

Hemophilia Life Stages and Changes Global Survey Fact Sheet

sanofi

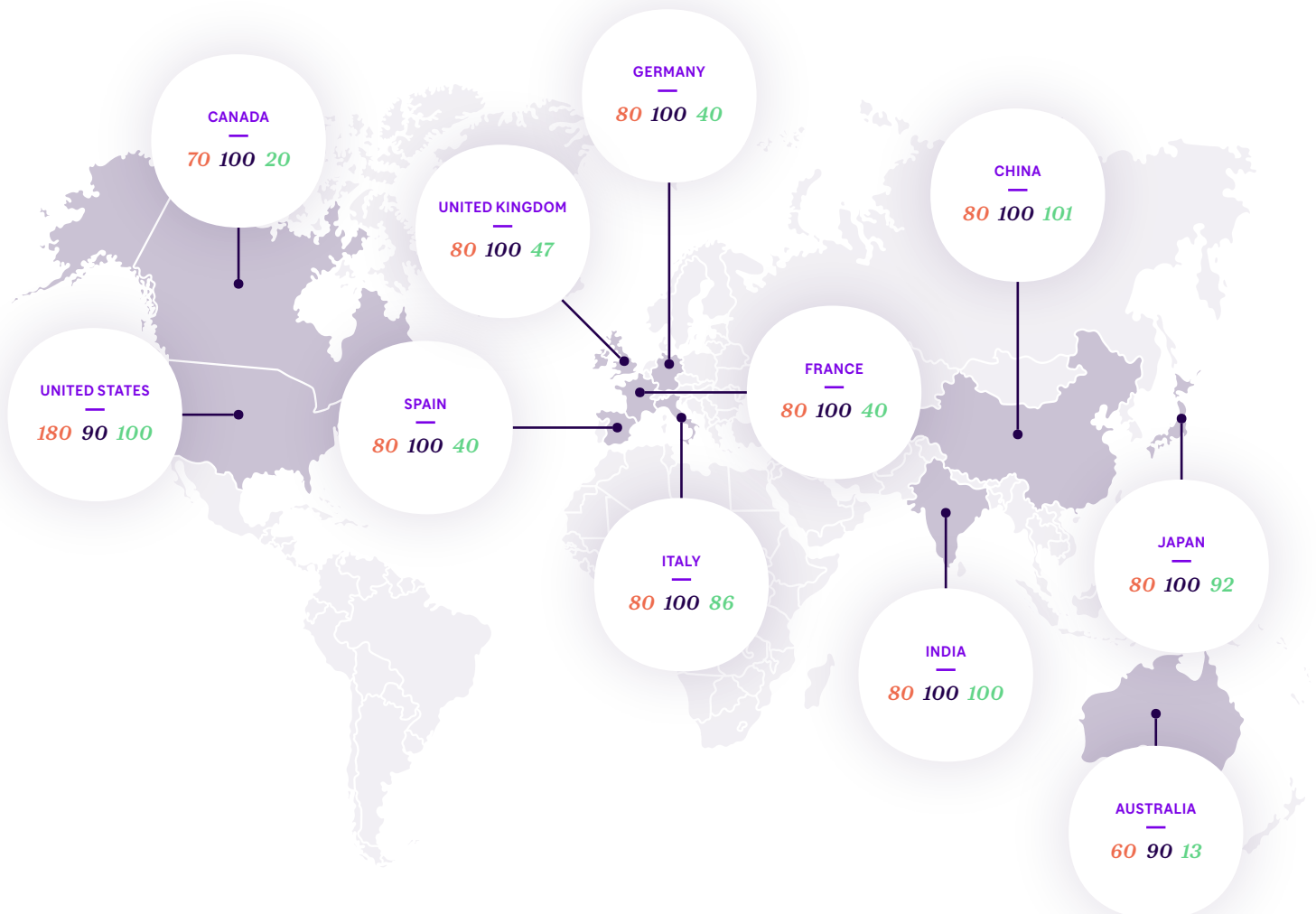
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About Hemophilia

Hemophilia is a rare, lifelong condition in which the ability of a person's blood to clot properly is impaired, leading to excessive bleeds and/or spontaneous bleeds into joints, muscles, and soft tissues that can result in joint damage, chronic pain, and potentially impact quality of life.

The severity of hemophilia is determined by the level of clotting factor activity in a person's blood, and there is a negative correlation between risk of bleeding and factor activity levels. Globally, over 1 million people are estimated to have hemophilia, and sustainable access to diagnosis and treatment remains a challenge.¹

A GLOBAL SURVEY



TOTALS: **950** People living with hemophilia **1,080** Caregivers **679** Hematologists

About the Hemophilia Life Stages and Changes Global Survey

As part of our ongoing commitment to better understand challenges within the hemophilia community, Sanofi commissioned The Harris Poll to conduct the Hemophilia Life Stages and Changes Global Survey.

The survey is a global assessment of the needs, experiences, and attitudes of people living with hemophilia (PLWH), their caregivers, and hematologists who treat the disease across eleven countries. The purpose is to better understand the current hemophilia experience

worldwide, including an assessment of unmet needs, evolution across life stages, emotional impacts, communication gaps, shared decision making and more.

The results of the survey provide valuable insights for caregivers, PLWH, healthcare professionals, policymakers, and patient organizations worldwide. The goal is for results to drive action and dialogue that ultimately leads to new, innovative solutions to improve care for people living with hemophilia.

Survey Methodology

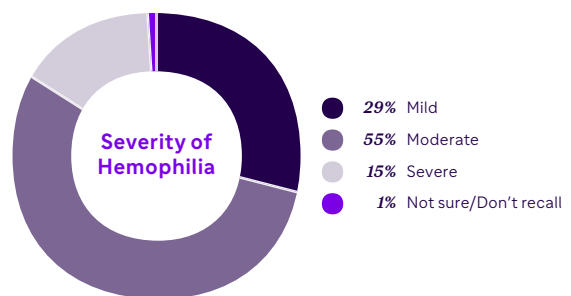
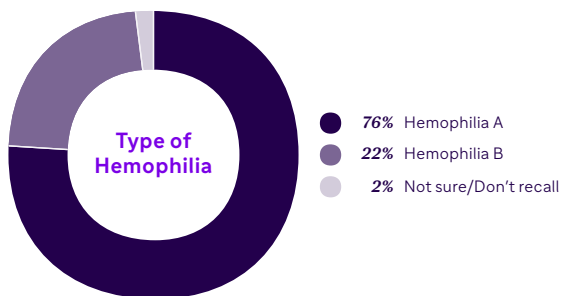
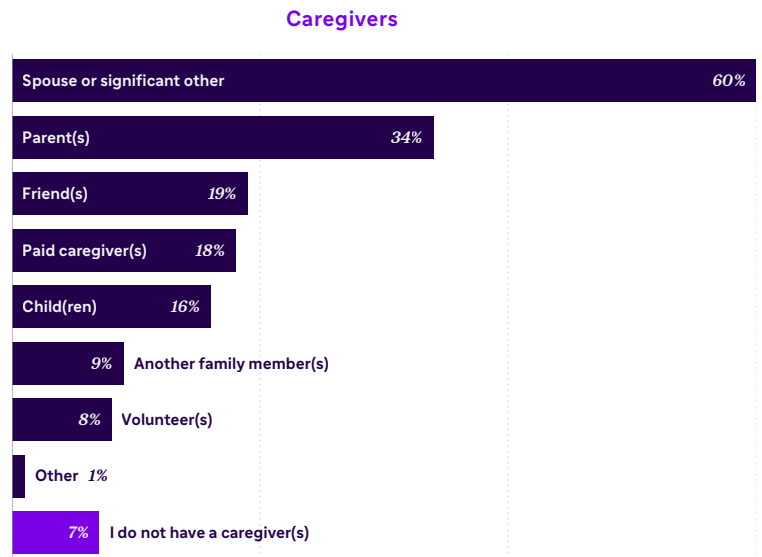
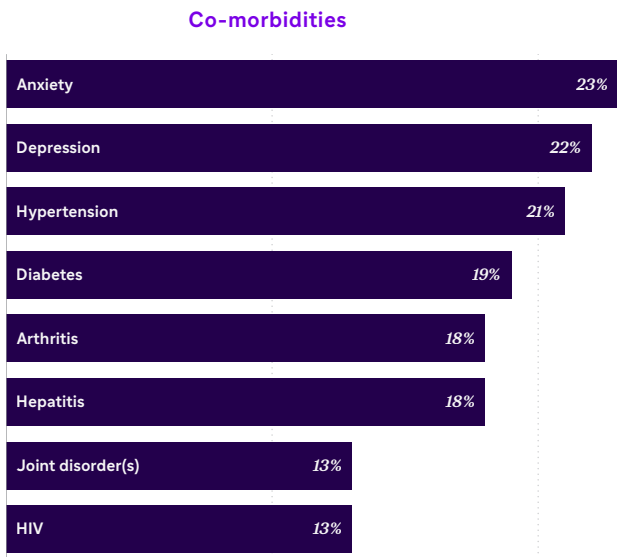
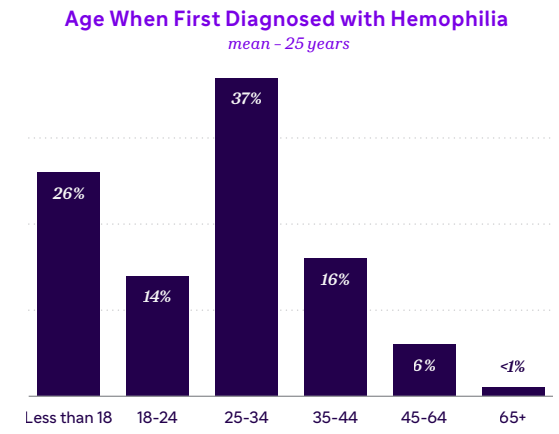
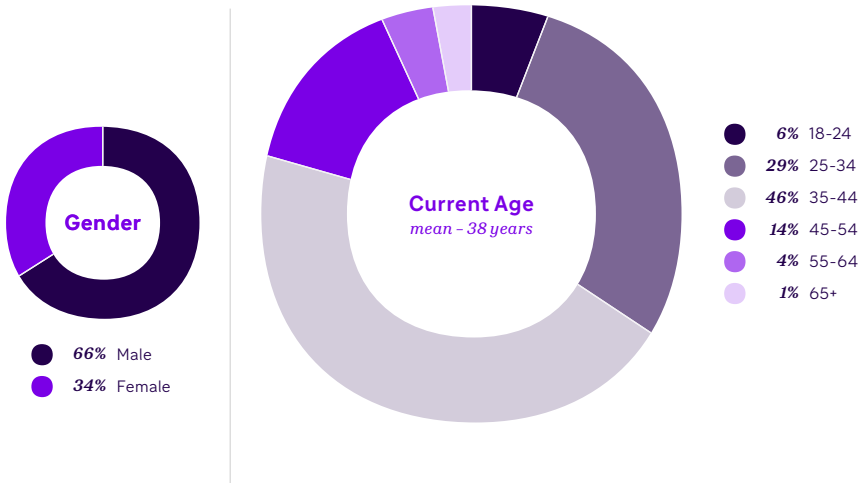
- Conducted online between February 27—April 10, 2023
- Surveyed people living with hemophilia 18 years of age or older in Australia, Canada, China, France, Germany, India, Italy, Japan, Spain, United Kingdom, and United States
- Surveyed hematologists who practiced within the surveyed countries and who see/treat at least 2 hemophilia patients each month
- Surveyed caregivers 18 years of age or older within the surveyed countries who provide care or support to a friend/family member living with hemophilia
- Participants were asked questions about: Current health, persistent unmet needs, evolution of needs over time, emotional impact, communication, and shared decision making
- Raw data were not weighted to adjust for geodemographics, except to provide each country equal share of voice, so thus are therefore only representative of the individuals who completed the survey
- Responses may not add up to 100% due to weighting, computer rounding and/or the acceptance of multiple responses



