

Impact of mild to severe hemophilia on education and work by US adult men and women and caregivers of children with hemophilia B: the bridging hemophilia B experiences results and opportunities into solutions (B-HERO-S) study

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Objective

B-HERO-S was designed to better understand the psychosocial impact of hemophilia B on employment/career for adults with mild-moderate-severe hemophilia (PWH) and caregivers (CG) of children with hemophilia (CWH) and in particular to explore impact on PWH education/work and CG/partner work.

Introduction

- Initiated in 2009, the global HERO program and subsequent 10-country HERO quantitative study investigated the psychosocial issues affecting PWH and CG/families.^{1,2}
- The HERO study highlighted challenges with work for moderately-severe PWH and the mostly female CG of male CWH. The study identified gaps relating to the impact of hemophilia on education for PWH, consideration for impact on responding CG's spouse/partner, or the underlying reasons why PWH/CG never worked or were no longer working.
- HERO covered mostly males with moderate-severe hemophilia (PWH/CWH), so it did not assess the impact of mild-moderate hemophilia or impact of hemophilia on affected women and girls (FIX <40%).
- B-HERO-S was designed in collaboration with healthcare professionals, advocacy organizations, and patients/CG to identify needs in this population.

Methods

- US PWH (either gender, age ≥18 years) and CG (age >18 years) of CWH (either gender, age <18 years) were recruited through patient organizations to complete distinct IRB-approved internet surveys from Sept. 24 to Nov. 3, 2015.
- Surveys assessed, in part, the impact of hemophilia on education and work.

Results

Demographics

- Respondents included 299 PWH (median age 29 years) and 150 CG (median age 35 years); 134 with partners (married/long-term relationship) (Table 1).
- Most PWH (273) and CG (146) completed their formal education at a median age of 23 years; the majority completed a 4-year college or a graduate degree.
- A surprisingly high percentage of PWH work in positions involving manual labor; the most common industries were construction/manufacturing/production (35%) and computers/IT (26%).

