

Digital Engagement in the Sickle Cell Community

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Disclosures

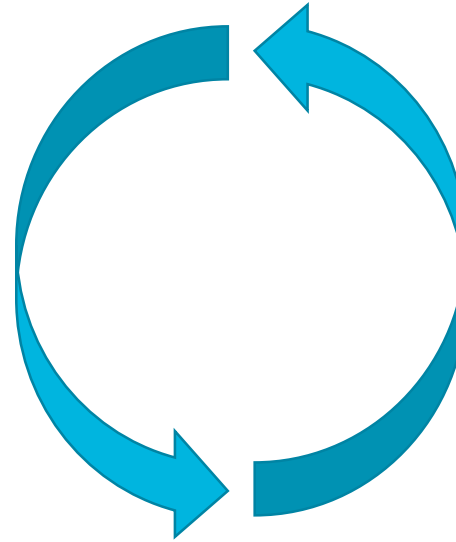
- Robin C. Howard is an employee and shareholder of Global Blood Therapeutics, Inc.
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- This study was supported by Global Blood Therapeutics, Inc.

Introduction

Many parts of the U.S. **lack access to adequate sickle cell care** due to the small number of physicians with expertise treating the condition

Connecting families with educational resources is important to help them better understand

- + The condition
- + Available treatments
- + Sources for support



Education is crucial to

- + Promote health literacy
- + Improve communication with health care providers
- + Foster dialogue with the broader community

Study Goal

Understand how caregivers and individuals with sickle cell **engage digitally** to:
Find, Use, & Share
information related to the condition

Methods

- In December 2017, a 25-question online survey was fielded by Return on Focus on behalf of Global Blood Therapeutics, Inc. (GBT) to:
 - Determine the digital educational resources the sickle cell community uses for disease education
 - Understand how information found online is accessed, used, and shared
- Eligible participants included primary caregivers of children aged 6-17 years and adults aged 18-60 years with sickle cell
- Participants were required to reside in the U.S.
- Participants were recruited via an online panel
- A total of **61 participants** completed the survey
 - 51 adults with sickle cell
 - 10 primary caregivers of children with sickle cell

Participant Characteristics

Individuals With Sickle Cell



n=51

- + 65% male
- + Average age is 37 years (range, 22-55 years)
- + 41% Medicaid / 49% commercial
- + 84% current or past use of hydroxyurea
- + 56% saw a primary care physician for treatment of sickle cell; 33% saw a hematologist
- + 49% report attainment of bachelor's degree; 25% attained an advanced degree
- + 67% report household income level from \$60,000-\$99,999 annually