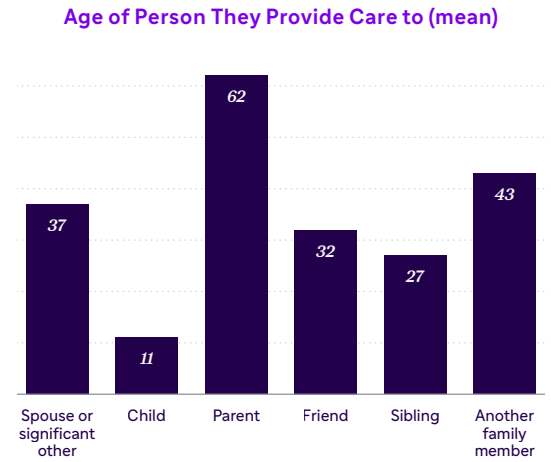
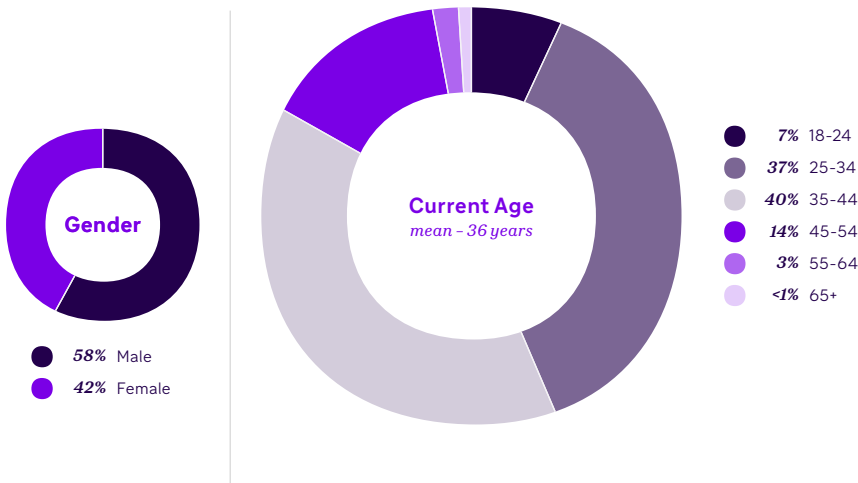
LEARN MORE

To view full survey details, including methodology, audience demographics, global survey data, and more, [click here](#) or scan the QR code.

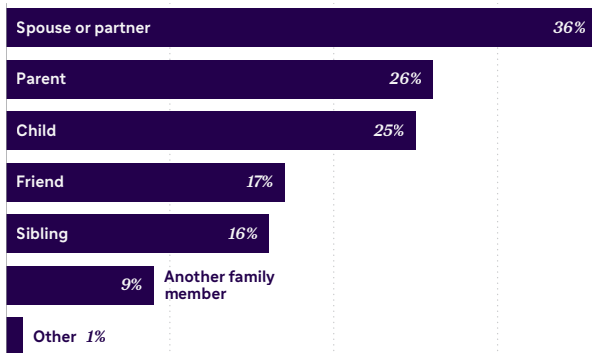
People living with hemophilia



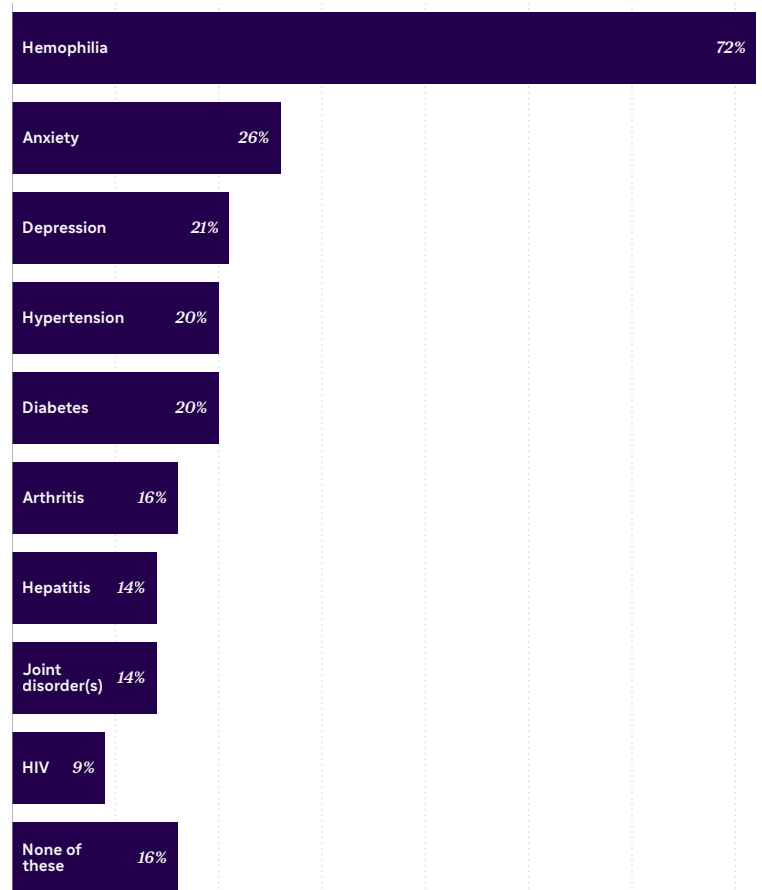
Caregivers



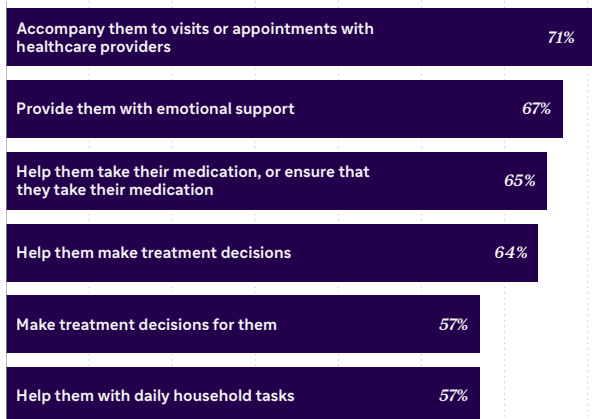
Caregivers' Relation to Individual They Provide Care to



