

Supplementary materials

Table S1. I have been satisfied with my quality of life in the last year/ the patient I take care of has been satisfied with their quality of life in the last year?

PwH (%)	CPwH (%)	Total (%)
48	42	46

Table S2. Have you heard about new treatment options in the last 6 months?

Answer	PwH (%)	CPwH (%)	Total (%)
Yes	55	63	58
No	45	37	42

Table S3. How much does the bleeding disorder affect your mobility / the patient you take care of in her/his mobility?

Answer	PwH (%)	CPwH (%)	Total (%)
Not at all	17	24	20
Slightly	26	30	27
Moderately	30	23	27
Very	18	17	18
Very much	9	6	8

Table S4. How much does the bleeding disorder affect your family life / the patient you take care of in her/his family life?

Answer	PwH (%)	CPwH (%)	Total (%)
Not at all	37	36	36
Slightly	30	30	30
Moderately	20	23	21
Very	9	10	9
Very much	5	2	4

Table S5. How much does the bleeding disorder affect your life with current partner or ability to find a partner / the patient you take care of in her/his life with current partner or ability to find a partner?

Answer	PwH (%)	CPwH (%)	Total (%)
Not at all	55	55	55
Slightly	19	20	19
Moderately	14	18	15
Very	5	6	5
Very much	7	2	5

Table S6. How much does the bleeding disorder affect your education/work life / the patient you take care of in her/his education/work life?

Answer	PwH (%)	CPwH (%)	Total (%)
Not at all	40	41	40

Slightly	22	22	22
Moderately	22	21	22
Very	9	11	10
Very much	6	5	6

Table S7. How much does the bleeding disorder affect your hobbies / the patient you take care of in her/his hobbies?

Answer	PwH (%)	CPwH (%)	Total (%)
Not at all	25	17	22
Slightly	22	28	24
Moderately	32	27	30
Very	13	19	15
Very much	9	10	9

Table S8. How much does the bleeding disorder affect your daily routines / the patient you take care of in her/his daily routines?

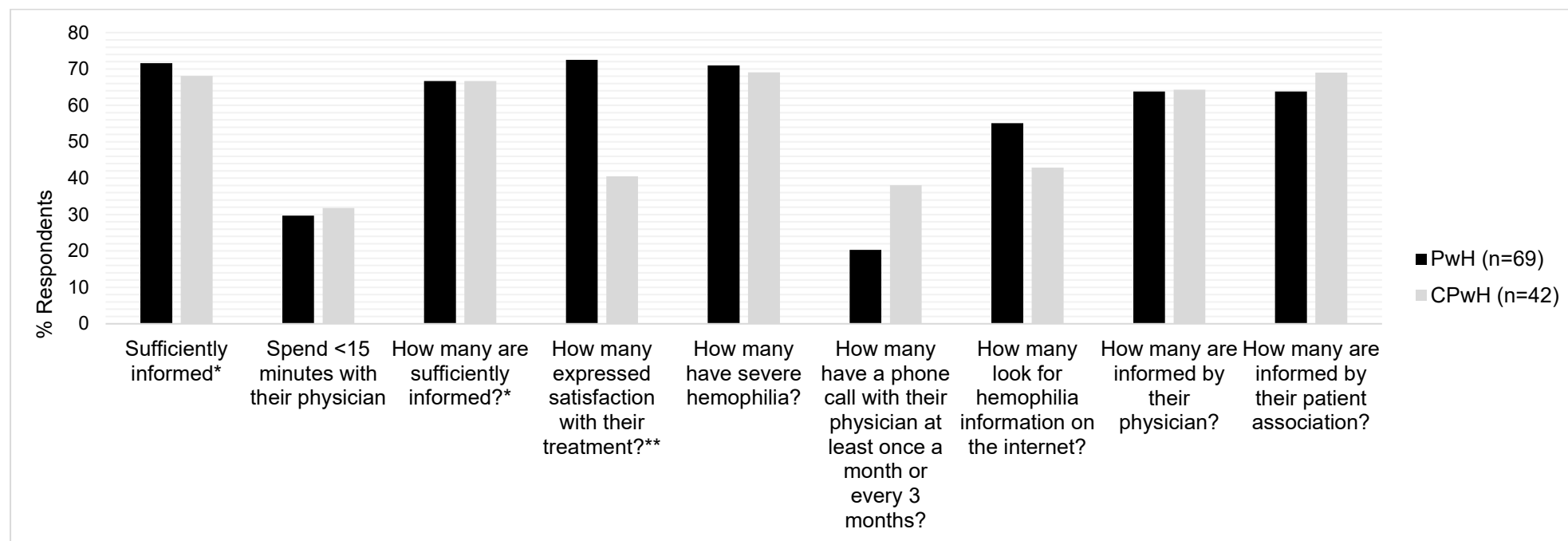
Answer	PwH (%)	CPwH (%)	Total (%)
Not at all	29	23	27
Slightly	30	38	33
Moderately	26	27	26
Very	9	10	10
Very much	6	3	5

Table S9. How much does the bleeding disorder affect your happiness / the patient you take care of in her/his happiness?

Answer	PwH (%)	CPwH (%)	Total (%)
Not at all	35	39	37
Slightly	22	23	23
Moderately	21	24	22
Very	10	10	10
Very much	11	5	9

CPwH: caregivers of people with hemophilia; PwH: people with hemophilia.

Figure S1. Profile of respondents spending <15 minutes with their physician at each follow-up visit



* Sufficiently informed = well or very well informed about living with hemophilia and the latest scientific developments.

** Satisfied with treatment = In the last year, I have been satisfied with my treatment / the patient I take care of has been satisfied with their treatment.

CPwH: caregivers of people with hemophilia; PwH: people with hemophilia.