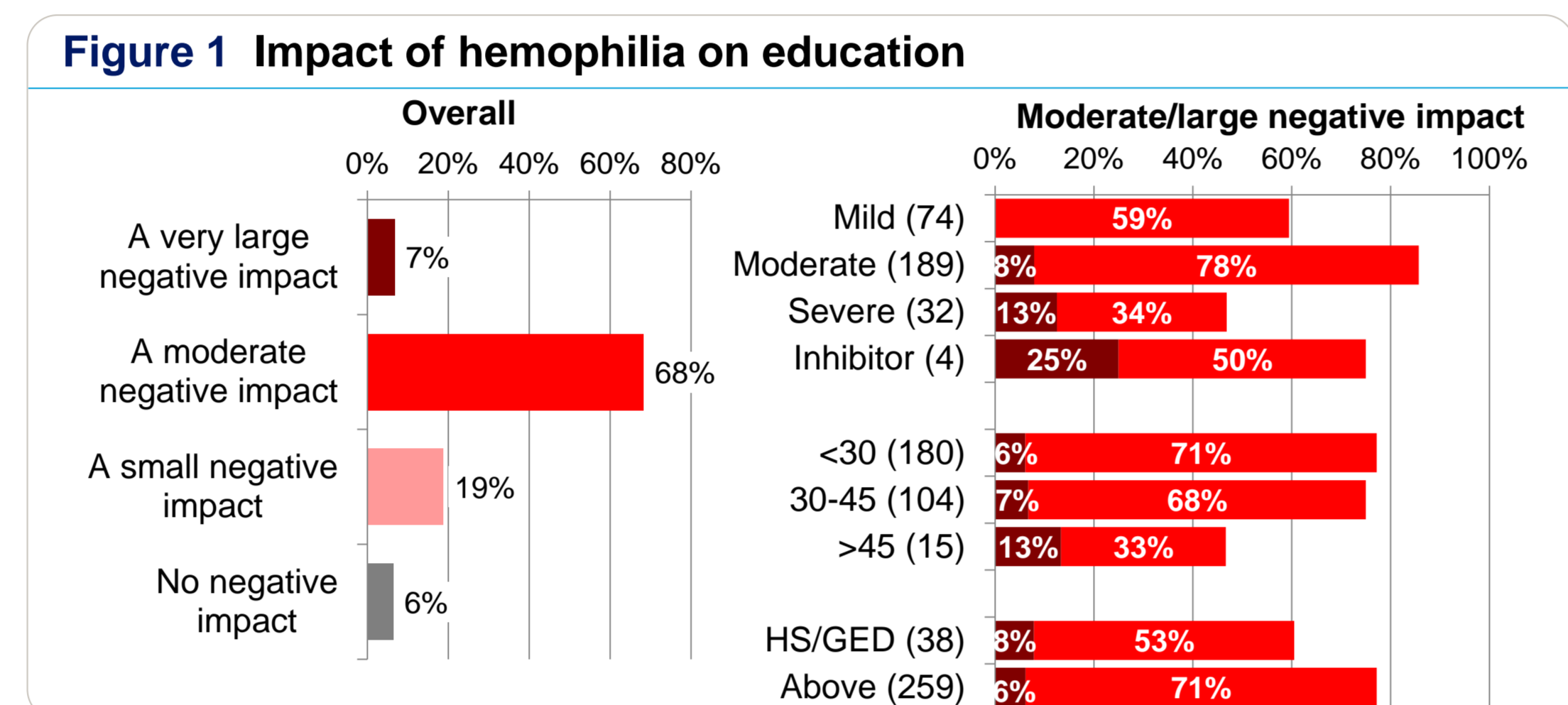
Table 1 Demographics

	PWH (N=299)	CG (N=150)	CG Partner (N=134)
Gender, n (%)			
Male	213 (71%)	34 (23%)	30 (22%)
Female	86 (29%)	116 (77%)	104 (78%)
Highest education, n (%)			
HS/GED	46 (15%)	30 (20%)	19 (14%)
College	211 (71%)	92 (61%)	88 (66%)
Graduate	52 (17%)	37 (25%)	36 (27%)
Currently working, n (%)			
Full/part time	241 (81%)	129 (86%)	130 (97%)
Not working	58 (19%)	21 (14%)	4 (3%)
Job type, n (%)			
Office-based	140 (58%)	94 (66%)	83 (64%)
Manual labor	93 (39%)	46 (32%)	41 (32%)
