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La systématisation de l'approche de l'optimal gender'

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Les fondements d'une fuite vers l'avant

Nœuds du débat actuel, et leurs paradoxes:

1) Prof. M. requièrent données probantes des défenseurs des droits humains comme condition à l'arrêt des pratiques, mais cette démonstration est impossible. (citation p. 3)



2) Prof. M. insistent sur une amélioration des pratiques, mais admettent ne pouvoir en faire la démonstration. (citation p. 4)



1) En l'absence de données long terme: Interventions > non-interventions

2) Exigence de démonstration: Prof. M. < Déf. DH

Primauté du statu quo
= continuité des pratiques



- Sur quelles évidences se sont fondées les interventions non consenties?

Peter A Lee*, Amy B Wisniewski, Laurence Baskin, Maria G Vogiatzi, Eric Vilain, Stephen M Rosenthal, Christopher Houk and on behalf of the Drugs and Therapeutics Committee of the Pediatric Endocrine Society. (2014). «Advances in diagnosis and care of persons with DSD over the last decade». *International Journal of Pediatric Endocrinology*, 1, 19, p. 4.

Since long-term outcome data are limited, some of the recommendations for deferral of surgery until the individual can give full consent can be viewed as lacking medical evidence and may therefore constitute a type of medical experimentation.

Mouriquand, Pierre, A. Caldamone, P. Malone, J.D. Frank et P. Hoebeke. (2014). «Editorial: The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)». *Journal of Pediatric Urology*, n. 10, p. 8-10

«It is critical to understand that the outcomes which one evaluates today result from surgery performed 20 or more years ago with techniques which are now considered obsolete. It does not guarantee superior results from modern techniques but one will have to wait another 15 years to evaluate current procedures.»

Références étudiées

[KI] John Money et Joan Hampson. 1955 [21 janvier 1954]. «Psychological aspects of the sexual orientation of the child with particular reference to the problem of intersexuality». *Interuniversity Roundtable by the medical faculties of the University of Pennsylvania and Johns Hopkins. Journal of Pediatrics*

[KI] Hampson, Joan. 1955 [3-4 novembre 1954]. «Hermaphroditic Genital Appearance, Rearing and Eroticism in Hyperadrenocorticism. *Symposium Adrenal Function in Infants and Children*

[KI] Money, John. 1955 [3-4 novembre 1954]. «Hermaphroditism, gender and precocity in CAH : Psychological findings». *Symposium Adrenal Function in Infants and Children*

[KI] Roundtable discussion. 1955 [3-4 novembre 1954]. *Symposium Adrenal Function in Infants and Children*

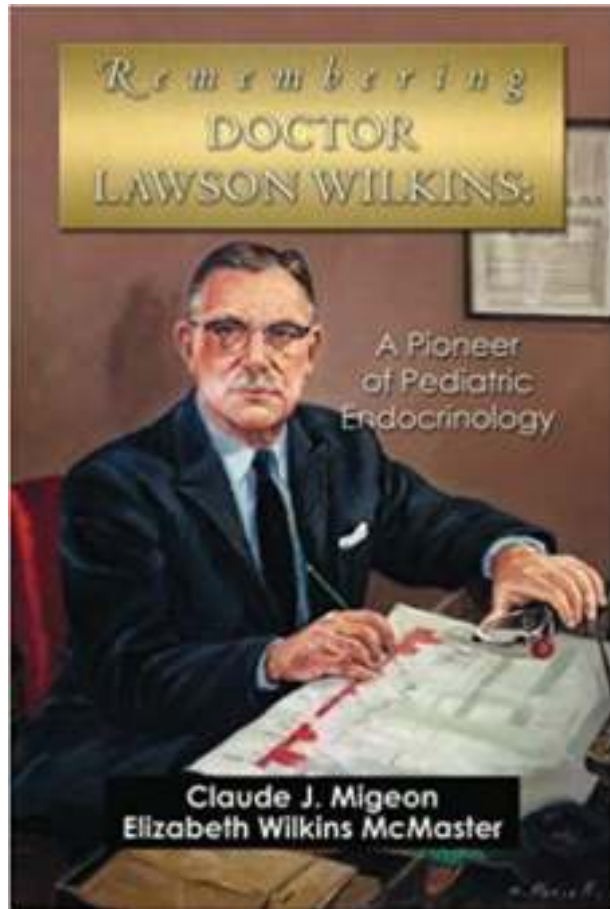
Hampson, Joan. 1955. « Hermaphroditic genital appearance, rearing and eroticism in CAH». *Bulletin of the Johns Hopkins Hospital*