Caregivers of Children With SCD

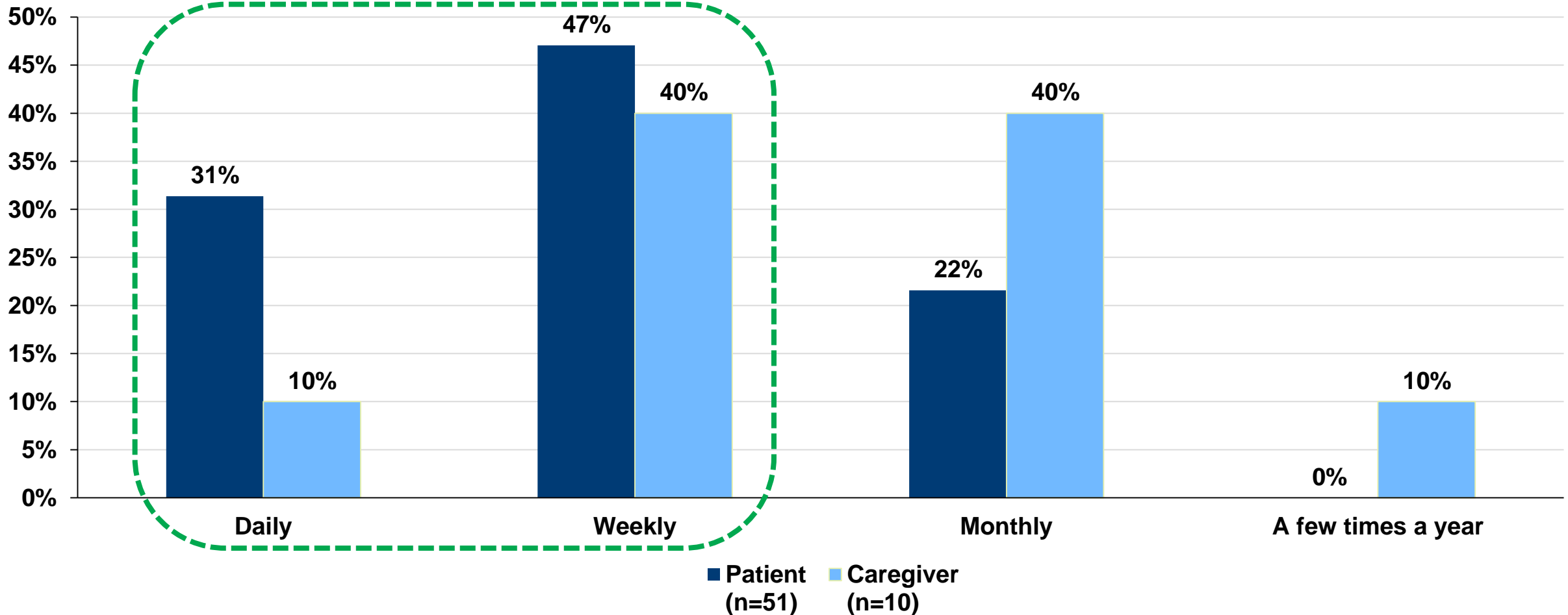


n=10

- + 60% care for a male child
- + Average age of child is 10 years (range, 6-15 years)
- + 40% Medicaid / 40% commercial
- + 70% current or past use of hydroxyurea
- + 50% saw a primary care physician for treatment of sickle cell; 30% saw a hematologist
- + 60% report attainment of bachelor's degree; 30% reporting only some college
- + 50% report household income level from \$20,000-\$59,999 annually