Mainly inactive	8 (3%)	3 (2%)	5 (4%)

N, number of respondents; n, number of responses; HS, high school; GED, general education development

Impact on Education for PWH

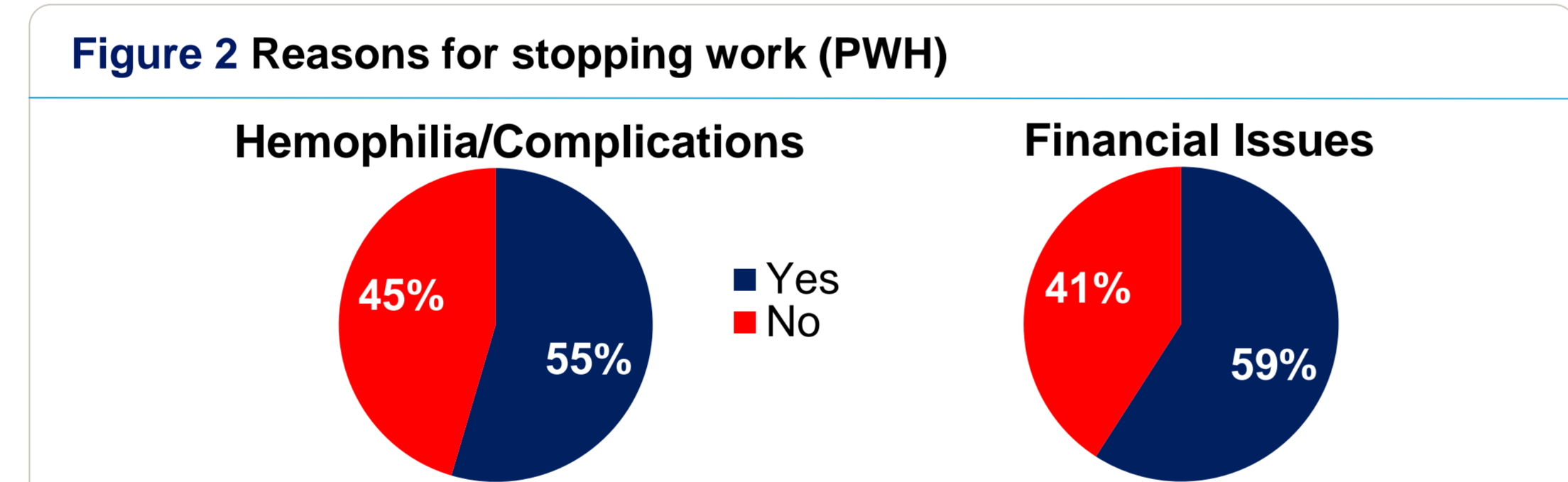
- Most PWH reported an impact on education (94%); 75% reported a moderate/large impact including those with mild-moderate disease (Figure 1).
- The most common reasons for impact were difficulty concentrating at school due to bleeds or pain (69%), difficulty attending school or doing activities due to mobility (44%), and hemophilia-related absences (32%).