Hampson, John, Hampson, Joan, Money, John. 1955 [5 avril 1955]. «The syndrome of gonadal agenesis (ovarian agenesis) and male chromosomal patterns in girls and women : psychological studies». *Bulletin of the Johns Hopkins Hospital*

[KI]= référence relevée par Ulrike Klöppel. (2010). XXXOXY Ungelöst: Hermaphroditismus, Sex und Gender in der deutschen Medizin. Eine historische Studie zur Intersexualität. Bielefeld: Transcript Verlag.

Money, John, Hampson, Joan, Hampson, John. 1955. Hermaphroditism : Recommendations concerning assignment of sex, change of sex, and psychologic management. Bulletin of the Johns Hopkins Hospital

Wilkins, Lawson, Grumbach, Melvin, Van Dijk, Judson, Shepard, Thomas, Papadatos, Constantine. 1955. Hermaphroditism : Classification, diagnosis, selection of sex and treatment. *Pediatrics*



L'évidence qui satisfait l'équipe

Lawson Wilkins. (1950). *The Diagnosis and Treatment of Endocrine Disorders in Childhood and Adolescence*, p. 224.

*Since the hypertrophied clitoris later becomes a source of extreme embarrassment and erotic stimulation, its removal is probably advisable. There should be a complete extirpation of both corpora cavernosa and not merely an amputation which will leave a hard stump. **Although some workers object to this procedure on the grounds that it may deprive the patient of future sexual gratification, the writer believes that it is justified because it removes some of the tensions and problems which cause serious difficulties.***

Interuniversity Roundtable (21 janvier 1954)

Personnes étudiées par l'Unité de recherche psychohormonale (N=44)

- 1) Les changements de l'identité de sexe sont source de troubles (N=10; 4=«précoces», 6=«tardifs»)
 - Hamson: «(...) *though we are **not committed to any absolutely definitive point of view**, we feel reasonably sure that if anyone wanted to make a study of experimentally produced neurosis, **it would be a surefire thing** to take a child of more than 2, 3, or 4 years on up and subject them to a change of sex*». (p. 786-787, mon emphase)
 - Money: «**All available evidence** concerning change of sex in hermaphrodites strongly contraindicated change after the age of learning to talk. (...) **The exceptions** are notable when the change is voluntarily requested and the patient is beyond middle teenage» (p. 782, mon emphase)

Interuniversity Roundtable (21 janvier 1954)

«Now a word or two in conclusion about the general psychologic adjustment and psychologic stability of the individuals we have seen. We found that 75 per cent of them have been, to all intents and purposes, well adjusted, and this includes all the cases where change of sex has been imposed, too.» (p. 781)

Symposium Adrenal Function in Infants and Children (3-4 novembre 1955)

2) Les effets de la clitoridectomie ne sont pas nocifs (N=6)

Yet, many surgeons have hesitated to deprive a patient of what some authorities have declared the most significant erotic zone in the female (Hampson, 1955, p. 125)

Partial amputation of an enlarged phallus in a girl is an operation approached with hesitation by many surgeons, in the fear that serious loss of erotic sensitivity may ensue (Hampson, Money, Hampson, 1956, p. 551)

Table II : Reported orgasm in 6 women before and after clitoral surgery (Hampson, 1955)

Age at time of clitoridectomy	20	4	8	15	34	46
Age at time of study	30	22	14	26	35	49
Report of orgasm						
Before surgery	-	-	-	-	-	+
After surgery	-	+	+	+	+	+