Most SCD Report Searching for SCD Information at Least Weekly

Frequency of Seeking Information About SCD

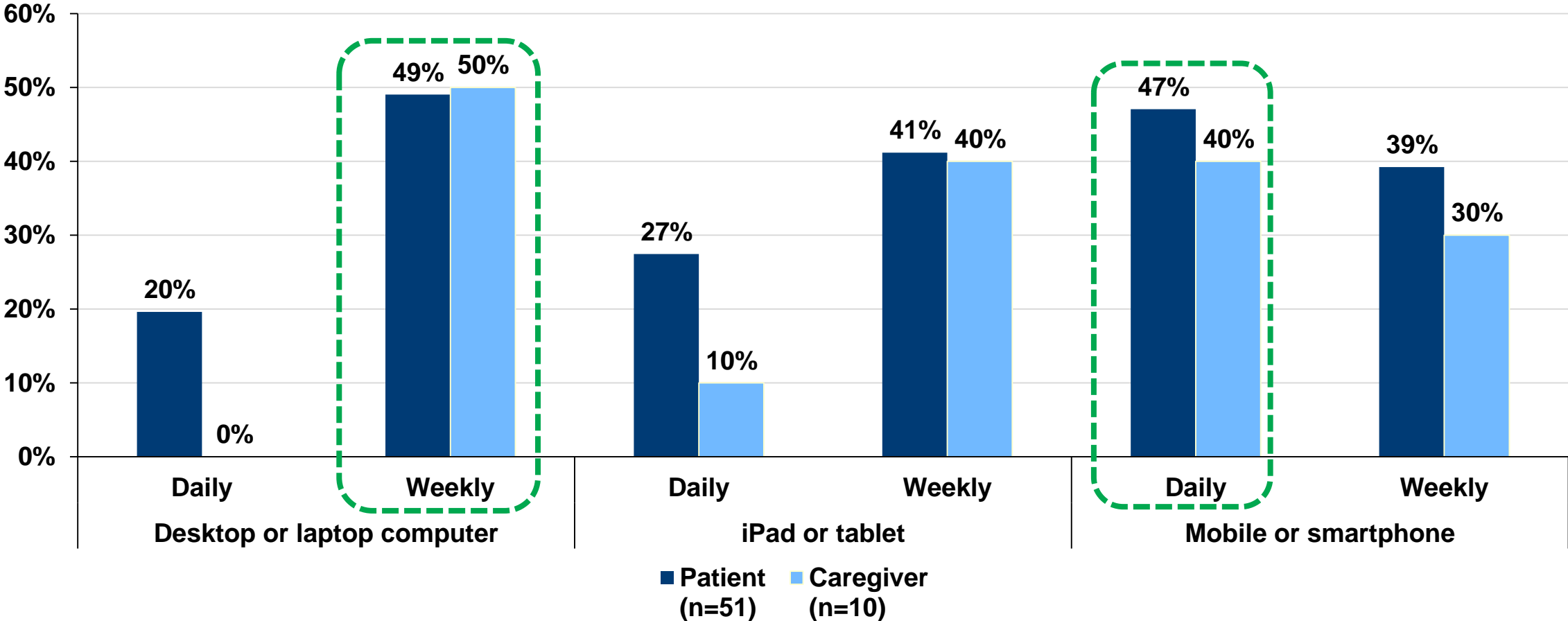


Source: Return on Focus Channel Survey n=61. January 2018

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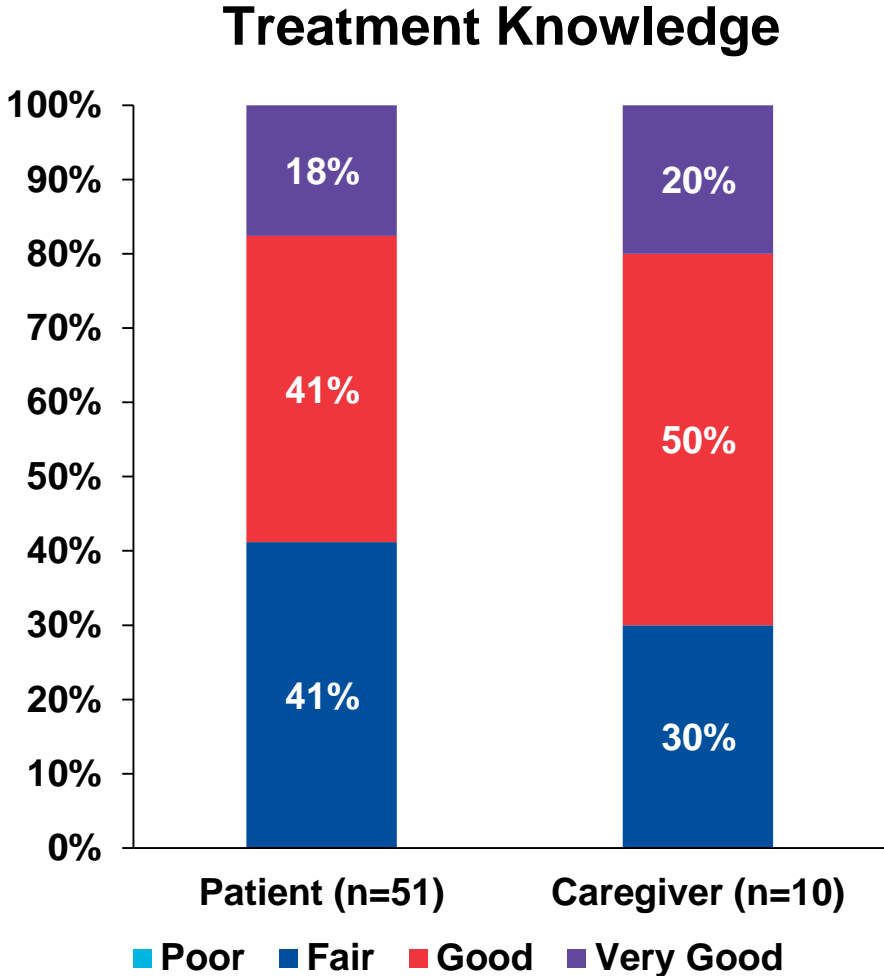
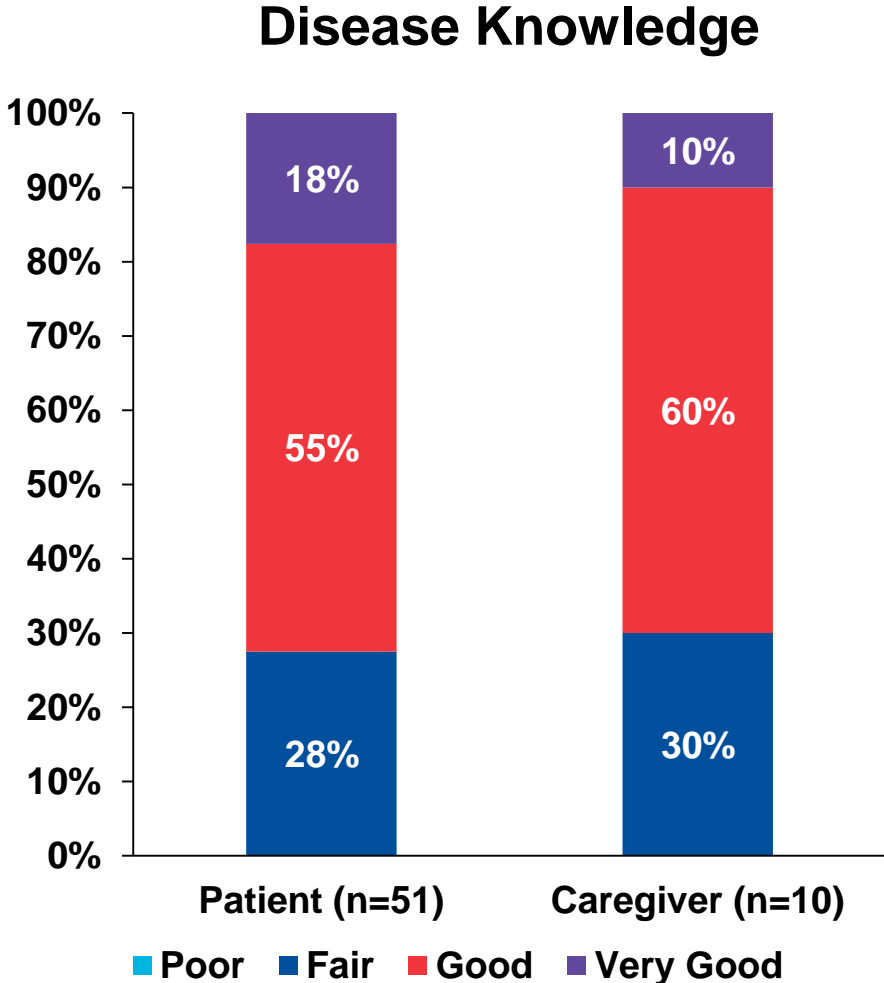
SCD Community Frequently Uses Mobile or Smartphones to Search for SCD Information, but Computer Use Is Also Common

