

Motor disability, rare diseases and motherhood : a longitudinal study

Sylvie Viaux-Savelon^{1,2*}, Drina Candilis, Marc Dommergues

sylvie.viaux@psl.aphp.fr · drinacandilis@wanadoo.fr · marc.dommergues@aphp.fr

¹ Department of Child and Adolescent Psychiatry, Unité Petite Enfance et Parentalité Vivaldi, APHP, GHU Pitié-Salpêtrière, Paris, France.

² SAPPH, Institut Paris Brune, FHSN, 26, Boulevard Brune, Paris, France.

³ Department of Gynaecology Obstetric, APHP, GHU Pitié Salpêtrière, Paris, France

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Background:

About 10% of women in age of procreating are living with a handicap that hinders their everyday life. These women have the same legitimacy of having a child than any women, but they have to face the negative reactions of their relatives or from healthcare professionals.

The specific data concerning parenthood of women suffering from rare diseases with motor impairment are rare. (1)

These diseases are very diverse, and it is a hard task to list them all. Yet, they share some features: upgradability during life with sometimes a start at childhood, frequency of multiple disabilities (affection of the 4 limbs, respiratory complications...), frequency of genetic causes which arises the problem of transmission to descendants, ignorance of the issues of these diseases by the majority of healthcare professionals, even specialized ones.

The goal of our study was to describe access to parenthood in women suffering from rare motor diseases and to compare them to women with a frequent motor impairment.

Methods: (Clinical Trial ID : NCT02727010)

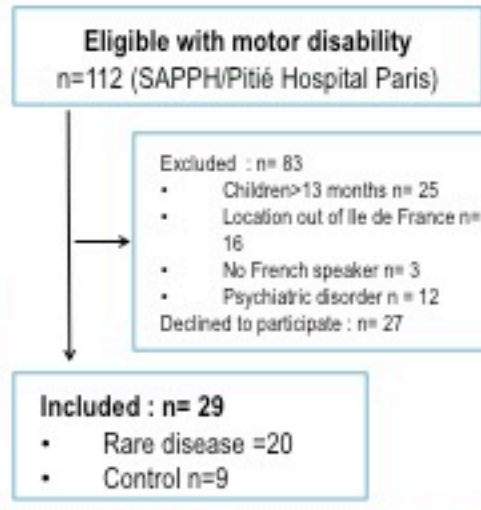
Retrospective study of access to parenthood and Observational longitudinal study of mother suffering of motor rare or not rare disability and their child recruited in 2 clinical centers.

115 pregnant women with motor disability were eligible, 29 were included within 16 with rare motor disability. We followed them during 3 times: inclusion, child's 3 and 12 months.

Tools : Socio demographic and obstetrical data, history of accession to parenthood, precarity level (EPICES), autonomy (Barthel), anxiety status (STAI), depression status (EPDS), social support (Cutrona) were collected. Child developmental level was assessed at 3 and 12 months with the Brunet Lezine test and parent child interaction level by PIRGAS.



Prenatal training in SAPPH unit



Rare motor disability	Prevalence / incidence
Spinal Muscular Atrophy Type 2 (n= 2)	1/71 000
Ataxia of Friedreich	1-3/100 000
Charcot Marie Tooth Disease (CMT)	1/1 000 000
(Metz-Davies Syndrome (n=2)	1-3/100 000
Multiple Sclerosis (n=3)	1-3/10 000
Tetraparesis (tumor at 4 age old)	2-4/100 000
Cerebellum syndrome (+ others disabilities associated)	1/1 000 000
Astrocytoma medullary	1-3/100 000
Polyarthritis	1-3/100 000
Hypophosphatasemia	35 000 in Europe
Heart disease + stroke (hemiplegia + memory disorder)	1/1 million
Legs Right congenital malformation (neurological lesions and epilepsy)	Incidence?
Myopathy (ankleknock arthropathy)	Incidence?
Autosomal Myopathy	Incidence?
Sporadic Paraplegia	1-3/100 000
Neuropathy and Road accident	Incidence?

First results

General results

Somatic complications often affected these mothers during pregnancy, delivery or post partum (breath complications, aggravation of motor disability...).

Our population was characterized by low precariousness level (EPICES m=20), medium anxiety (STAI m=43), medium depression (EPDS m=8) comparable in the both group with relative autonomy (Barthel m=78) self reported in contrast with their high level of motor disability .