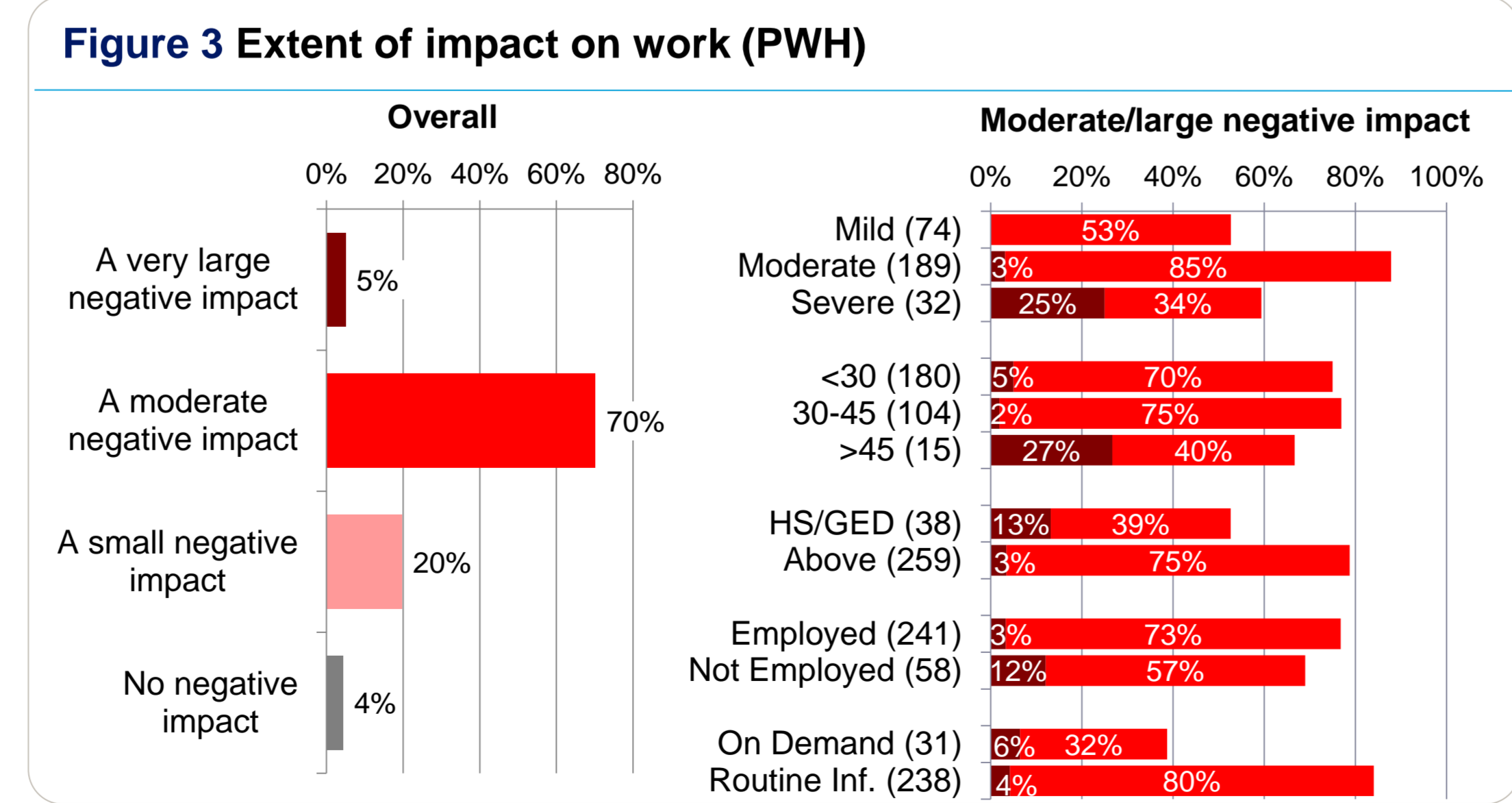
HS, high school; GED, general education development. (n): number of respondents.