Devices Used for Searches



Source: Return on Focus Channel Survey n=61. January 2018

SCD Community Perceive They Have Good or Very Good Knowledge About SCD and Its Treatments Overall



Source: Return on Focus Channel Survey n=61. January 2018

Multiple Channels of Information Are Influential for Individuals With SCD

Influence of Different Online Sources on Treatment Decisions

(Avg Rating 1-5, 5=most used)

	Patients (n=51)	Caregivers (n=10)	Total (n=61)
Sickle Cell Treatment Center	4.0	4.0	4.0
General Search Engine Results (e.g. Google, Yahoo)	4.0	3.3	3.9
Professional Society Websites (e.g. American Society for Hematology)	4.0	3.8	3.9
General Medical/Health Websites (e.g. WebMD, Mayo Clinic, KidsHealth)	3.8	3.7	3.8
SCD Advocacy Websites (e.g. SCDAAs)	3.8	3.6	3.8
Online Video Sites (e.g. YouTube, Vimeo)	4.0	2.7	3.8
Online Forums / Message Boards (e.g. Inspire or HealthUnlocked)	3.8	2.9	3.7
Facebook Pages	3.7	3.0	3.6
Government Agency Websites (e.g. CDC, PubMed, NIH)	3.6	3.0	3.5
Wikipedia	3.6	3.4	3.5
Mobile Applications	3.4	2.9	3.3
Twitter	3.4	2.1	3.2

