Poster n° 283

GLOBAL AND SEXUAL QUALITY OF LIFE IN 130 PATIENTS WITH MRKH SYNDROME : A COMPARATIVE STUDY BETWEEN SURGICAL VERSUS NON SURGICAL MANAGEMENT OF VAGINAL AGENESIS

Maud Bidet[ab], Alaa Cheikhelard[ac], Magali Viaud[ab], Caroline Elie[c], BJ. Paniel[ad], C. Louis-Sylvestre[ae], K. Morcel[f], MRKH study group, P. Touraine[ag], Yves Aigrain[ac], Michel Polak[abh].

[a]Centre de Référence des Pathologies Gynécologiques Rares et [b] Département d'endocrinologie gynécologie et diabétologie pédiatriques, Hôpital universitaire Necker-Enfants Malades, [d]Département de chirurgie pédiatrique viscérale et urologique, Hopital Necker-Enfants Malades, APHP, Paris, France, [e]Département de biostatistique, Hôpital Necker-Enfants Malades, APHP, Paris, France, [d]Département de chirurgie gynécologique, Centre Hospitalier Intercommunal de Créteil, [e]Département de gynécologie, Institut Mutualiste Montsouris, Paris, [f]Département de gynécologie, CHU de Rennes [g]Département E3M, endocrinologie, gynécologie et médecine de la reproduction, Hôpital universitaire Pitié-Salpêtrière, APHP, Paris,, [h]IMAGINE Affiliate.

Background

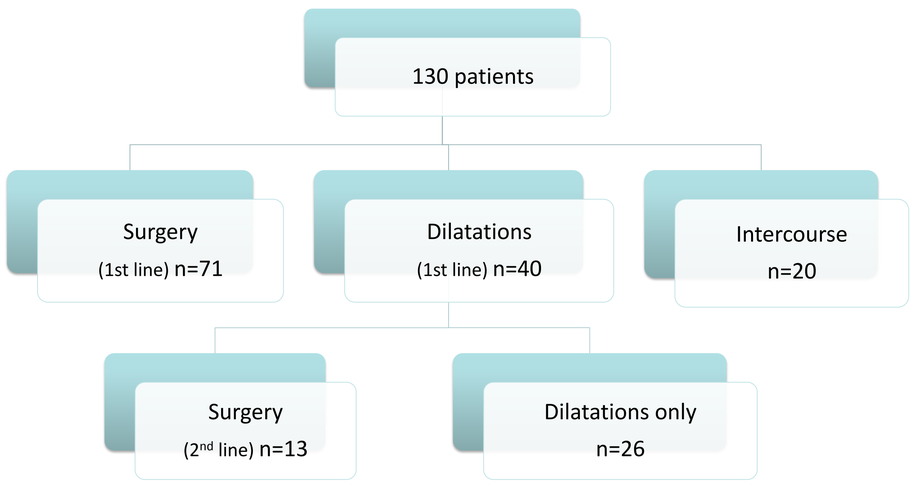
- MRKH syndrome is a rare disease affecting 1/4500 females.
- The patients have 46 XX caryotype, nomal ovarian function and uterine and vaginal agenesis (VA)
- VA management aims to help sexual life ans can be non surgical (dilatations) or surgical (various types of vaginoplasties)

Objectives

Our aim was to compare dialations versus surgery in terms of global and sexual quality of life and anatomical results in a multicentric population of MRKH syndrome.

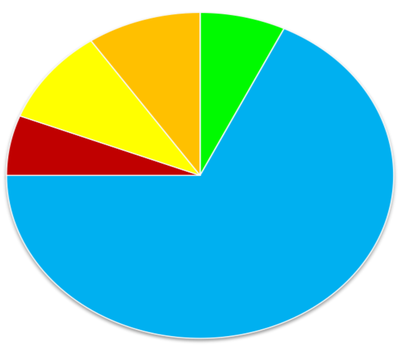
Subjects and Methods

We realized a multicentric observationnel study included 130 patients older than 18, at least one year after completing vaginal agenesis management They aged 26.5 years (18-41). All had medical evaluation including normalized pelvic exam, and filled WHOQOL-BREF (General Quality of Life), FSFI and FSDS-R (Sexual QOL) scales.



Results

84 patients had surgery



Sigmoïdovaginoplasty	n = 57	67 %
Peritoneum	n = 8	9,5 %
Epithelialization	n = 8	9,5 %
Vecchietti	n = 6	7 %
Labia	n = 5	6 %

- **34 patients (40.5%) had complications**, needing 20 additional procedures in 17 patients. Stenosis (23%, n=8), hemorrhage (21%, n=7), myofacial and vestibular pain (17.6%, n=6), pulomnary embolism (5.8%, n=2), bowel adhesions (2.9%, n=1), others (11%, n=4)
- **17 patients (20%)had an abnormal pelvic exam** (introit stenosis, vaginal narrowing, myofacial pain syndrome)
- **49 patients had dyspareunia**, significantly more often after sigmoidovaginaplasty (70%, p=0.014) compared other techniques.

