

Intersession. During the weekend she participated in a workshop inspired by Gendlin's Focusing (Gendlin, 1991) with the therapist, which became a helpful tool in her introspection process.

Session 8. Liang came very happy; she had two good pieces of news: Her brain scanner had been normal, which was a good prognosis, and her partner had asked her for marriage. Different topics were treated. Among them a great anger, frustration, and rebellion against life emerged for not allowing her to have children in a natural way. Afterwards she became very tired and, as Christmas was approaching, the therapist gave her permission to rest until January. It was a good gift that she took with a smile of complicity.

Session 9. Liang arrived worried and angry on January 11. She recognized the restorative effect that the rest permission had on her but the previous week she had requested an urgent visit the therapist could not attend due to vacations. This caused a transference conflict. Ancient schemas were activated in the therapist-patient dyad: Liang's need for responsive contact was frustrated; that fired her anger, the feeling of abandonment and her subsequent detachment. The impasse was worked out by accompanying her feelings and sensations. Her emotional confusion between past and present was elaborated. This therapeutic bond repair (Safran & Muran, 2005) enabled her to grow by reconstructing the safe place of therapy from the Adult, not from the Child's idealization of a figure always available.

The urgent demand was precipitated by a conference on Bullying she had been asked to give in her village. This opened the memory of when she was herself a victim of bullying at age 13, when her family moved to live there:

> "*They messed with my body, they sneered at my name, they pushed me ... they even hit me*."

The therapist proposed to focus her anguish. Liang connected with an intense feeling of shame. Experiential processing revealed a transgenerational trauma that contaminated her own trauma: The shame of her mother for her childhood abuse experiences emerged; the shame of the alcoholic father; her own embarrassment

during bullying, the mockery of her surname, which represented the father...

The therapist helped her to decontaminate her own feelings of those of her parents; also decontaminated the 13 years old girl's embarrassment of the present. In a regression state, she performed a Self-parenting work. When her Child calmed down, the therapist invited her to continue differentiating herself from her mother, with whom she still maintained an important symbiosis.

> Therapist: "Now look at mom and tell her you're sorry about what happened to her." Liang cried and cried while having several insights:
> - From her Nurturing Parent, she understood her mother's Child.
> - From her Adult state, she understood she should not be her mother's mother.
> - From her Adult state, she understood she should not act as her mother's therapist.
>
> She then verbalized: "*I panic about passing all my mother's shit on to my kids*".

The therapist differentiated the genetic disease inherited from her mother from the psychological aspects she had received transgenerationally but did not belong to her. Liang, in a state of high perception in this long and intense session, understood and could discriminate it.

To conclude, the therapist gave her a restorative message: "Dedicate next Thursday's conference on Bullying to the 13-year-old Liang as a tribute." Liang smiled. She left moved but happy and calm.

Session 11. She came sensitive, talking about "*my sensitive part".* The therapist proposed to listen to this part, to see what it needed and take care of it.

> "*I can't*!" A hard part emerged: "*Even when I meditate, I'm demanding*!
> The therapist reminded her: "Sure, connecting is threatening ..."
> Liang agreed to focus this sensitive part. She connected with the girl who vomited without making noise and began to feel bad.
> After a while, the therapist invited her: "Let go forward and trough up, I'll hold your head."
> Liang could re-experience while being accompanied. She felt great relief.
> After this experience, the image of a crying baby emerged in her mind. She took her lovingly in her arms, and the girl calmed down and fell asleep.
> Liang smiled and had a powerful insight: "*I am this babe!*"
> She lived a spontaneous experience of Self-parenting. Naturally, her Nurturing Parent was able to care and calm her helpless Girl.

March, April, May sessions. During the following months, Liang had several dreams about death. Taking into account her initial demand, we assumed her subconscious was indicating she was prepared to enter into this fear. Dreams were worked in depth.

The latter was a very significant dream: Liang was a pregnant bride dressed in white. Her mother was also in white and pregnant. In the dream, Liang filled with

strength, faced her and shouted: "*If I want to wear white, I will! And I do want to have this baby!*" Her mother replied: "*Really? Now you'll see*!" And began devouring and swallowing her by her feet.

This would return her to the intrauterine fusion state but is a horror scene. The dream showed how Liang was confused with her mother and the threat of breaking the symbiosis. She made conscious her need to differentiate herself and take responsibility for living her own life. This was an important step of individuation. She appropriated her self and her desire to build her own family. Liang de-identified from the mother-death and made an affirmation of Life, a redecision that entailed a profound change of script.

Session 18. She came happy, expansive, pro-life. She said: "*Suffering is over, the hole is behind*". Within the couple they had made important intimate decisions; among them: "*We still don't want children but we are clear that we'll do IVF and preimplantational. It's a matter of responsibility."*

> That day she wanted to do something playful and the therapist proposed her to write a Tale of Animals: "*Once upon a time a little bear ..."* The teddy bear grew and felt the weight of responsibilities, but as a counterpart he created a family and a home that gave him love and warmth. The tale ended: "*The bear was happy, but in his heart there was a hint, a bittersweet sensation of knowing this is ephemeral and one day will end*."
>
> After elaborating the story, the therapist asked: "Can you reconcile yourself with this ending about life-death duality?" Liang, grateful, smiled: "*Yes. After all, this is my search engine: To reconcile myself with the fact that death is implicit in life*."
>
> It was an integrative end. Therapist and client agreed to close the therapy process.

FINAL COMMENTS

Liang needed some sessions to face the process when she was summoned to start the genetic diagnosis. Later, she changed her life plans and returned to live in her place of origin. Genetic results validated the diagnostic hypothesis: the 774C>A (Y258X) family mutation was detected at the Endoglin gene confirming an HHT1. After being thoroughly informed of both advantages and disadvantages of preimplantation diagnosis and embryonic selection, the couple changed their decision regarding maternity. They understood that in one way or another they had to take risks, and decided to abandon control and rely. They risked being parents by natural means and now they have a son of two years. He is the final result of a deep redecision:

"*I want to live with health and trust in life*".

Villegas says that the process of therapeutic change is like a passage from

psychological constriction to personal liberation (Villegas, 2001). Liang's case is a clear example of this beautiful process, which was achieved thanks to the integration of two intimately related disciplines: Human genetics and psychotherapy.

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