SCDAA, Sickle Cell 101, WebMD, and Mayo Clinic Are Top Websites Visited in Last 6 Months

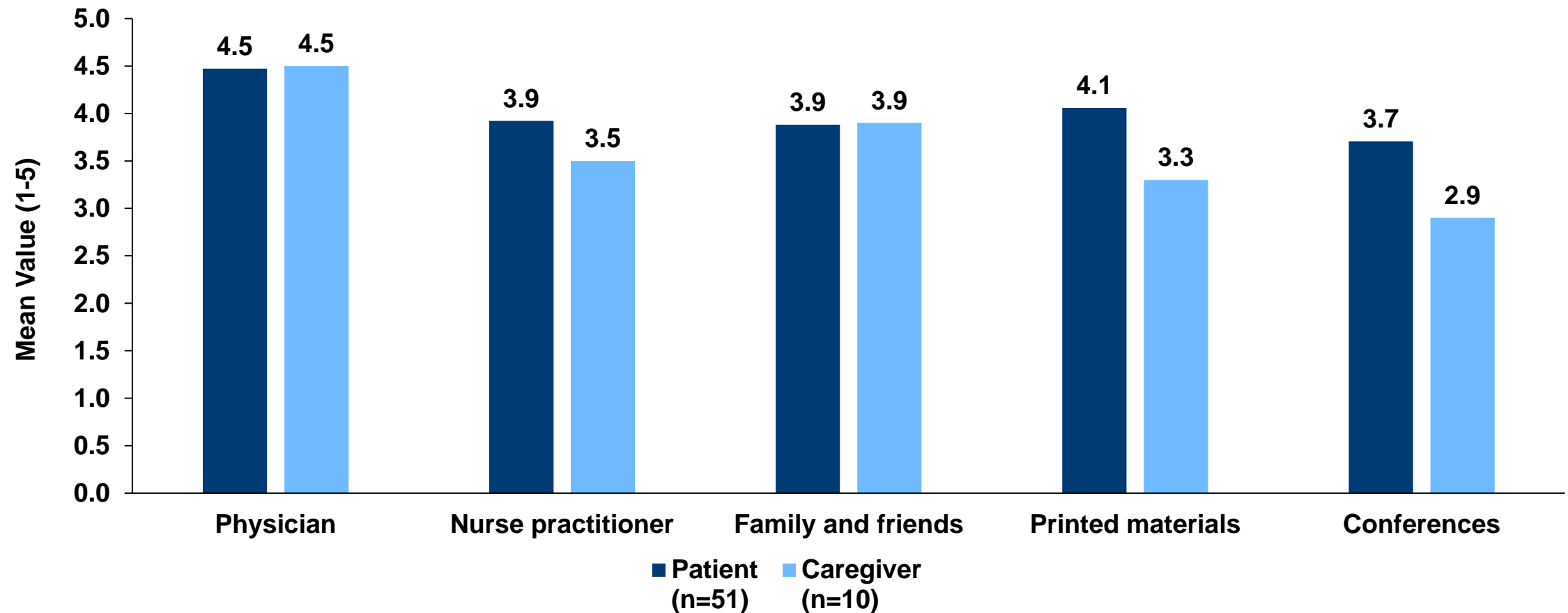
Sites Visited in Last 6 Months to Learn About Sickle Cell & Treatment Options

(Avg Rating 1-5, 5=most used)

	Patients (n=51)	Caregivers (n=10)	Total (n=61)
Sickle Cell Disease Association of America	49.0%	60.0%	50.8%
Sickle Cell 101	37.3%	10.0%	32.8%
WebMD	29.4%	50.0%	32.8%
Mayo Clinic	29.4%	10.0%	26.2%
Sickle Cell Warriors	25.5%	10.0%	23.0%
Sickle Cell Disease Coalition	19.6%	30.0%	21.3%
Sickle Cell Information Center - Emory	21.6%	20.0%	21.3%
Kids Health	13.7%	50.0%	19.7%
CDC Foundation	15.7%	10.0%	14.8%
Martin Center	11.8%	10.0%	11.5%
Indiana Hemophilia & Thrombosis Center	9.8%	0.0%	8.2%
I don't know/remember if I have visited any of these websites	3.9%	0.0%	3.3%