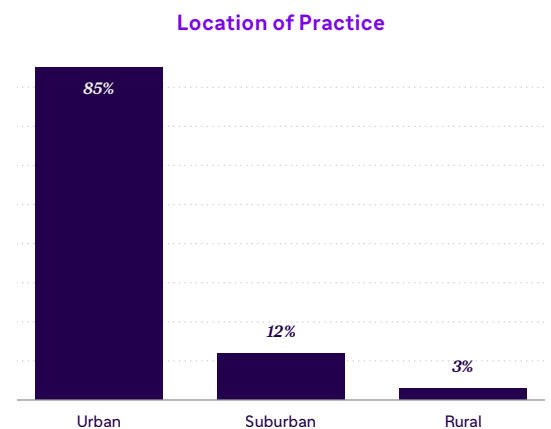
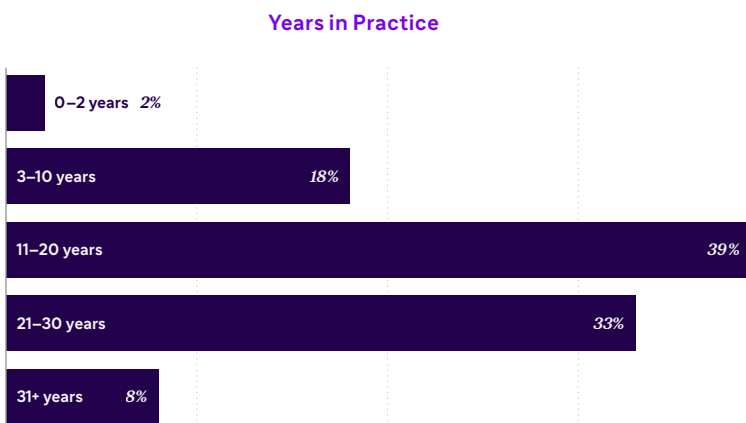
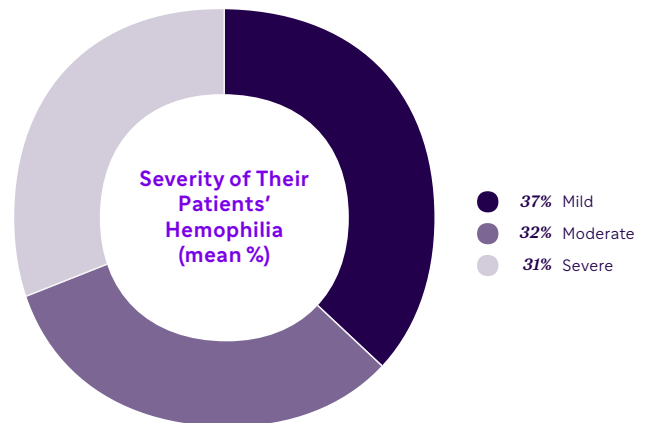
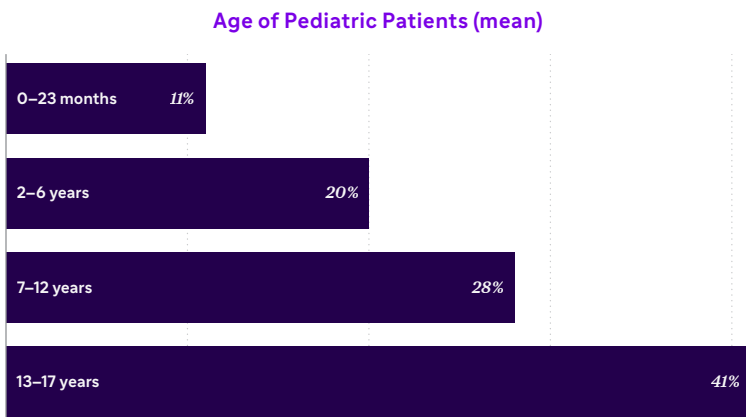
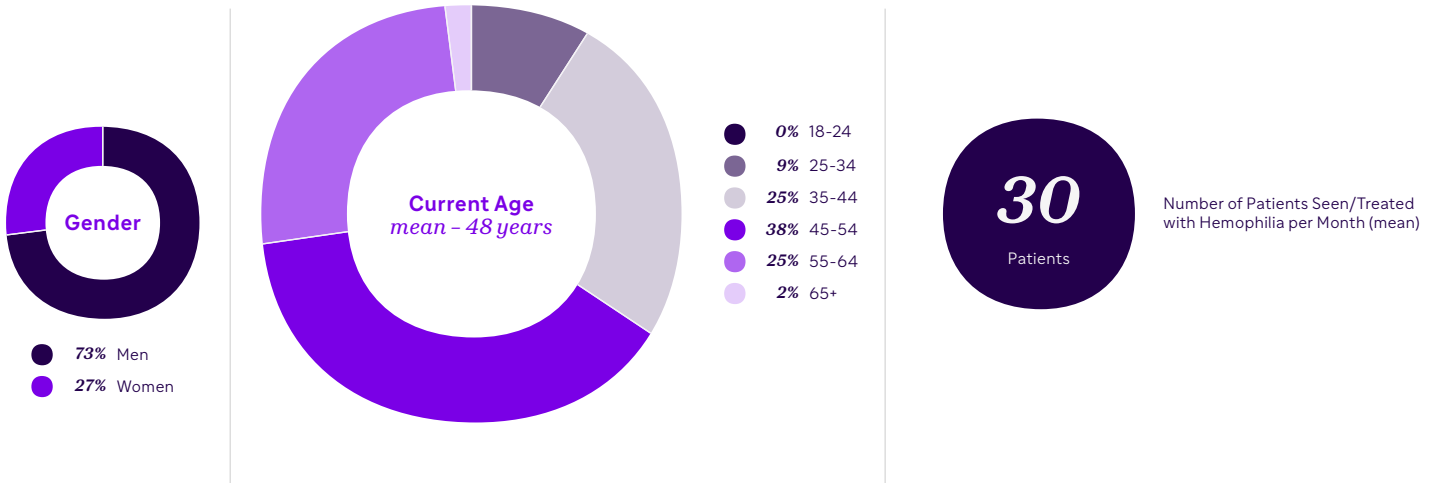
Health Conditions of Caregivers



Level of Involvement in Providing Care



Hematologists



A Look at the Current Health of People Living with Hemophilia (PLWH):

Patients are carrying much of the emotional as well as physical burdens of the disease on their own.

PLWH experience daily physical and emotional health impacts but oftentimes hide their symptoms from others.

- More than half of patients (54%) with hemophilia report having fair or poor health, though many tell their healthcare provider they are fine (71%).
- Most commonly, patients experience acute pain (48%), swelling in the joints (38%), and hematomas (38%).
- 87% of patients are concerned for their current health and a top worry is how hemophilia might cause long-term health problems (30%).
- 51% of patients try to hide their symptoms from others about once a week or more often.
- 68% of patients avoid telling friends about their hemophilia.

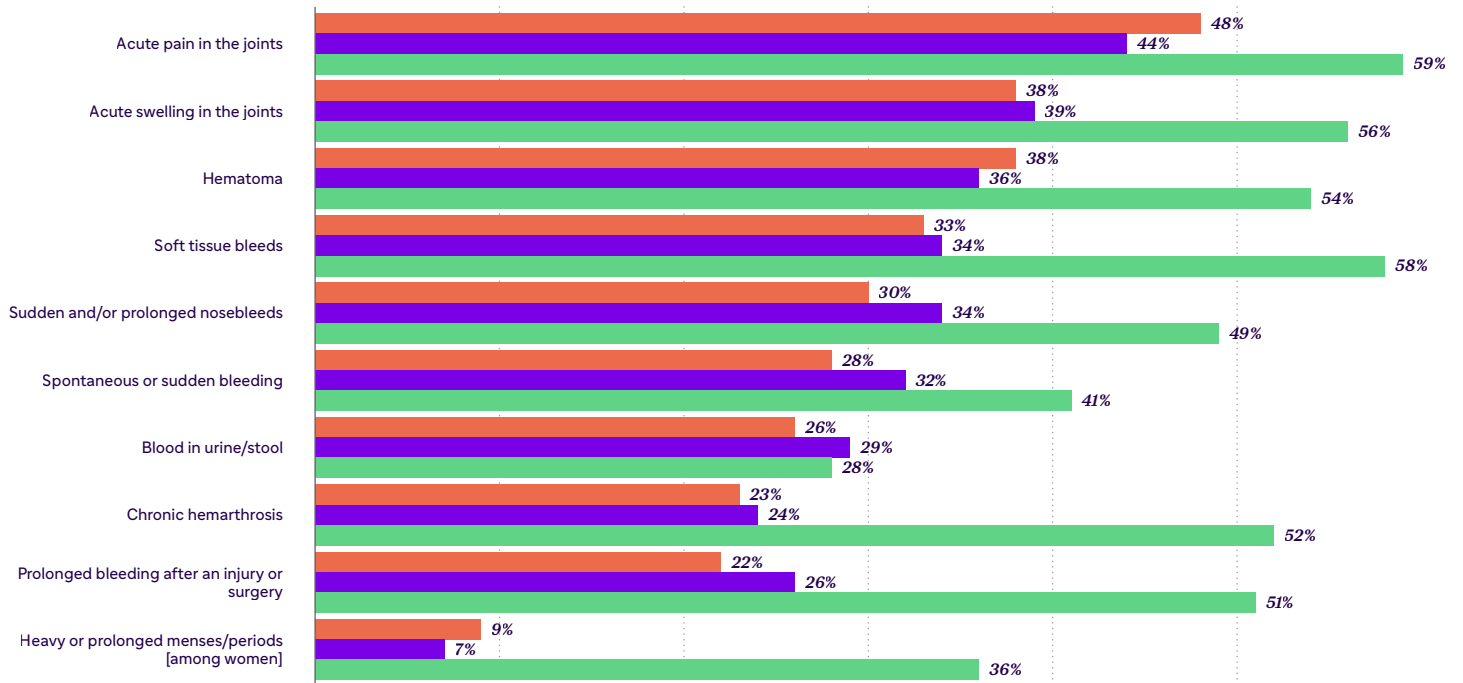
Patients are doing or taking a myriad of treatments to manage their hemophilia and its symptoms.

- Including prescription pain relievers (40%), exercise (38%), diet (35%), physical therapy (33%), and factor replacement therapy (30%).
- Hematologists are commonly recommending factor replacement therapy (79%) and pain relievers (51%).
- 56% of patients surveyed are on prophylactic treatment.
- Nearly all patients surveyed (92%) and caregivers (89%) report that care is currently received through a hemophilia treatment center or a comprehensive care center either in-person or virtually, and 75% report that their primary healthcare provider is a hematologist.
- Patients have seen their hematologist 9 times, on average, in the past year.
- Conducting daily activities without discomfort or worry of a bleed and reducing impact on personal relationships are among patient's top goals.