L'évidence qui satisfait les pairs

Recommandations (Bulletin of Johns Hopkins, 1955; Pediatrics, 1955; Journal of Clinical Endocrinology and Metabolism, 1956)

1. Les changements de l'identité de sexe sont source de troubles (N=11; 5=«précoces», 6=«tardifs»)
2. Les effets de la clitoridectomie ne sont pas nocifs (N=12/6)
«Subsequent surgical feminization and hormonal regulation can be thoroughly successful, thereby preserving areas of erotic sensation, fortifying the feminine rôle and safeguarding the opportunity for eventual child bearing» (p. 288, mon emphase)
3. Détresse devant l'absence d'interventions non exposé:
Table I shows in very brief summary the findings concerning those individuals who, for «one reason or another, did not receive surgical correction of their genital deformity in infancy and who lived with a contradictory genital appearance fort at least five and as many as 47 years (...). All this illustrates, if nothing else, the surprising adaptability of the human organism. In all but one instance, the person had succeeded in coming to terms with his, or her anomaly (...) (p. 120, mon emphase)

Recommandations (Bulletin of Johns Hopkins, 1955; Pediatrics, 1955; Journal of Clinical Endocrinology and Metabolism, 1956)

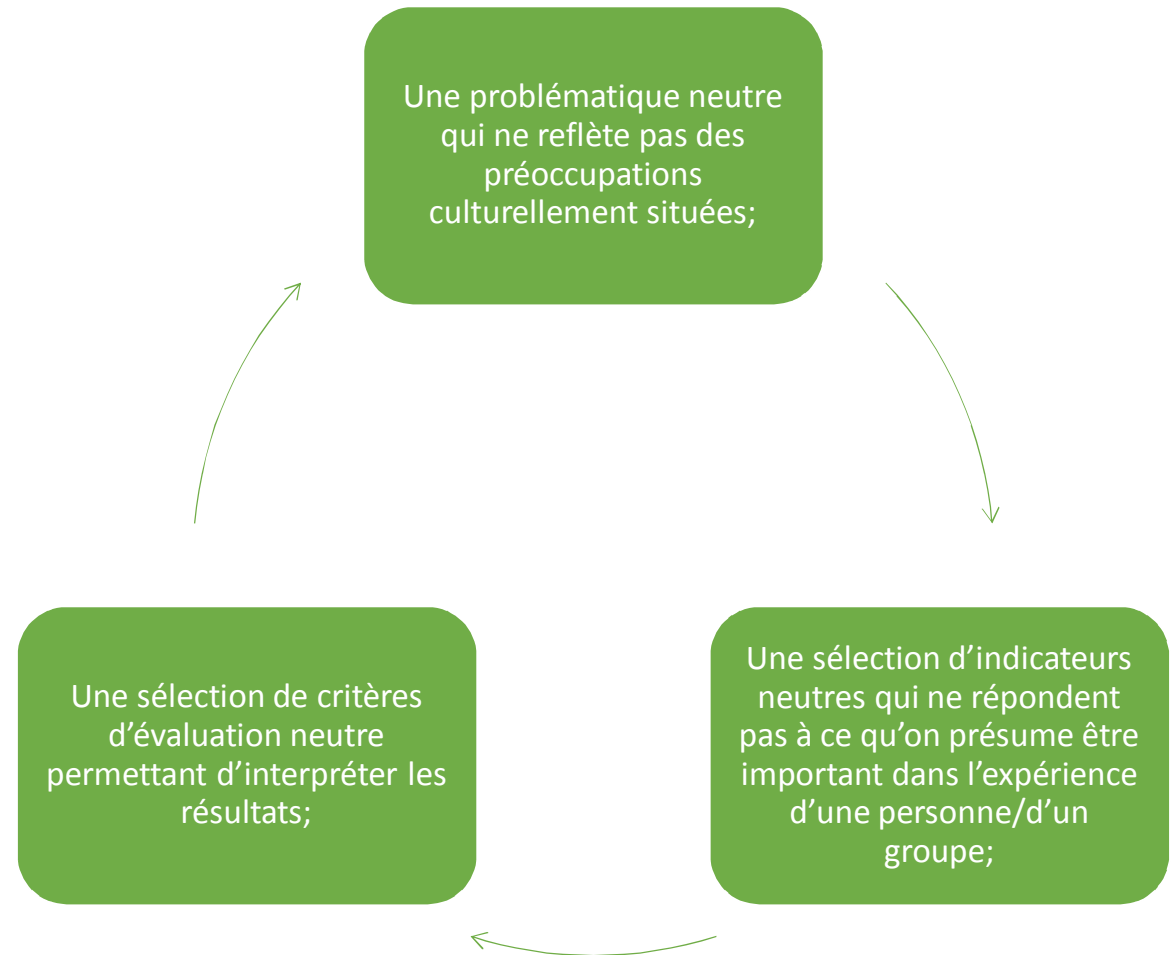
4) Un déni imprégné dans l'instauration du protocole (Money, Hampson et Hampson, 1955)