Women describe a good level of social support (Cutrona m= 79). The baby development is good and the interaction slightly trouble. One of the dyad has been addressed to social worker. 7 fathers have personal assistance status.



Sociodemographic and motor disability data

	n (%)
Age range (yr)	
25-29	7 (24%)
30-39	18 (62%)
>40	4 (14%)
Family status	
In couple	27 (93%)
Alone	2 (7%)
Working status	
Partial work in normal environment	12 (41%)
No working	5 (17%)
Others (parental vacancies, invalidity)	5 (17%)
Student	7 (23%)
No information	4 (14%)
Study level	
Undergraduate	5 (17%)
Bachelor	4 (14%)
Post graduate	5 (17%)
University degree	15 (52%)
Source of income	
Salary	17 (58%)
Allowance*	18 (62%)
Housing	
Personal housing	27 (93%)
Housed by family	2 (7%)
Adapted housing	10 (34%)

*Allowance can be completed by self salary or partner salary

	n (%)
Type of motor disability	
Tetra paresis	10 (41%)
Para paresis	3 (12.5%)
Mono paresis	2 (8%)
Hemiplegia	2 (8%)
Hemiparesis	1 (4%)
Amputation	3 (12.5%)
Motor disability no systematized	3 (12.5%)
Age at first motor disorder onset	
< 1 year	10 (41%)
1-14 years	8 (32%)
>15 years	6 (25%)
Genetic transmission modalities (n=24)	
None transmission risk	11 (46%)
Autosomal dominant	3 (12.5%)
Autosomal recessive	6 (25%)
Mitochondrial	1 (4%)
Unknown	3 (12.5%)

Access to parenthood and pregnancy

	n (%)
Contraception at first sexual intercourse*	
Yes	23 (79%)
No	6 (21%)
Age in first sexual intercourse (yr)	
<10	1 (3%)
10-17	5 (17%)
18-19	9 (31%)
>20	14 (48%)
Sexuality information during teenage	
Speaking sexuality with mother*	
Easy	10 (34%)
Difficult	10 (34%)
No contact	1 (3%)
Didn't want speak about sexuality with her mother	8 (27%)
Speaking sexuality with educator*	
Easy	7 (24%)
Difficult	11 (37%)
No contact	1 (3%)
Didn't want speak about sexuality with educator	10 (34%)
Pregnancy	
Contraception before pregnancy*	
Yes (contraceptive pills +/- other modality)	27 (93%)
Condom only	1 (3%)
None	1 (3%)
Fecundation**	
Insemination with partner's sperm	1 (3%)
Natural fecundation	20 (69%)
No information	8 (27%)
Pregnancy**	
Planned	22 (75%)
Unplanned	6 (21%)
Pain during pregnancy*	
Frequency	13 (45%)
Multipain	16 (55%)
Hospitalization during pregnancy*	
Yes	16 (55%)
No	3 (10%)
No information	8 (27%)
Somatic history during pregnancy	
Respiratory deterioration	4 (14%)
Motor deterioration without normalization after birth	7 (24%)
Motor deterioration with normalization after birth	3 (10%)

Birth, dyad and child development

	n (%) or mean
Childbirth modalities (n=4)	
Vaginal	14 (88%)
Emergency cesarean	7 (23%)
Planned cesarean	3 (14%)
Gestational age at birth (mean)	38 GW
Maternal prematurity (35, 36GW)	N= 2
Birth Weight (mean)	3689 g
Pediatric history	
Pediatric event	8 (34%)
Hospitalization (12 d, 15 d, 21 d, 45 d)	4 (34%)
Feeding modalities	
Breastfeeding	5 (17%)
Mixed breastfeeding and bottle	8 (27%)
Feeding bottle	7 (24%)
Nasogastric tube	1 (3%)
Brunet Lezine score (Q) (mean)	
Global score	100
Language	100
Sociality	95
Coordination	100
Posture	101
W-ADBB (Alarm Distress Baby) (n=4)	
No disorder	16 (74%)
Withdrawn	5 (21%)
PIRGAS (level of interaction) (n=)	
<70 perturbed	5 (21%)
70 troubled	8 (27%)
>80 good	16 (41%)

Conclusion

Women with motor disability, rare or not, can access to parenthood with good abilities to help their child to develop. They need ergonomic adaptation and intensive and specific health care during perinatal period. Dyadic difficulties are more linked to usual risk factors than level of motor disabilities.

References

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