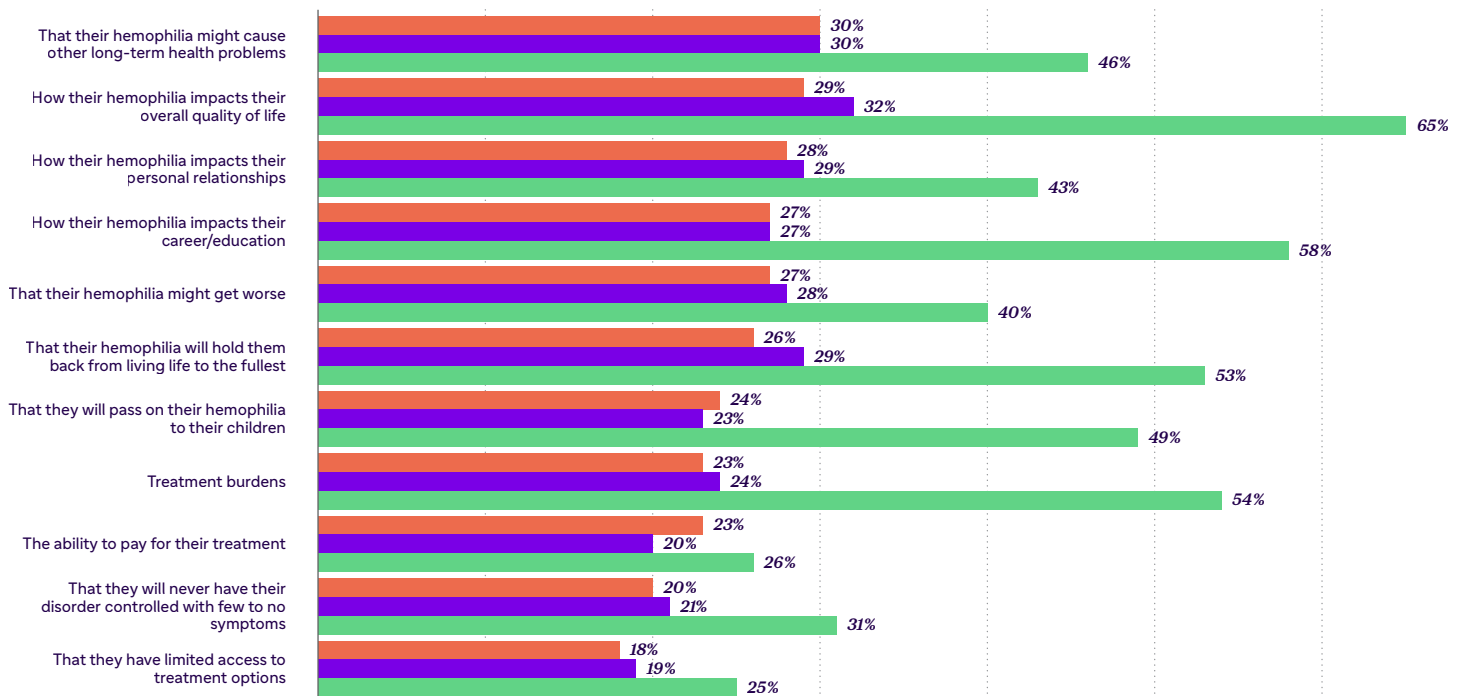
TOP-LINE SURVEY FINDINGS

● Patient Data ● Caregiver Data ● Hematologist Data

Patient Reported Symptoms in Past 6 Months/Most Commonly Reported



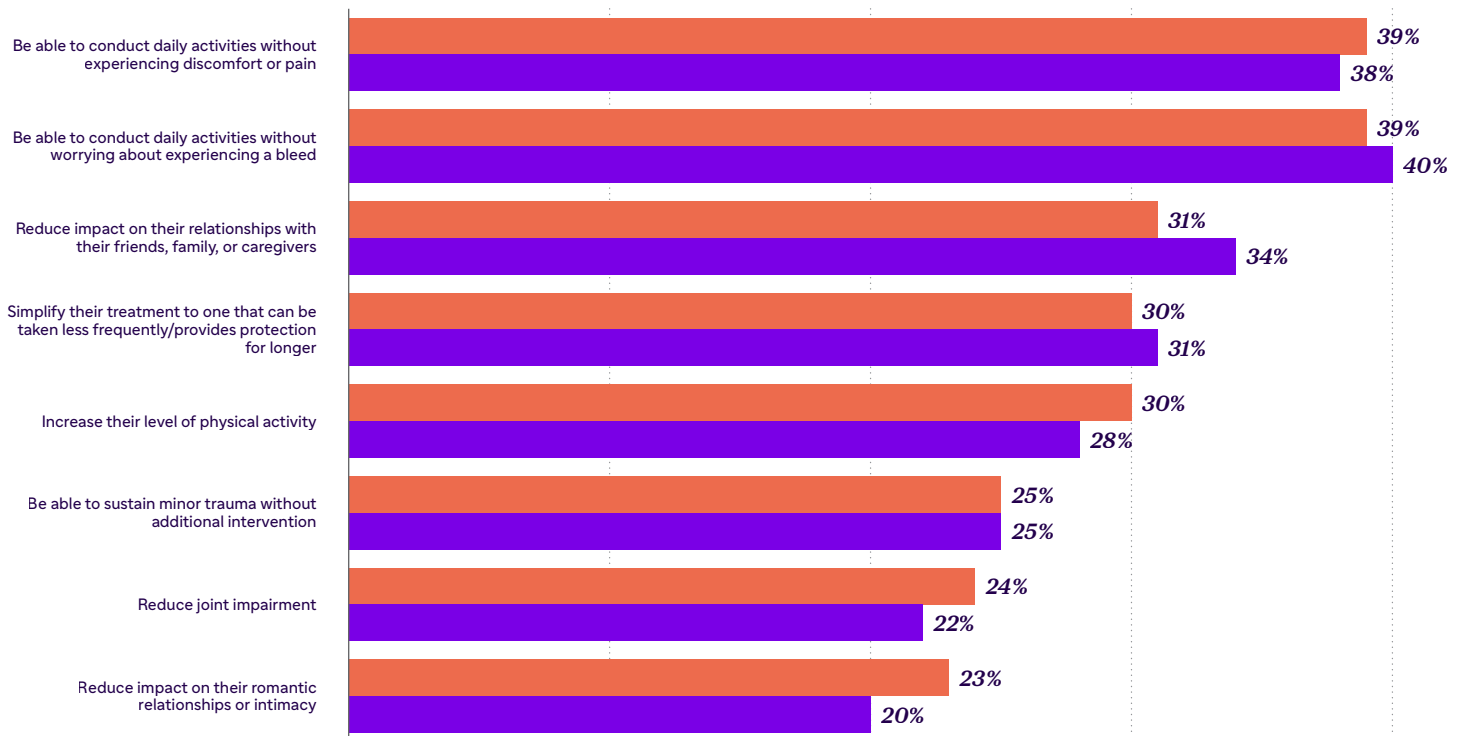
Top Worries for Hemophilia Patients



TOP-LINE SURVEY FINDINGS

● Patient Data ● Caregiver Data

Top Patient Goals for Managing Hemophilia



Understanding Communication and Gaps Between Parties:

Most patients and their caregivers want more discussions with their hematologist about treatment options.

All three audiences are generally satisfied with their conversations related to the disease but agree they would like more discussion.

- 91% of patients are satisfied with communications with their hematologist, which include discussing current lifestyle, symptom tracking, health related concerns and support resources.
- 73% of patients say they and their healthcare provider don't discuss their priorities and needs regarding hemophilia treatment as much as they would like.
- 95% of caregivers are satisfied with communications with their patients' hematologist.
- 87% of hematologists are satisfied with communication with their patients.
- 73% of hematologists report they initiate discussions about treatment priorities and patient needs.

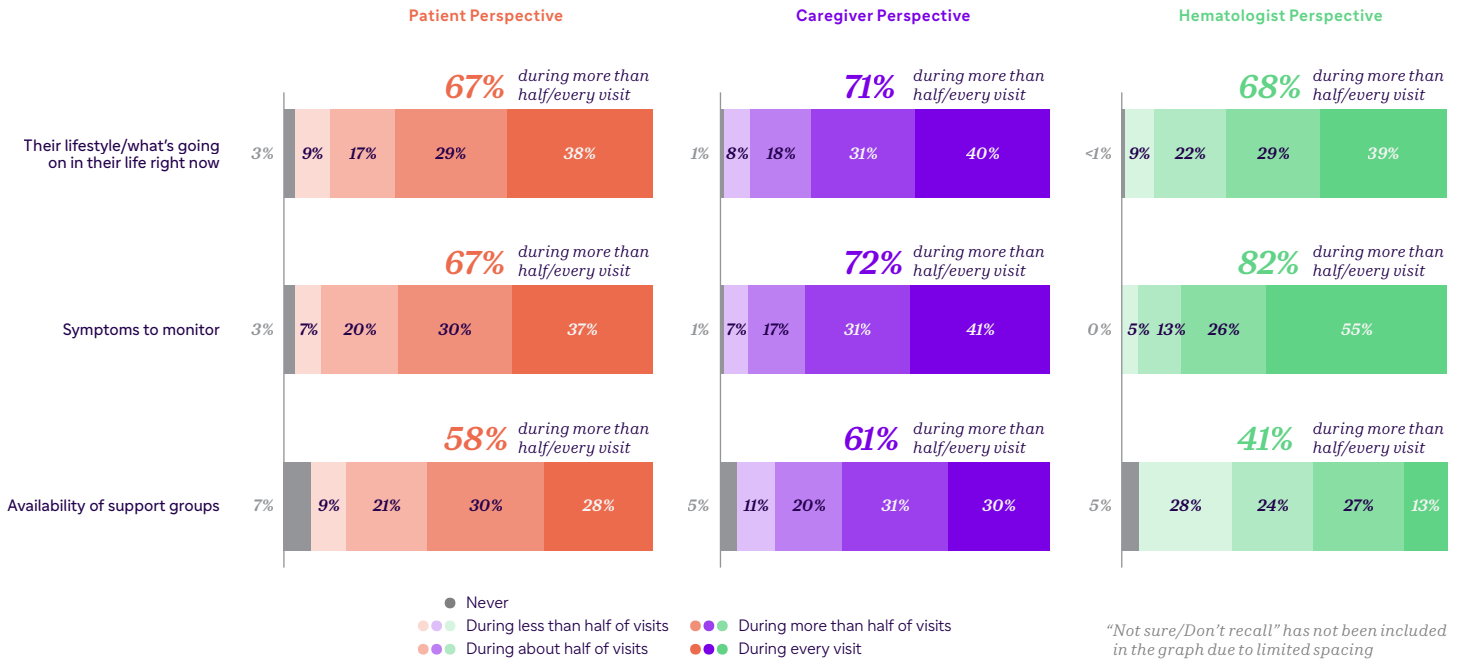
Despite open communication, there are certain topics that are not as often discussed between patients and hematologists.

- 86% of patients and 88% of caregivers feel comfortable raising concerns and fears with their/their loved one's hematologist.
- Discussing topics like how different hemophilia treatments work (87%), new research about hemophilia treatments (86%), and differences between various treatment options (86%) with their hematologist would be helpful for most patients.
- Topics like lifestyle and symptom tracking are frequently discussed at appointments, whereas the availability of support groups are discussed less frequently (only around 2 in 5 hematologists discuss support groups during more than half/every visit).