Impact on Work for PWH

- 81% of PWH were employed, the 58 PWH not working included 62% who never worked. Higher percentages of PWH with mild/moderate (69%/63%) vs. severe hemophilia and those aged <30 years (73%) never worked.
- Of those who worked previously, more than half stopped due to hemophilia-related financial issues or hemophilia and/or its complications (Figure 2).

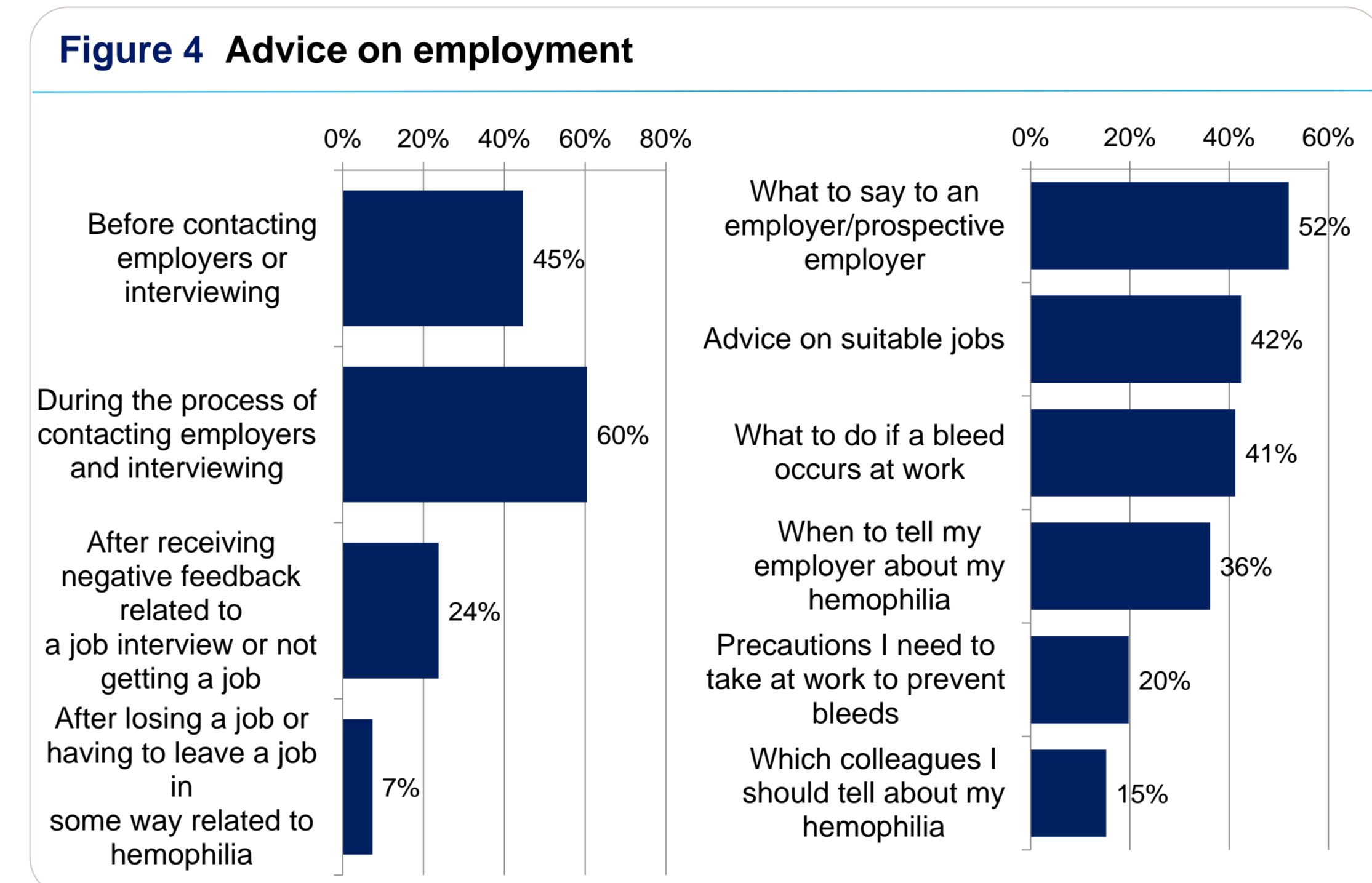