- *A three year old girl about to be clitoridectomized, for example, should be well informed that the doctors will make her look like all other girls and women. Girls should know, incidentally, that whereas boys have a penis, girls have a vagina – in juvenile vocabulary, a baby tunnel – **as a double insurance against childish theories of surgical mutilation and maiming**. It is also useful to inform children, as a matter of course, of preoperative and anesthetic routine and of what to expect postoperatively, for **these apparently trivial details are the source of their most intense anticipatory terrors and misconceptions** (p. 295, mon emphase)*
- *'Got to call my Mommy'. There was a look of stark terror about him, and a note of frantic urgency in his voice. He did not object to a genital examination, but kept perseverating, uneasily : 'The nurse cut my wee-wee. (...) The nurse hurt me. Cut on my wee-wee. (...) 'Got to call my Mummy. Take me in the choo-choo train. Home'. By implication, he wanted to get out of the hospital before there was any more cutting on his wee-wee. (...) **he had grossly misconstrued his surgical experiences to signify that his penis was being mutilated** (...) (p. 297, 298, mon emphase)*

L'insuffisance d'une approche basée sur les évidences

Ce que l'évidence ne peut pas offrir

(Pour exemple, voir citation p. 15)



*The articles that proposed to measure sexual satisfaction, when referring to it, were predominantly limited to asking how dilated the vagina was; whether there was the presence of orgasms, lubrication, and pain when ejaculating; capacity to penetrate or to be penetrated; having stable relationships; or the evaluation, by an external observer, of the aesthetic of the genital; and, in fewer cases, how he or she feels concerning the surgery. (...) In most cases, success was defined by the opinion of the team, even when it contradicted the presented data. For example, one emblematic article with “positive results” evaluated, in a prospective follow-up consultation, the surgical results and the sexual satisfaction of 47 patients in an average of 12 years after an intestinal vaginoplasty took place. **According to the authors, the result was positive because besides the excellent surgical outcome, 38.3 percent of the sample was sexually active and 8.5 percent was married. Nevertheless, 17 out of 47 patients had complications from the surgery, such as necrosis of part of the genital, abdominal abscess, and vaginal prolapse** (Lima et al., 2010) (Machado et al. 2015, p. 4)*

Machado, P. S., A. B. Costa, H. C. Nardi, A. M. V. Fontanari, I. R. Araujo, et D. R. Knauth. 2015. « Follow-up of Psychological Outcomes of Interventions in Patients Diagnosed with Disorders of Sexual Development: A Systematic Review ». *Journal of Health Psychology*, février, 1-12.

Quelques conclusions à tirer

Si l'on reconnaît que les interventions non consenties ont été instaurées et systématisées sans données probantes

- À partir de quand des données probantes auraient été introduites pour justifier ces pratiques (ou une partie d'entre elles)?

Si l'on reconnaît que des valeurs et croyances étaient à l'origine de l'instauration et de la systématisation

- Comment peut-on être certain qu'elles n'ont pas orienté la recherche de données probante et l'interprétation de ses résultats?

Prof. M ne peuvent faire l'économie des valeurs ou des principes dans l'orientation des pratiques

- L'exclusivité de l'expertise médicale est questionnable