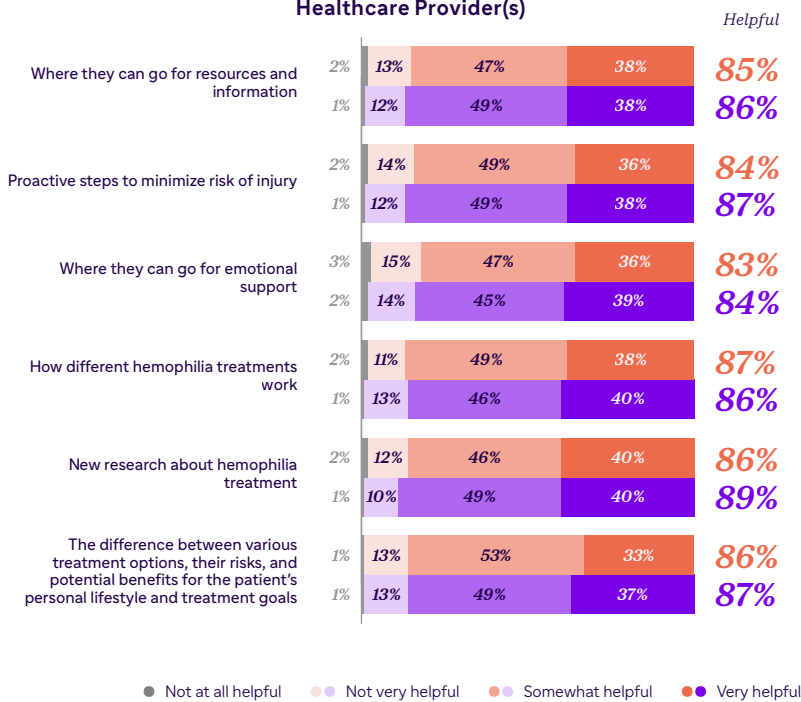
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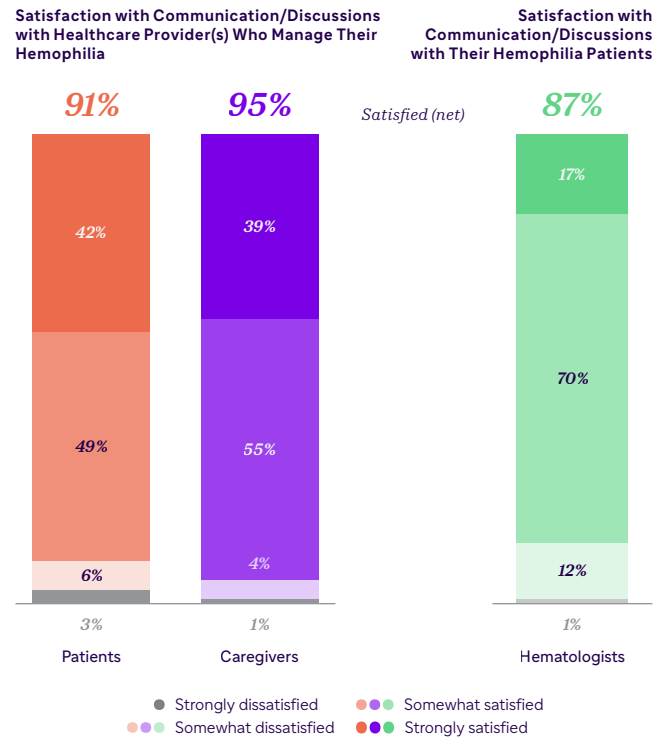
Frequency of Discussions with Healthcare Provider(s)



Helpfulness of Discussing Topics with Healthcare Provider(s)



Satisfaction with Communication/Discussions with Healthcare Provider(s) Who Manage Their Hemophilia



Bringing to Light the Emotional Impact & Burden of Hemophilia:

The emotional and mental strain of hemophilia weighs heavily on people living with hemophilia, their caregivers and hematologists as well.

Negative emotional impacts frequently accompany having hemophilia – high rates of anxiety, fear of bleeds, and depression are present.

- At least once a week, 59% of patients reported feeling anxiety and 51% reported feeling depression related to their hemophilia.
- 61% of patients reported having a lack of self-confidence due to their hemophilia, and 66% of hematologists believe hemophilia has a great deal/a lot of negative impact on their patients' lives.
- 83% of hematologists agree that their patients feel anxious about their hemophilia.
- 82% of patients also report feeling more appreciative of their health because of their hemophilia.

Physicians agree talking about emotional impact is important to a patient's overall wellbeing but report that these discussions are difficult to have.

- 84% of patients and 87% of caregivers feel their/their loved one's healthcare provider understands the emotional impact hemophilia has on their life.
- 91% of hematologists say they understand the emotional impact hemophilia has on patients' lives.
- 81% of hematologists wish it were easier to discuss the emotional impacts of living with hemophilia with their patients.

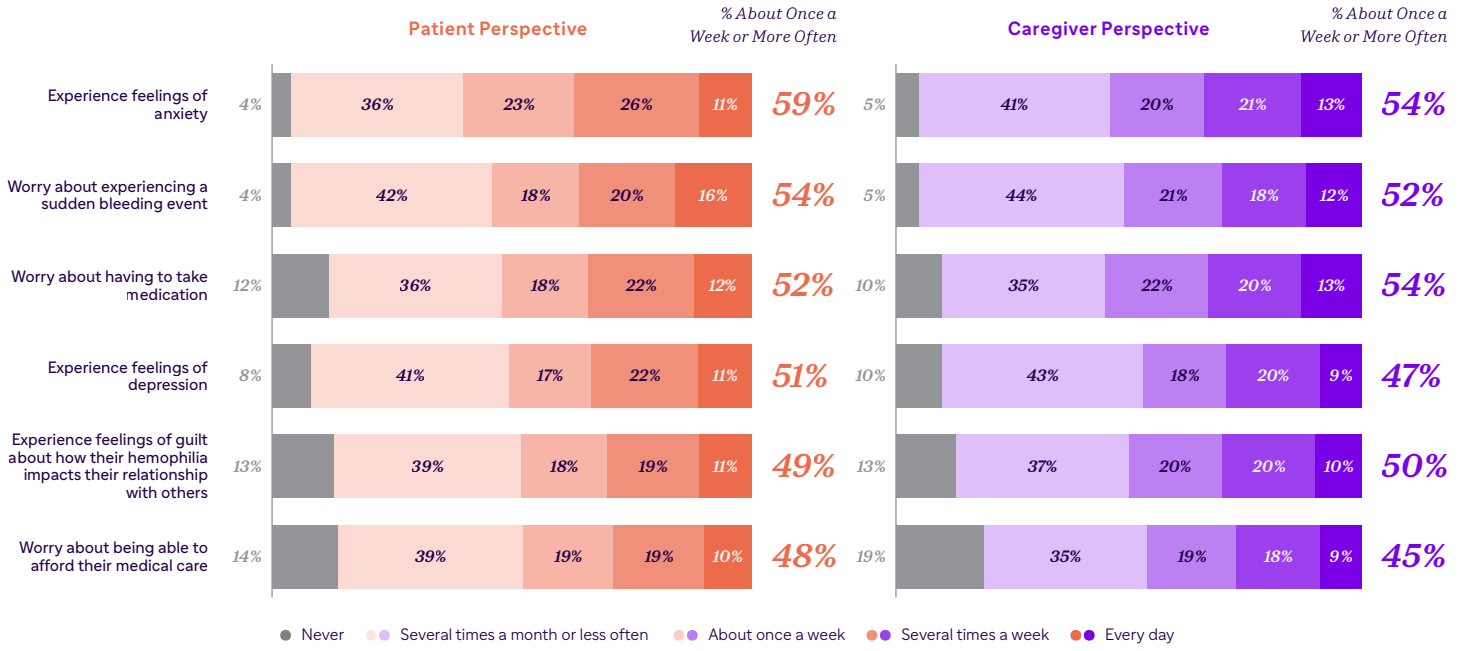
93% of patients have a caregiver, and caregivers also experience negative impacts to their mental and physical health.

- 80% of caregivers feel both physically and mentally drained.
- 64% of caregivers report a negative impact on physical and/or mental health.
- 86% of caregivers wish they could do more for their loved ones to help manage their hemophilia.
- 67% of caregivers provide emotional support to their loved ones living with hemophilia.

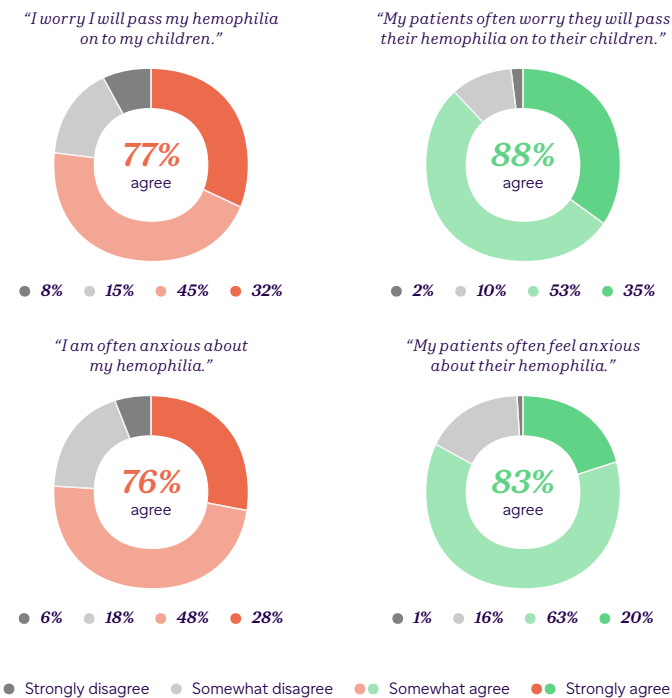
TOP-LINE SURVEY FINDINGS

● Patient Data ● Caregiver Data ● Hematologist Data

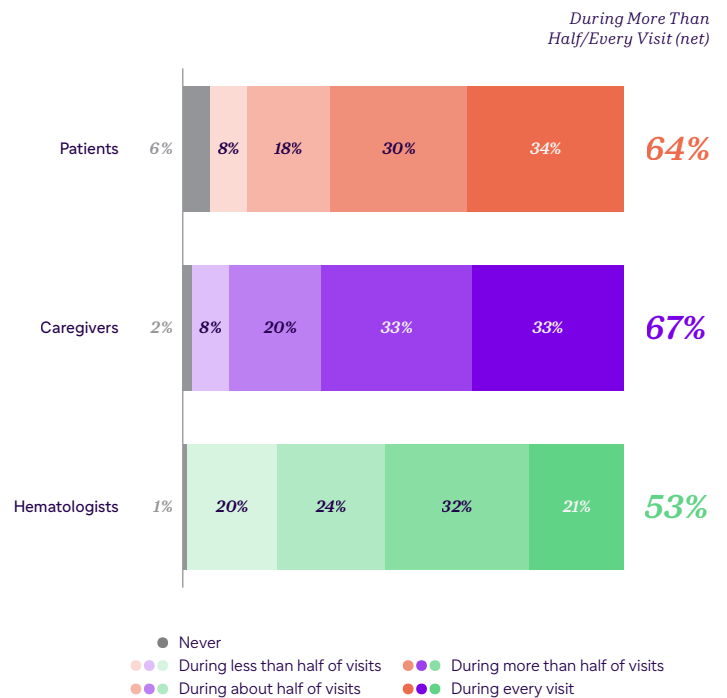
Frequency of Hemophilia Patients' Emotional Experiences