- Almost all PWH (95%) reported a negative impact on work (Figure 3). Having moderate disease (86% receiving routine infusions), comorbidities, a higher education and/or routine infusions increased the impact. Only 10% reported no impact on job choice.



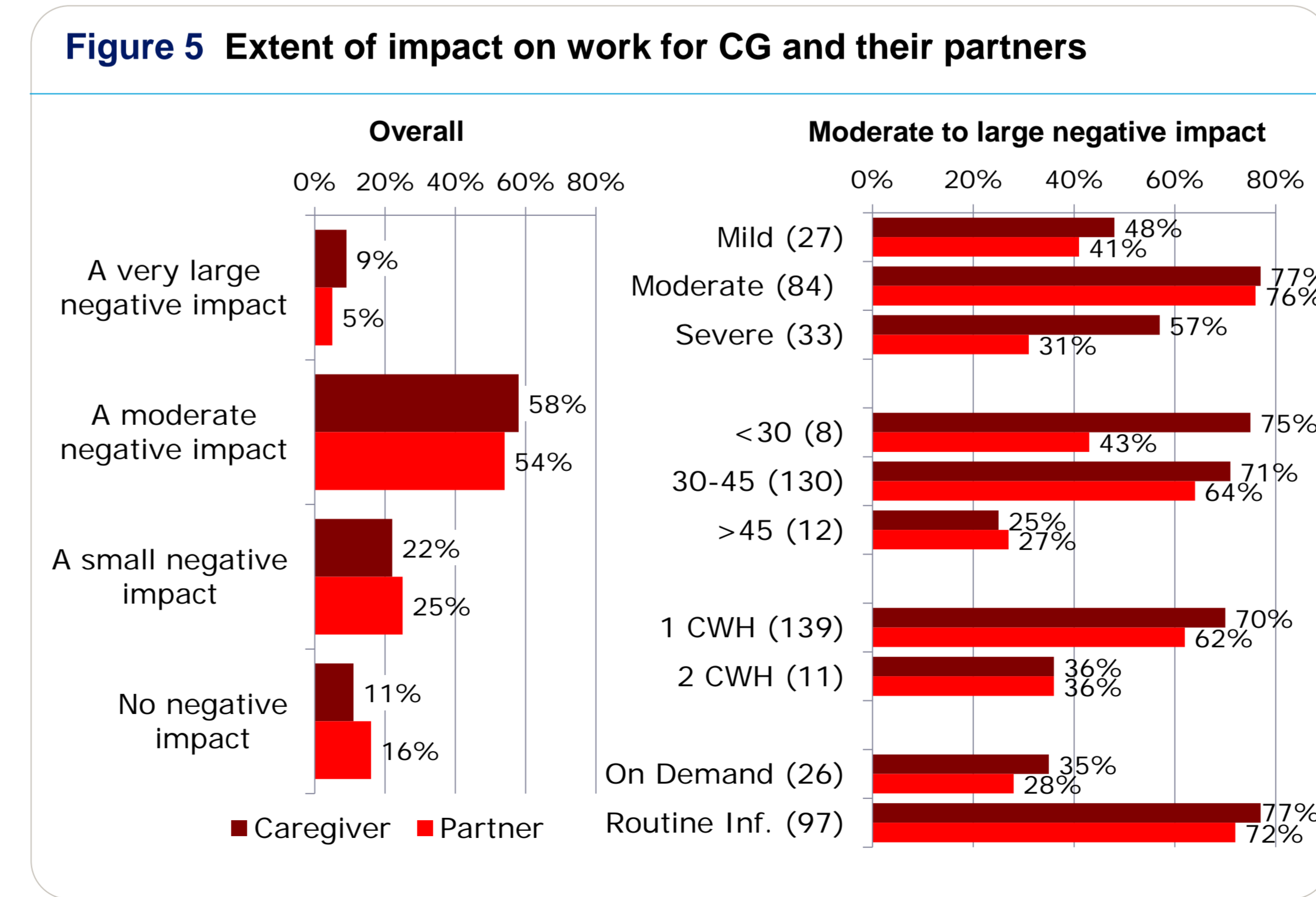
HS, high school; GED, general education development; (n): number of respondents; Routine Inf.: routine infusions.