Anatomical results

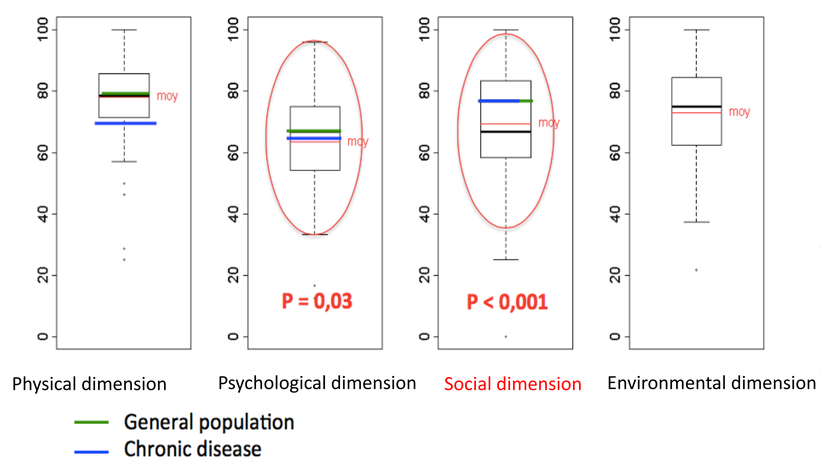
Vaginal size: 10,17 cm (Sd = 1,77)
less than 6,5 cm n = 4
less than 9 cm n = 30 (23,8 %)

Surgery	**11**	+/- 1,7
Dilatations	**9,25**	+/- 1,9
Intercourse	**11**	+/- 1,6
	p=0,037	

Vecchietti	**11,25**	(Sd = 1,72)
Sigmoïd	**11**	(Sd = 1,72)
Labia	**12**	(Sd = 1)
Peritoneum	**8,5**	(Sd = 1,31)
Epithelization	**9,2**	(Sd = 1,37)
	p=0,002	

Vaginal length was significantly lower after dilatations and after peritoneum/epithelium techniques in the surgical group, but remained within normal range (9.6 cm (6.2-12.5), Llyod, BJOG 2005)

Global quality of life (WHOQOL)



Global QOL in MRKH patients was lower than in the general population, especially for social scores (include sexual life) in the younger patients.

Sexual Activity:

- Age at fisrt intercourse: 18 years ±2.6 ans
- Time between diagnosis and first intercourse: 2.2 years ±3.7 (NS)
- Time between managment and first intercourse: 6 months (NS)

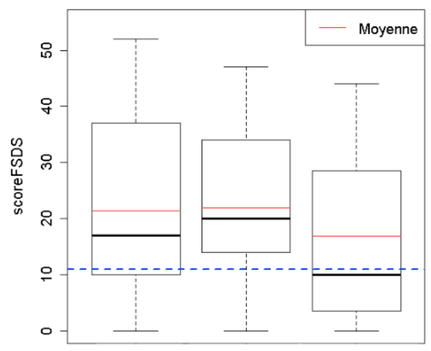
Sexual quality of life (FSFI):

	FSFI	Desire	Excitation	Lubrication	Orgasm	Satisfaction	Pain
All	26	4,2	4,5	4,8	4,4	5,2	3,6
Surgery	25,95	4,2	4,5	4,8	4,2	4,8	3,2
Dilatation	24,7	4,5	4,35	4,65	3,6	4,8	3,6
Intercourse	30,2	4,5	4,5	4,65	4,8	6	5,4
p	*0,04*	*0,17*	*0,57*	*0,56*	*0,32*	*0,03*	*0,22*

- Global FSFI scores in MRKH patients were similar to the general poulation
- There were no significant differences in the sexual QOL between dilatation and surgery group, and between the different surgical techniques. The intercourse group had a signifcantly higher sexual QOL, because a higher score in the satisfaction dimension.
- There were no differences in FSFI scores depending on vaginal lengh, except in the 4 patients who had vaginal length shorter than 6.5 cm.

Sexual Distress (FSDS_R) :

FSDS-R scores > 11 espress sexual distress



	FSDS-R	FSDS-R > 11
All	18 (0-52)	70 %
Surgery	17 (0-52)	72 %
Dilatation	20 (0-47)	77 %
Intercourse	10 (10-44)	50 %
p	*0,37*	*0,1*

Sexual distress was very high in all MRKH patients, unrespective of the type of management.

Conclusions

Surgery is not superior to autodilatations, bears more complications and should therefore be only a second-line treatment. Sexual distress is high in the majority of patients. Psychological counseling is mandatory at diagnosis and during therapeutical management.

The French MRKH-Study Group

PHYSICIANS:
M. BIDET, A. CHEIKHELARD, M. POLAK, Y AIGRAIN (Necker, 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
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

55ESPE 339--P1
Gonads & DSD
magali VIAUD
DOI: 10.3252/pso.eu.55ESPE.2016
Poster presented at: ESPE 2016 PARIS