Sentiments Around Emotional Impact of Hemophilia

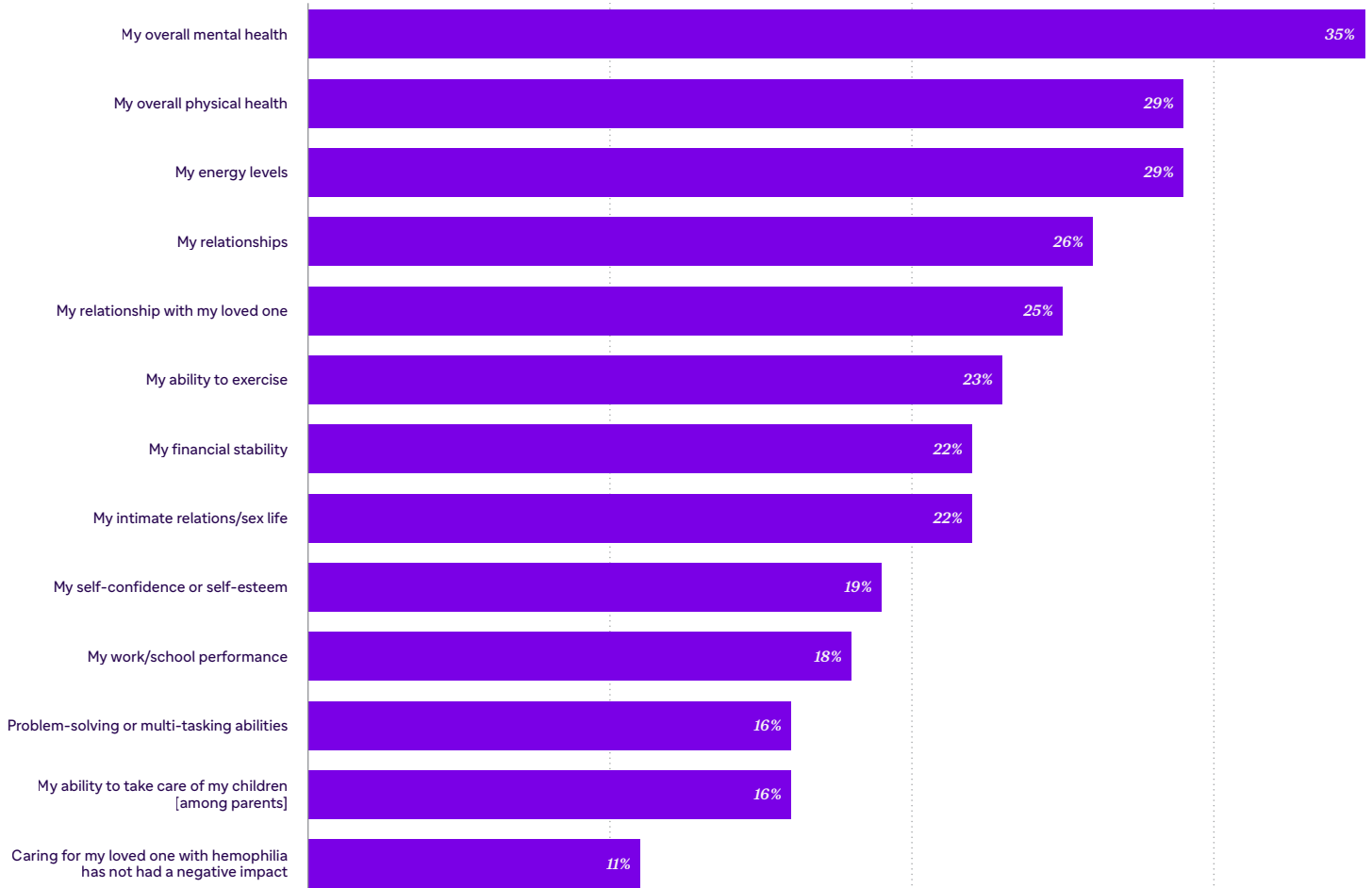


Frequency of Discussing Emotional Impacts of Hemophilia with Healthcare Provider(s)



Caregiver Data

Negative Impact of Caring for Their Loved One with Hemophilia on Their Own Life



How Needs Evolve over Time/Life Stages and Unmet Needs of People Living with Hemophilia:

The limitations for people living with hemophilia are pervasive throughout every stage of life – from sports and related activities in their youth to work, travel and relationships as they age.

Patients feel their impacts, limitations, and needs change over time

- 83% of patients feel that their hemophilia impacts them differently across different life stages (childhood, schooling, adulthood, parenthood).
- 86% of caregivers agree that the needs of their loved ones change throughout their lives.
- 81% of patients feel that they have to accept limitations on their lives/lifestyles due to their hemophilia.
- Patients missed out on activities more than their peers because of their hemophilia (45%).

Hemophilia patients often missed out on participating in activities, especially sports, during their childhood.

- 4 in 10 patients stopped participating (43%) or did not participate (35%) in a school sport because of their hemophilia.
- Caregivers of those under the age of 18 report similar actions, as 44% say the minor with hemophilia doesn't or will not participate in some school sports because of their hemophilia.

- For hematologists, slightly more than half (55%) report that most/all of their pediatric patients avoided participating in a school sport, and nearly half (47%) missed out on being able to participate in certain activities more than their peers because of their hemophilia.

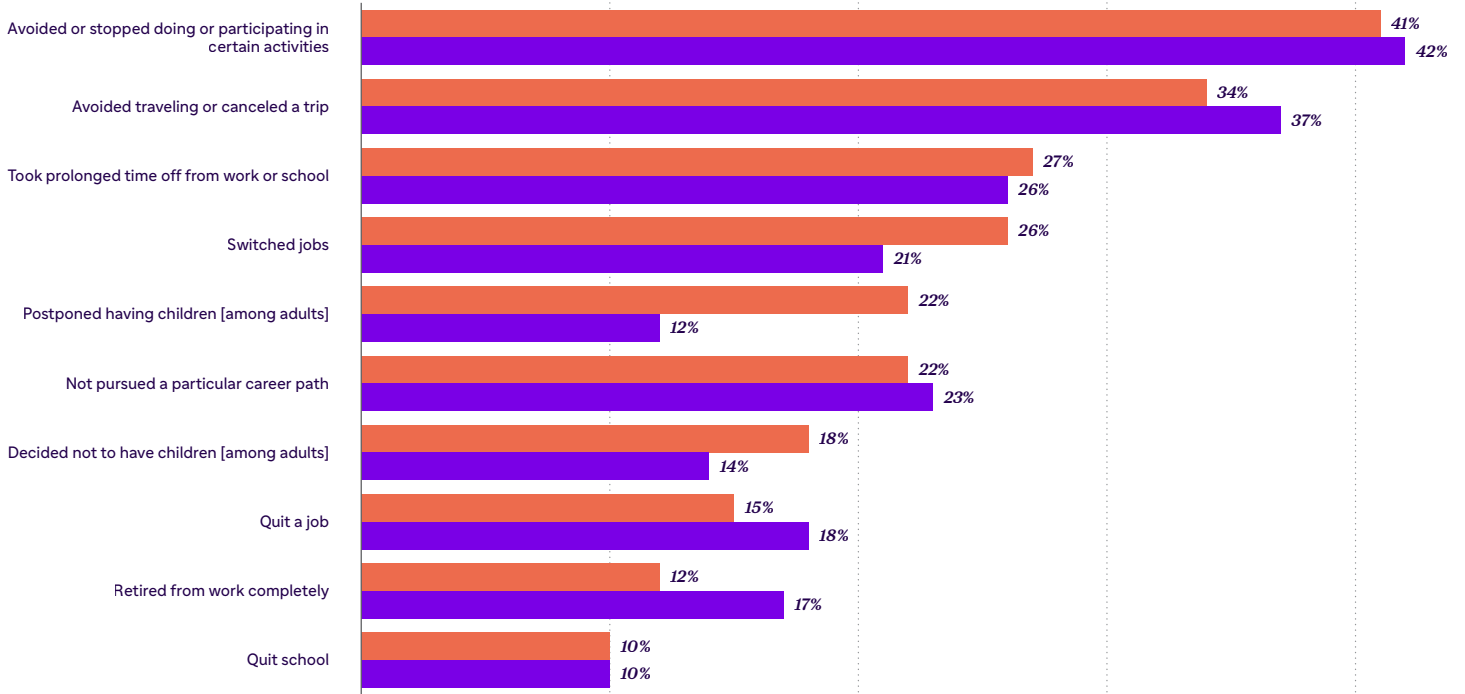
From household tasks to work travel to social outings, people living with hemophilia often avoid or are not able to fulfill these activities.

- The ability to manage other health conditions and obligations are most important to people living with hemophilia, yet for around one quarter or more, their ability to do so is majorly impacted by their hemophilia.
- About one-third of patients (34%) avoided traveling/canceled a trip and more than one quarter (27%) took prolonged time off from work or school.
- For about 6 in 10 patients, their hemophilia has negatively impacted various aspects of their lives a great deal/a lot, including their job/career (64%), career aspirations (62%), and romantic relationships (59%).
- Patients also experience negative impacts on their ability to be independent (62%), and about 57% of caregivers report they help their loved ones with daily household tasks.