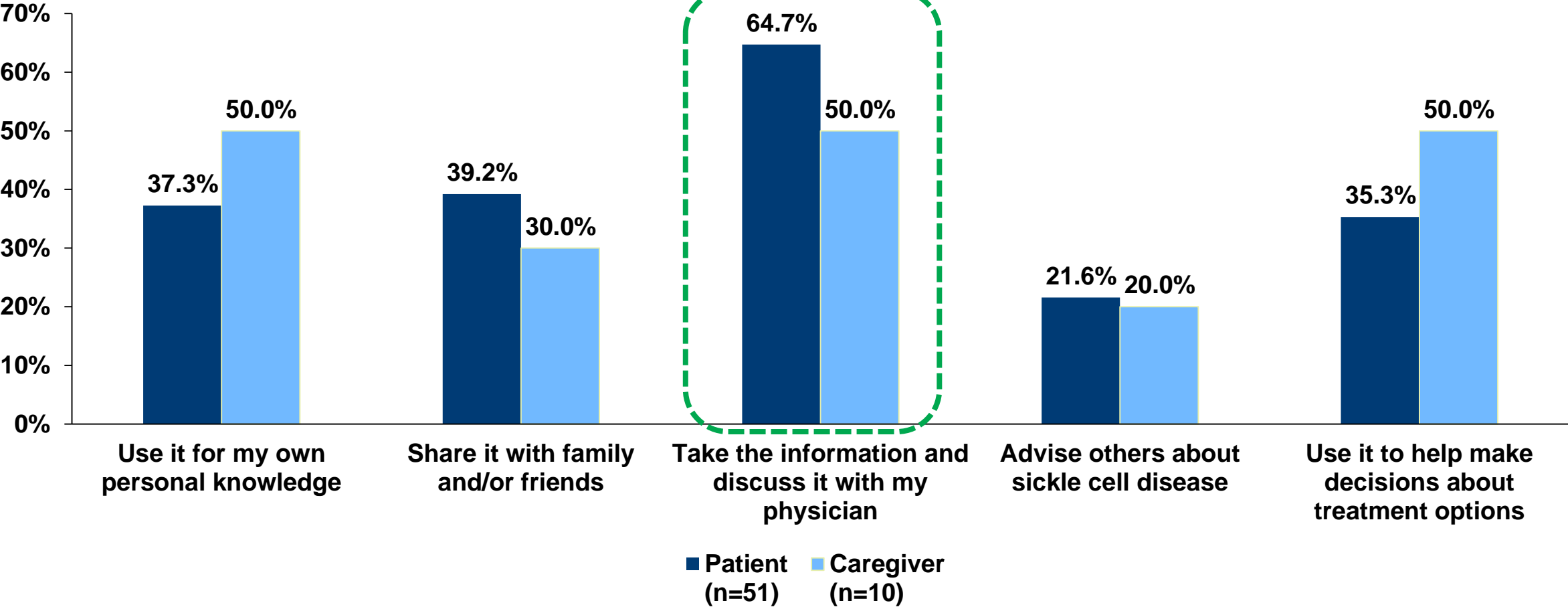
Individuals With SCD Value Treatment Information From Multiple Sources

Perceived Value of Sickle Cell Treatment Information Sources



A Significant Number of Individuals Use Information Obtained Digitally to Facilitate Discussions With Health Care Providers

How Information Is Used



Source: Return on Focus Channel Survey n=61. January 2018

Conclusions

- Individuals and primary caregivers of children with sickle cell are active seekers of information online
 - Many are using information that they find digitally to help inform and empower discussions with health care providers
- Community sourced advice is as important as education received from health care providers, and digital sites should consider sourcing content from a variety of perspectives
- Various devices are used for online searches, and digital education content should be formatted across a variety of screen sizes, to ensure readability and an overall good user experience
 - Materials should also be developed for ease of printing or sharing
- It is important for digital education sites to update content regularly to ensure accuracy of information
- Given the high reliance on Internet searches to seek information, it is important for content providers to consider search engine optimization

QUESTIONS?



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