













PSYCHOLOGICAL IMPACT IN YOUNG WOMEN OF ANNOUNCEMENT OF A UTERO-VAGINAL MALFORMATION (Mayer-Rokitansky-Küster-Hauser – MRKH syndrome) AND ITS TREATMENT

Karinne Guenicheabc, Chloé Oualloucheab, Nicole Natafa, Maud Bidetab, Alaa Cheikhelardad, Magali Viaudab, Caroline Eliee, BJ. Paniel^{af}, C. Louis-Sylvestre^{ag}, K. Morcelⁱ, MRKH study group, P. Touraine^{ah}, Yves Aigrain^{ad}, Michel Polak^{abjk}

^aCentre de Référence des Pathologies Gynécologiques Rares et ^bDépartement d'endocrinologie gynécologie et diabétologie pédiatriques, Hôpital universitaire Necker-Enfants Malades, ^cLaboratoire de Psychologie Clinique Psychopathologie et Psychanalyse, Université Paris-Descartes-Sorbonne, d'Département de chirurgie pédiatrique viscérale et urologique, Hôpital Necker-Enfants Malades, Département de biostatistique, Hôpital Necker-Enfants Malades, APHP, Paris, France, Département de chirurgie gynécologique, Centre Hospitalier Intercommunal de Créteil, gDépartement de gynécologie, Institut Mutualiste Montsouris, Paris, hDépartement E3M, endocrinologie, gynécologie et médecine de la reproduction, Hôpital universitaire Pitié-Salpêtrière,

APHP, Paris, Département de gynécologie, CHU de Rennes, IMAGINE Affiliate, Faculté de Médecine, Paris-Descartes

Background: Few studies have addressed the question of the psychic impact and long term outcomes, including well-being, emotions and feelings, in MRKH patients.

Objective and hypotheses: Our multi-centric study aimed to assess patient experience in the syndrome announcement, medical treatment perception, impact on psychic functioning, social-professional integration, affective and sexual life and quality of life in a cohort of MRKH patients.

Subjects and Method: First 40 MRKH patients aged 19 to 34 recruited from 137 included and who accepted this protocol with a semi-directive interview and two projective tests (Rorschach and TAT). Diagnosis is made at 15.2 (9-18). Medico-surgical management takes place at 17.6 (14-24). 75% had surgery and 25% just vaginal dilatations. 20% underwent one psychological interview or psychotherapy between diagnosis and treatment.

Main results: 30% stated diagnosis had an impact of school life; 100% displayed depressed mood and disruption of social and family life; 50% had feelings of shame with taboo sometimes, and "fear of being discovered" and unaccepted during an intimate encounter with a man; 100% were heterosexual but with complaints (desire, pleasure and pain) despite a normal gynecological examination; 77.5% were in couple, 15% were single and 7.5% had never had love relationships; 87.5% revealed desire for children, with 1 adoption and 4 currently adoption processes.

<u>Interviews underline differents issues in the narratives</u>

- -Long wandering before diagnosis
- > Denial and repression (in girls, parents and doctors) generating blur and ignorance in 52.5%
- Trauma to the announcement
- At the announcement, MRKH is considered as a disease
- > Focus on the absence of uterus until the treatment decision
- Feelings of being different
- Frequency of transient and reversible eating disorders in post-announcement (12.5%/0.5% in general population)
- \succ 5 patients of whom: 2 with anorectic and 4 with bulimia disorders (1 with both)
- Procedure in the secondary of the second
- Frequence of the parent's influence, specially mothers, for all the medical decision.

Conclusion

- Avoid the risk of progression to surgical act and wait for the young woman's treatment demand fueled by her desire for a romantic and sexual life
- Eating disorders in patients as: a psychic reaction to the traumatic announcement; then, as a psychic reorganization post-trauma

We suggest:

- A psychological treatment just after the announcement (psychopathological disorders)
- To avoid rapid surgical correction and favor dilatations
- To wait for the young woman's demand for treatment fueled by her desire for a romantic and sexual life

DOI: 10.3252/pso.eu.55ESPE.2016

MRKH as a way of increasing our psychopathological knowings on the psychic construction of body interiority in women.

> The French Study Group **PHYSICIANS:**

M. BIDET, A. CHEIKHELARD, M. POLAK, Y. AIGRAIN (Necker, Paris), P. TOURAINE (Pitié-Salpêtrière, Paris), C. LOUIS-SYLVESTRE (IMM, Paris), B. PANIEL (Créteil, Paris), K. MORCEL (Rennes), A. RANKE (Nancy), E. DARAI, R. ROUZIER (Tenon, Paris), P. LEGUEVAQUE,

C. PIENKOWSKI (Toulouse), P. LOPES (Nantes), P. DESCAMPS (Angers), JL. BRUN (Bordeaux), C. LOUIS BORRIONE (Marseille)

CLINICAL RESEARCH ASSISTANT: M. VIAUD, V. JOLAINE, C. TURUBAN

PSYCHOLOGISTS: C. OUALLOUCHE, K.GUENICHE, N. NATAF

BIOSTATISTICIANS: A. BAPTISTE, C. ELIE **National Hospital Protocol of clinical research**

Projet AP-HP: AOM11168 - P110124 Num ID RCB: 2011-A01517-34 Clinical Trials Gov Identifier: NCT01911884