TOP-LINE SURVEY FINDINGS

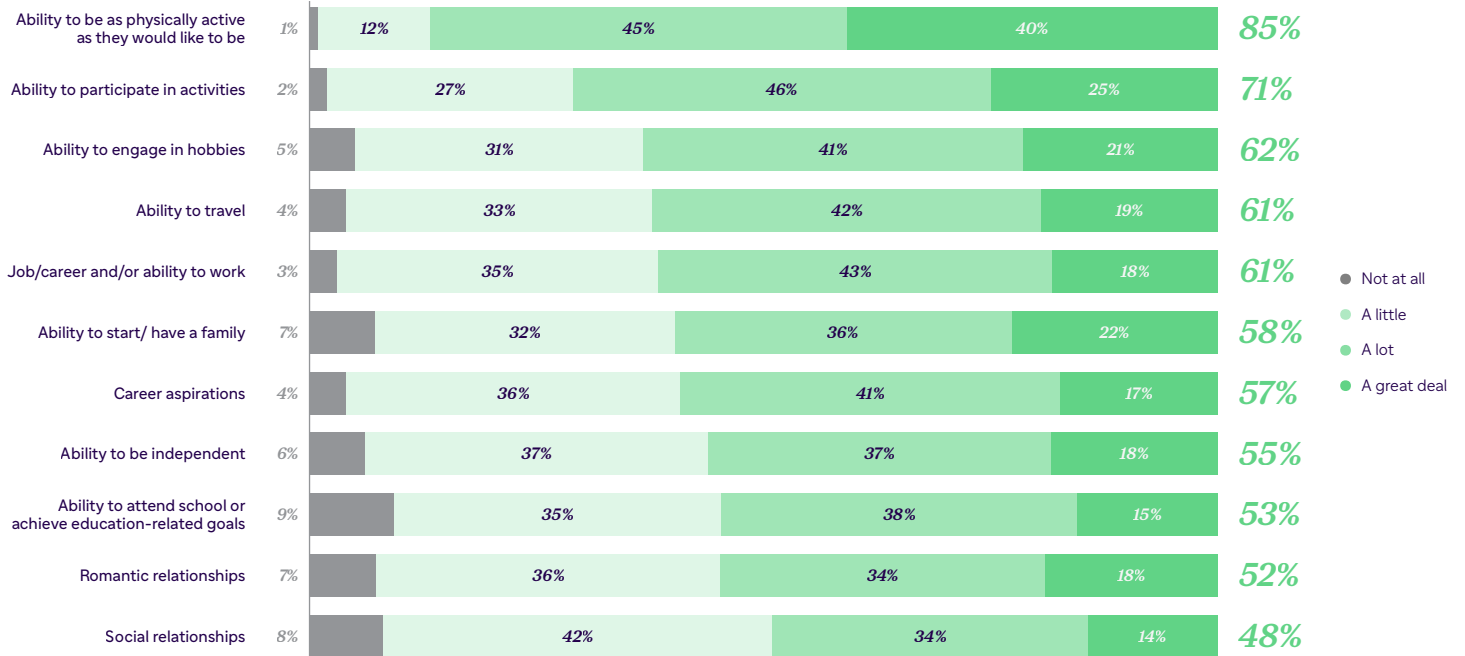
● Patient Data ● Caregiver Data ● Hematologist Data

Actions of Hemophilia Patients as a Result of Their Condition



Hematologists' Perspective on Negative Impact of Hemophilia on Patients' Life/Lifestyle

A Lot/A Great Deal (net)

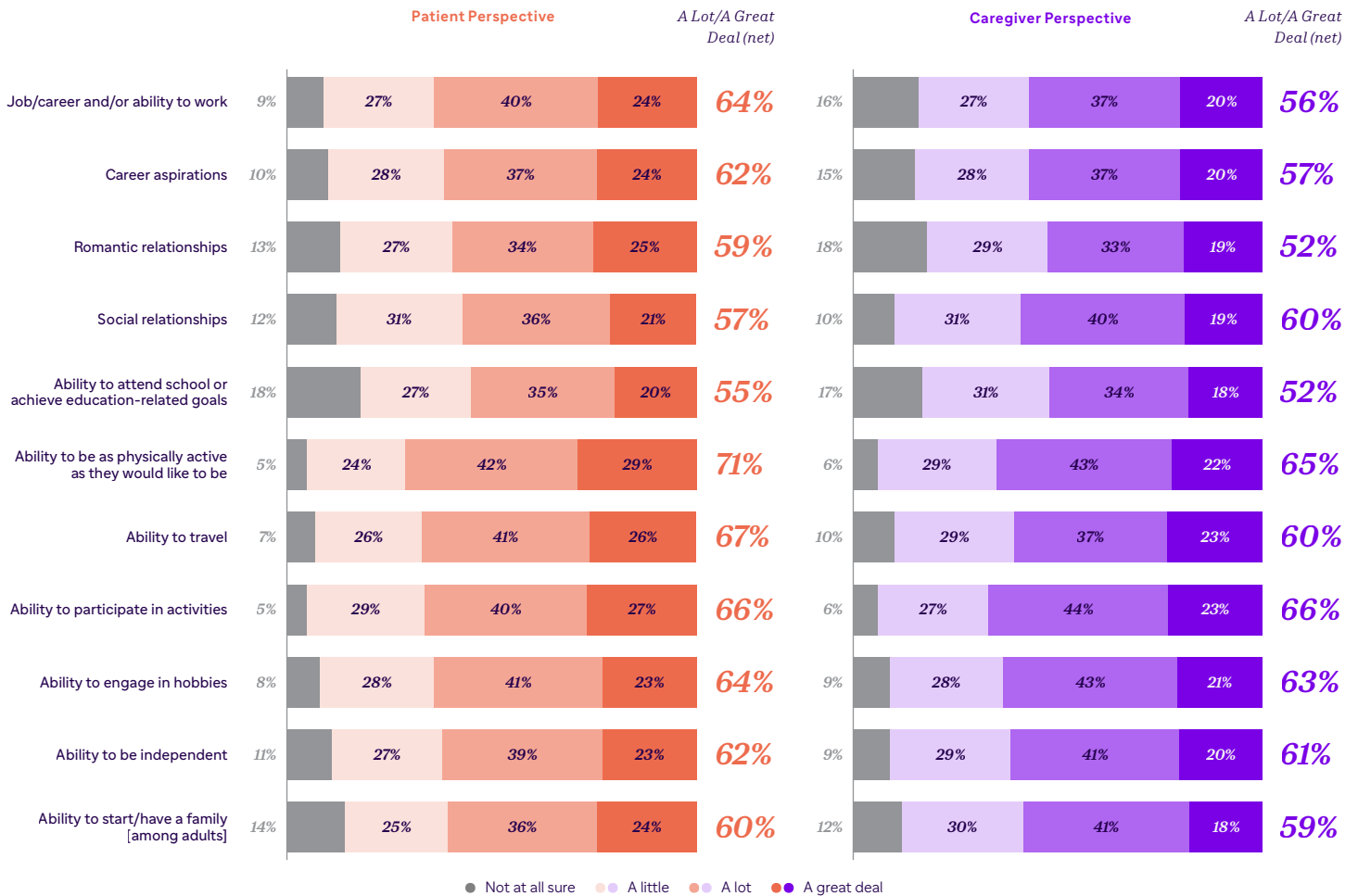


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TOP-LINE SURVEY FINDINGS

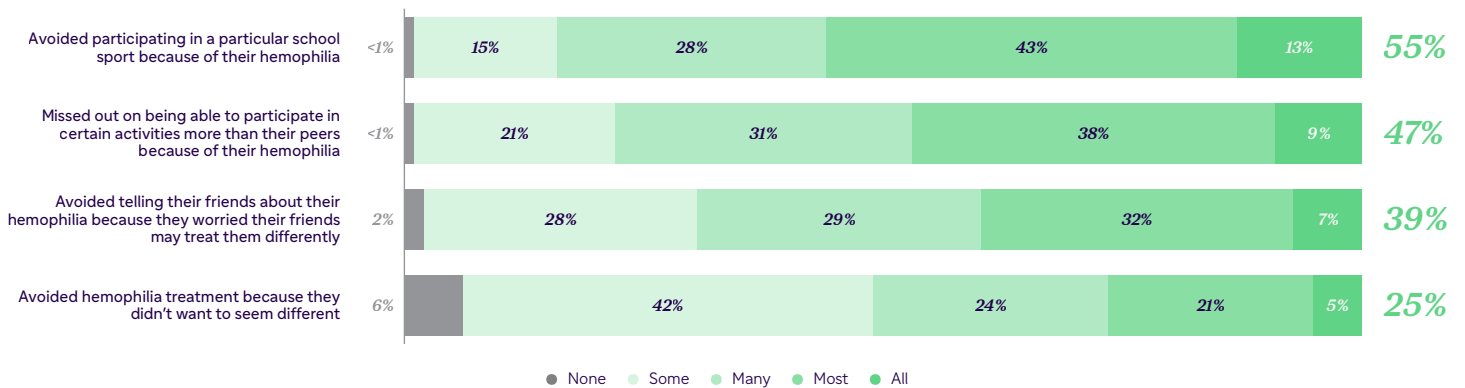
● Patient Data ● Caregiver Data ● Hematologist Data

Negative Impact of Hemophilia on Patients' Life/Lifestyle



Hematologists' Perspective on Number of Pediatric Hemophilia Patients Who Have Done Each

Most/all (net)



"Not sure/Don't recall" has not been included in the graph due to limited spacing

Focusing on Shared Decision Making and Patient Agency for Hemophilia Treatment:

Patients want a more active role in dictating their treatments and more options, and while hematologists agree on more involvement, they are satisfied with current treatment options.

Patients want a more active role in treatment decisions, and hematologists appear receptive.

- 83% of patients want a more active role in treatment decision making, a sentiment shared by hematologists - 84% of hematologists want their patients to be more involved in the process.
- Only 35% of patients feel their hematologist involved them in discussions regarding the course of treatment.
- 64% of caregivers help make treatment decisions for their loved ones, and 81% of caregivers want a more active role in making treatment decisions.
- 85% of patients agree their hematologist takes their personal life goals into consideration when discussing treatment plans, and 93% of hematologists agree they take their patient's personal life goals into consideration when discussing treatment plans.

Patients want more and better treatment options, citing change in frequency of treatment administration as a top improvement to make.

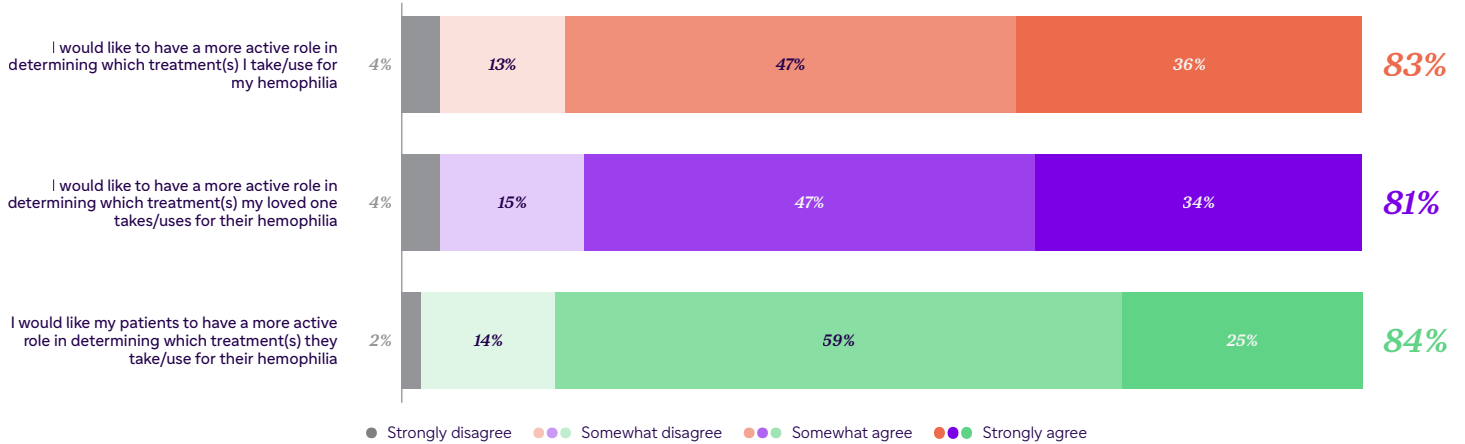
- Aside from having a more active role, patients (84%), caregivers (88%), and hematologists (91%) agree that they wish there were more treatment options for hemophilia available.
- 84% of patients want more available treatment options (with 81% wishing it was easier to get access to treatment options and 77% saying their treatment often disrupts their everyday life).
- 83% of hematologists are satisfied with the current prescription options available, yet 85% of hematologists wish it was easier for patients to access treatments.
- Around 4 in 5 hematologists think the mode (82%) and frequency (78%) of treatment administration is burdensome to their patients.