- Current treatment allows some PWH (30%) to work in most situations; more so for PWH with mild hemophilia (41%) or treated on-demand (48%). A lower percentage of PWH with moderate/severe hemophilia (27%/28%) or on routine infusions (27%) are able to work in most situations.
- Many PWH (59%) received healthcare professional advice; most often from hematologists (76%) (Figure 4). Advice was perceived as helpful (median 4.0).



Impact on Work for CG and their Partners

- The majority of CG (86%) and their partners (97%) are currently employed; Most CG/partners reported employment unrelated to hemophilia.
- Of the 21 (14%) CG and 4 (3%) partners not currently employed, 52% and 25%, respectively reported not-working due to caring for a CWH.
- Most CG (89%) and their partners (84%) reported a negative impact of caring for a CWH on work (Figure 5). Younger CG and their partners were affected more than those >45 years. CWH factors associated with greater impact included caring for one CWH, moderate severity (61% receiving routine infusions) and routine infusions in general.

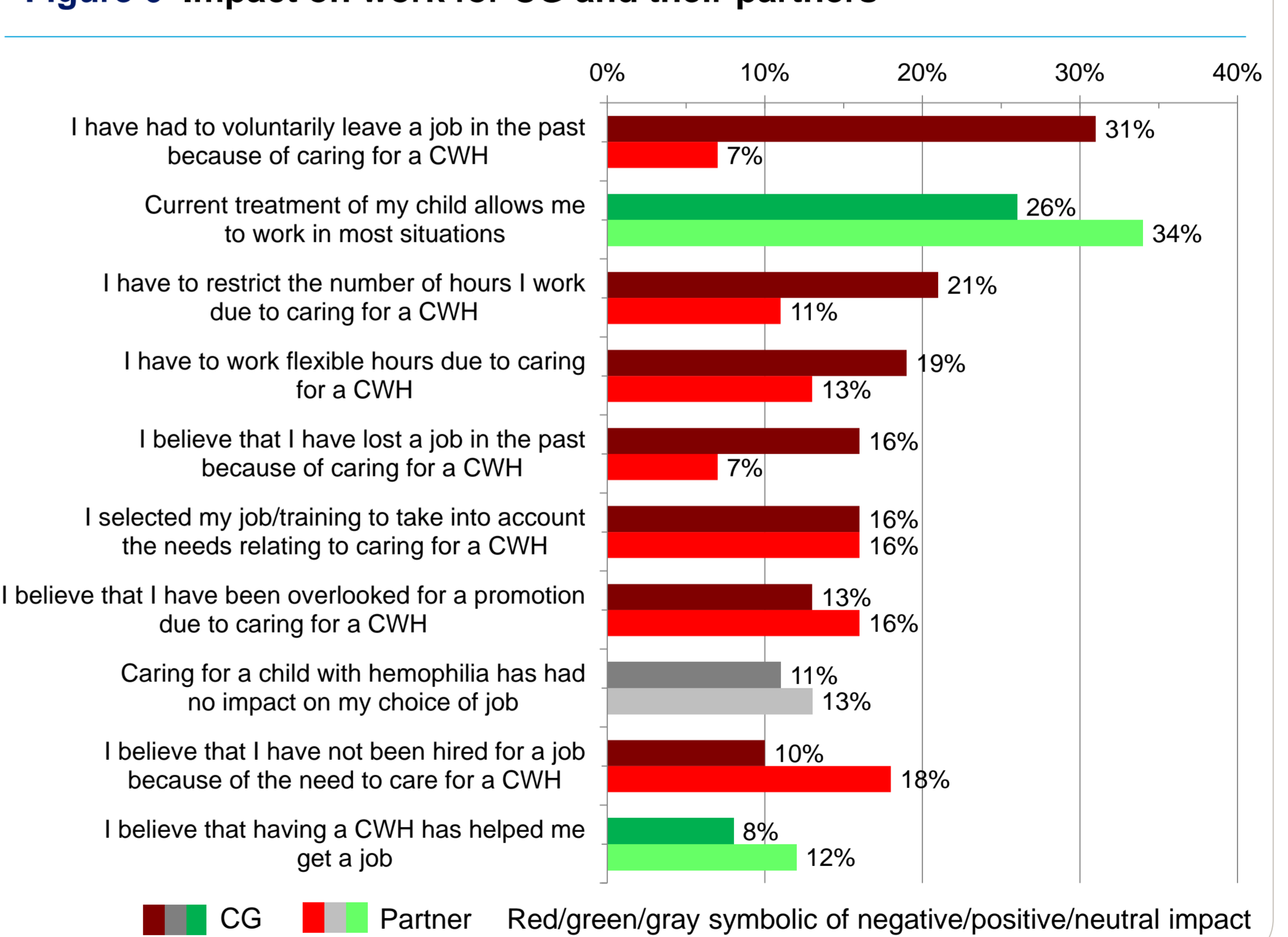


Routine Inf.: routine infusions.

Conclusions

- Results from the B-HERO-S survey documented significant impact of hemophilia B, including mild and moderate disease, on education and work for PWH.
- More than half of formerly employed PWH stopped work due to financial issues and/or hemophilia-related complications.
- Caring for a CWH impacted the working lives of both CG and their partners.
- While routine infusions given prophylactically might be thought to reduce impact on work, use in this mild-severe population (see PO-T-26) may reflect reactive use after a work-related event or a worse CWH phenotype.
- One-third of CG have voluntarily left a job due to caring for a CWH (Figure 6); more so with routine infusions (39% vs. 12% for on-demand therapy).
- More CG/partners of CWH on routine infusions (15%/26%) vs. on-demand therapy (0%/0%) believe caring for a CWH was the reason for not being hired for a job.
- A minority of CG (26%) and partners (34%) are able to work in most situations given current CWH treatment (Figure 6); with mild/moderate impact similar to severe for CG (33%/23% vs. 27%) and mild severity affecting partners more (45% for mild vs. 29%/35% for moderate/severe hemophilia).

Figure 6: Impact on work for CG and their partners



References

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- Witkop M, et al. Am J Hematol 2015 Dec;90 Suppl 2:S3-10.

Conflict of interest disclosure

All authors have potential conflicts of interest. Please refer to the abstract.

This trial was sponsored by Novo Nordisk and is registered with ClinicalTrials.gov (NCT02568202). The authors acknowledge the medical writing assistance of Kathy Carpenter, PhD, Novo Nordisk, Inc.

