

Fathers' and mothers' perceptions and communication on carrier status and diagnosis of congenital haemophilia: global results from the Haemophilia Experiences, Results and Opportunities (HERO) Study

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Introduction

- The Haemophilia Experiences, Results and Opportunities (HERO) initiative aimed to increase the understanding of psychosocial issues impacting people with haemophilia by collaborating with an International Advisory Board that included healthcare providers, patients, and caregivers.
- As part of the HERO study, parents of children with haemophilia answered questions regarding the communication of carrier status, the impact of a haemophilia diagnosis, and the use of genetic counselling.

Objectives

- To describe the perceptions and communication of carrier status between mothers and fathers of children with haemophilia, describe the reported impact of a haemophilia diagnosis, and describe the use of genetic counselling.

Methods

- Parents of children <18 years of age with haemophilia (only 1 parent per child) completed an online survey.

Results

Parent characteristics

- Overall, 561 parents responded.
 - The majority (76%) were mothers.
- The median (range) age of all parents was 39 (23-68) years (Table).

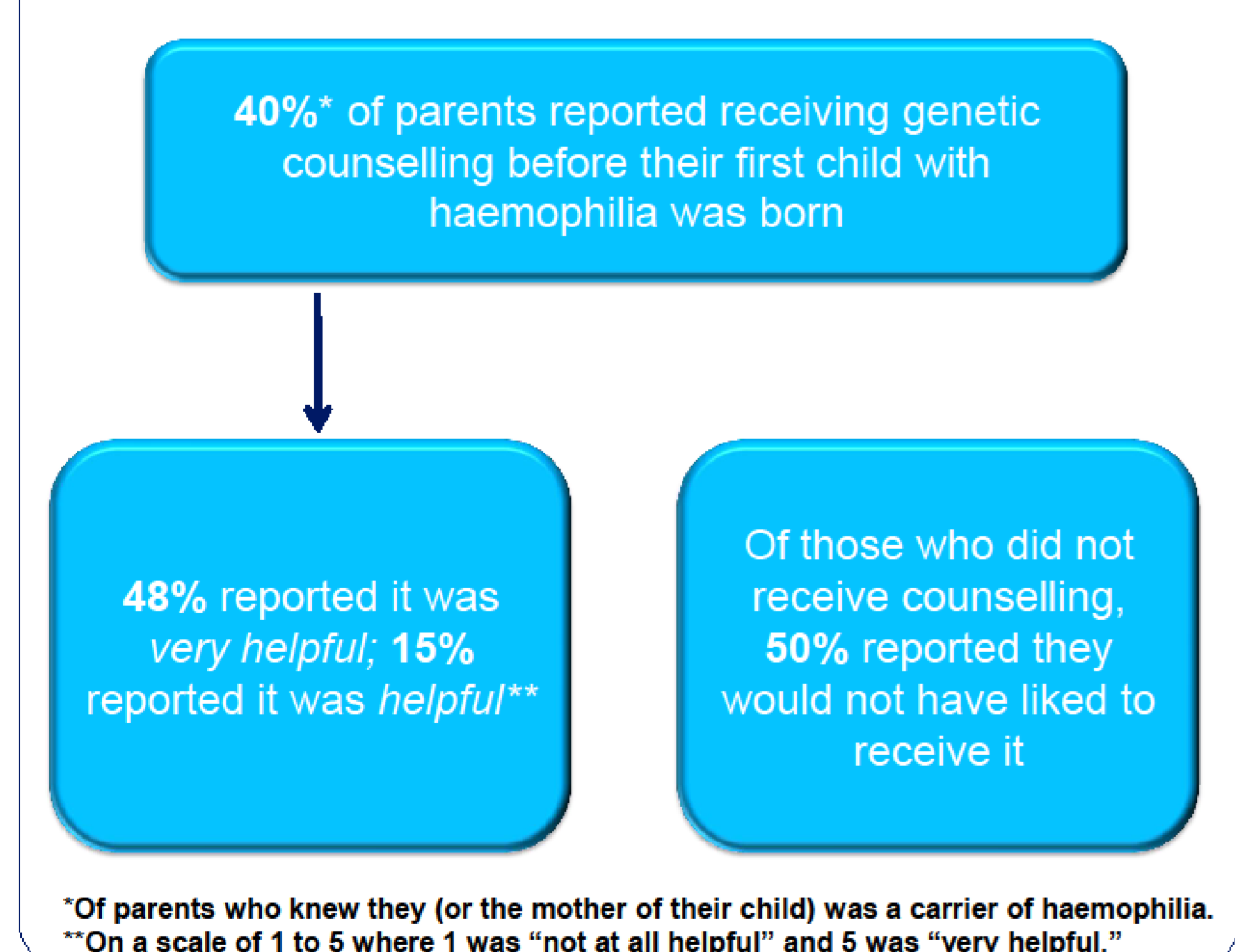
Table Parent characteristics

	Fathers n=137	Mothers n=424
Median (range) age	40 (23-66)	38 (23-68)
Formal education, n (%)	123 (90)	378 (89)
Employed, n (%)	121 (90)	271 (67)
Marital status, n (%)		
Married/In a long-term relationship	126 (92)	346 (82)
Divorced/Separated	9 (7)	52 (12)
Single	0 (0)	17 (4)
Number of affected children, n (%)		
One	118 (86)	357 (84)
Two	13 (9)	61 (14)
Three	5 (4)	6 (1)
Four	1 (0)	0 (0)

Genetic counselling

- Only 154 (27%) of 561 parents responded about genetic counselling.
 - 62 (40%) reported receiving counselling before their first son's birth (Figure 1).

