Impact of pregnancy in women with desmoid fibromatosis: An international retrospective observational study.

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Background: Desmoid fibromatosis (DF) often occurs during pregnancy/peripartum. Guidance for planning new pregnancies during active surveillance or following DF resection has been limited. Thus, we sought to evaluate outcomes and decision making in the peripartum. Methods: Women of child-bearing age with DF diagnosed between 2000 and 2020 were interviewed about procreation decisions, in a multicenter retrospective observational study (NCT05284305). Pregnancies simultaneous or after diagnosis were analyzed. Primary outcome was DF progression/ recurrence within 1 yr postpartum. Secondary outcomes were spontaneous regression, switch to active treatment, and obstetric risks. To estimate probability of progression, a random intercept logistic model was fit to account for correlation of progression in multiple pregnancies in the same patient. **Results:** Of 483 pts interviewed, 120 (24.8%) postponed, 32 (6.6%) interrupted, and/or 232 (48%) avoided pregnancy (in 93.3%, 50%, and 72.9% of cases because of DF), respectively. 147 pregnancies in 131 pts were concurrent with or after diagnosis: 26 (17.7%, Group A) concurrent with diagnosis, 48 (32.7%, B) after DF resection, and 73 (49.7%, C) with DF on surveillance. Estimated probability of progression was 12.0% (CI 2.0 - 48.4) during pregnancy and 15.8% (5.6 - 37.5) postpartum; for pregnancies after diagnosis (Groups B and C), these rates were 5.1% (0.4 - 40.0) and 9.0% (1.8 – 35.0). On multivariate analysis, age at pregnancy and size of primary DF were significant risk factors for progression (Table). Estimated probability of spontaneous regression was 3.6% (CI 0.2-40.7) during pregnancy and 7.1% (CI 0.3-67.2) postpartum. 7/38 (18.4%) spontaneously regressed after pregnancy-related PD, 4/23 (17.4%) in Groups B and C. Treatment for progression was needed in 9/79 (11.4%) postpartum, in 4/63 (6.3%) in Groups B and C. Obstetric complications were comparable to population data in developed countries. Conclusions: After DF diagnosis, pregnancy is safe with a risk of progression of 5% during pregnancy and 9% postpartum. Treatment is needed in only 6%. Spontaneous regression is less common but occurs even after initial progression. Patients decision making about procreation appeared to be influenced by their DF diagnosis. This study supports counseling that fertility options should be fully explored with expert guidance as intervention rates are low. Research Sponsor: None.

	OR	Lower 0.95	Upper 0.95	p-value
Age at pregnancy 38 vs 31	18.66	2.99	116.51	0.0017
Size 7 vs 3 cm	3.10	1.34	7.19	0.0084
Nr. of previous pregnancies 2 vs 0	1.56	0.28	8.67	0.6098
Pregnancy type				0.1853
A vs C	5.40	0.83	35.11	
B vs C	0.00	0.00	>10000	
Site				0.4915
Extremity vs Abdominal wall	0.92	0.11	7.69	
Intrabdominal vs Abdominal wall	11.07	0.11	1070.71	
Other vs Abdominal wall	0.27	0.02	3,44	
Hormonal stimulation before pregnancy Yes vs No	6.06	0.62	59.02	0.1209