TOP-LINE SURVEY FINDINGS

● Patient Data ● Caregiver Data ● Hematologist Data

Desire for More Active Role in Treatment Decisions

Agree (net)



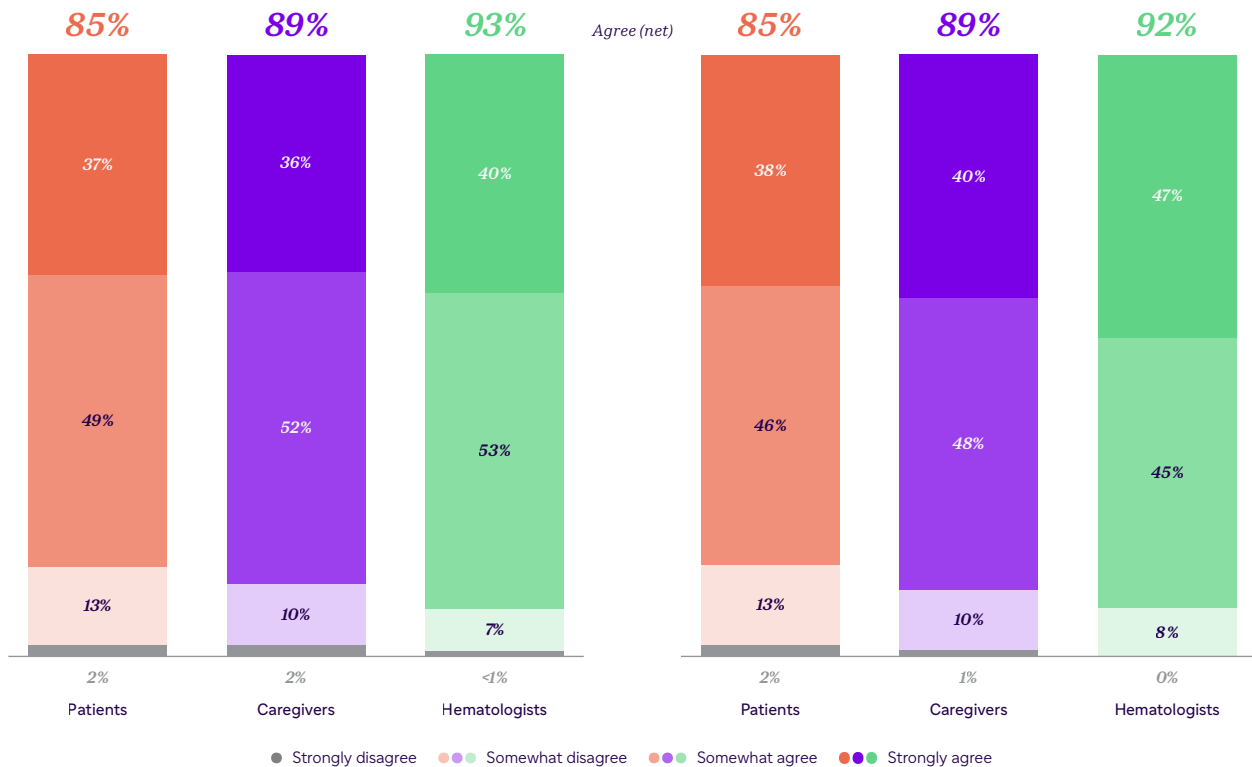
Considering/Discussing Patient Life Goals/Stages When Selecting Treatment

"I feel my/my loved one's healthcare provider takes my/their personal life goals into consideration when discussing treatment plans."

"I take my patients' personal life goals into consideration when discussing treatment plans."

"My healthcare provider and I/My loved one and their healthcare provider have discussed whether my/their hemophilia treatment is meeting their lifestyle at different life stages."

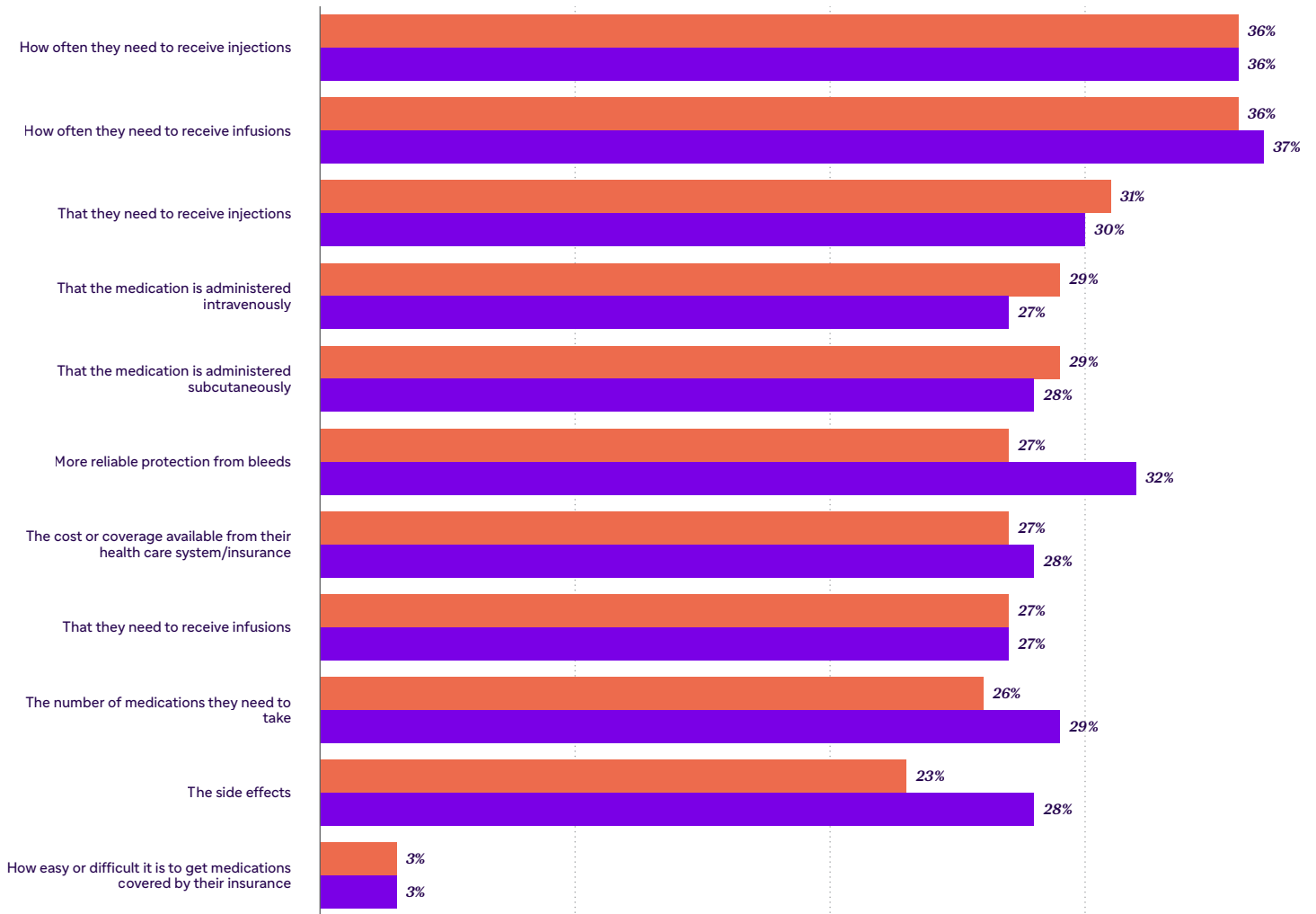
"It's important to discuss whether my patients' hemophilia treatment is meeting their lifestyle needs at different life stages."



TOP-LINE SURVEY FINDINGS

● Patient Data ● Caregiver Data

Desired Changes to Hemophilia Medications



Detailed Methodology Statement

The research was conducted online in the United States, United Kingdom, Germany, France, Italy, Spain, Japan, India, Canada, Australia, and China by The Harris Poll on behalf of Sanofi among 679 HCPs (health care providers whose primary medical specialty is hematology and see/treat 2+ patients with hemophilia per month), 950 patients (adults 18+ diagnosed with hemophilia), and 1,080 caregivers (adults 18+ who provide care or support to a friend or family member with hemophilia). The survey was conducted February 27—April 10, 2023.

Raw data were not weighted to adjust for geodemographics, except to provide each country equal share of voice, so thus are therefore only representative of the individuals who completed the survey. Respondents for this survey were selected from among those who have agreed to participate in The Harris Poll surveys.

The sampling precision of Harris online polls is measured by using a Bayesian credible interval. For this study, the sample data is accurate to within +4.7 percentage points for HCPs, +3.3 percentage points for patients, and +3.0 percentage points for caregivers using a 95% confidence level. This credible interval will be wider among subsets of the surveyed populations of interest.

All sample surveys and polls, whether or not they use probability sampling, are subject to other multiple sources of error which are most often not possible to quantify or estimate, including, but not limited to coverage error, error associated with nonresponse, error associated with question wording and response options, and post-survey weighting and adjustments.

Responses may not add up to 100% due to weighting, computer rounding and/or the acceptance of multiple responses.

References

1. <https://wfh.org/>