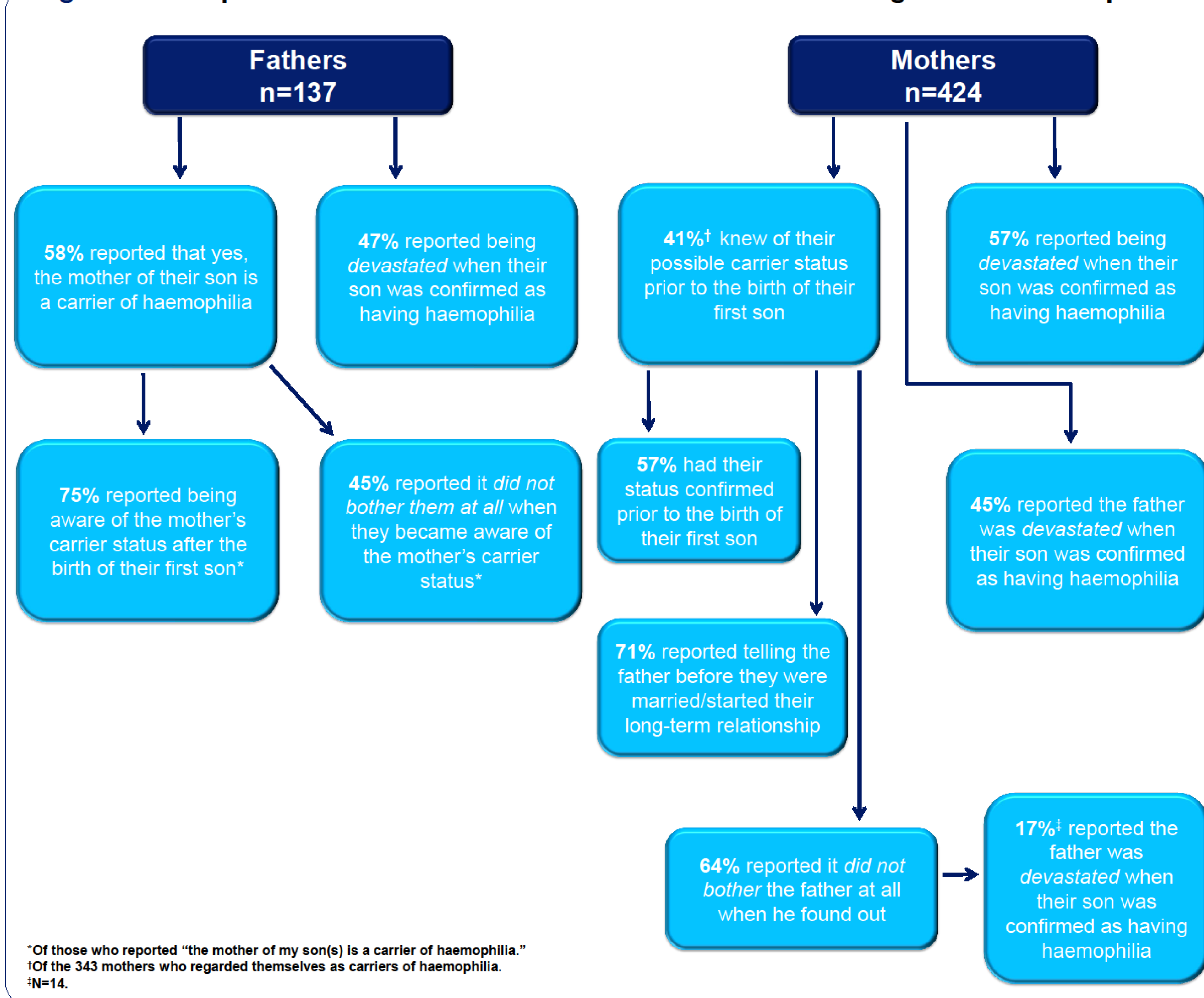
Figure 1 Genetic counselling of parents of children with haemophilia



Carrier status

- Overall, 81% of mothers regarded themselves as carriers of haemophilia.
 - This self-identification was more common in mothers with a formal education (82% vs 70% without; $P<0.05$) or when mothers had more than 1 child with haemophilia (99% vs 78% with 1 son; $P<0.05$).
- Of those who considered themselves carriers, 139 (41%) knew of their possible carrier status (57% had confirmation) before the birth of their first child (Figure 2).
- Overall, 58% of fathers considered the mother of their son to be a carrier of haemophilia.

Figure 2 Perceptions and communication on carrier status and diagnosis of haemophilia



Future perspectives

- Overall, 19% of parents reported they wanted to have additional children in the future.
 - This was similar between fathers (18%) and mothers (20%).
 - This was significantly higher in parents who had 1 son with haemophilia than in parents with more than 1 son with haemophilia (21% vs 8%; $P<0.05$).
- Regarding having future children, 43% of parents reported receiving genetic counselling.
 - 50% reported this counselling as "very helpful."
 - Only 18% of those who had not received counselling responded that they would like to receive genetic counselling regarding having future children.
 - This was significantly higher among fathers than mothers (31% vs 15%; $P<0.05$).

Conclusions

- In HERO, a difference was observed in disclosure of the mother's haemophilia carrier status between the fathers and mothers; most fathers reported finding out about the mother's carrier status after their son's birth whereas most mothers reported telling the father before marriage/starting their long-term relationship.
 - However, because the mothers and fathers in HERO are not parents of the same child and the number of parents who regard themselves or the mother of their child as a carrier are limited, a direct comparison cannot be made.
- Few parents knew of their carrier status and therefore few responded about genetic counselling. This may suggest a need for more discussion on promoting genetic counselling for possible carriers and/or for parents of children with haemophilia.

