Patients' Perceptions of Care at the US Federally Funded Hemophilia Treatment Centers

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Background

The National Hemophilia Program Coordinating Center (NHPCC) is funded by the United States Health Resources and Services Administration (HRSA) through the American Thrombosis and Hemostasis Network (ATHN) to facilitate and evaluate the activities of the eight federally funded regional networks of hemophilia treatment centers (HTCs). In this role, the NHPCC conducted the first national needs assessment of patients treated at the US HTCs. A third party consultant, Center for Community Health and Evaluation (part of Group Health Research Institute) collaborated with the NHPCC Needs Assessment Work Group to develop and implement a survey methodology.

Materials and Methods

In September 2013, 127 out of 135 HTCs mailed a four page survey with an electronic option in English and Spanish to 24,308 households of patients with hemophilia, von Willebrand (VWD) and other inherited coagulation disorders. These patients had a significant contact with an HTC during 2012, as defined by the National Hemophilia Data Set (HDS). The surveys were anonymous and linked by barcode to the patients' corresponding HTC. The survey questions were designed to answer:

- To what extent do patients report they received—(a) care and services they needed, (b) information they needed, and c) support for the transition to adulthood?
- How well did the services they received meet their needs?
- What are patient perceptions regarding care delivery—(a) barriers to care/services, (b) patient-centered visits/ interactions with HTC team members, and c) coordination of care?

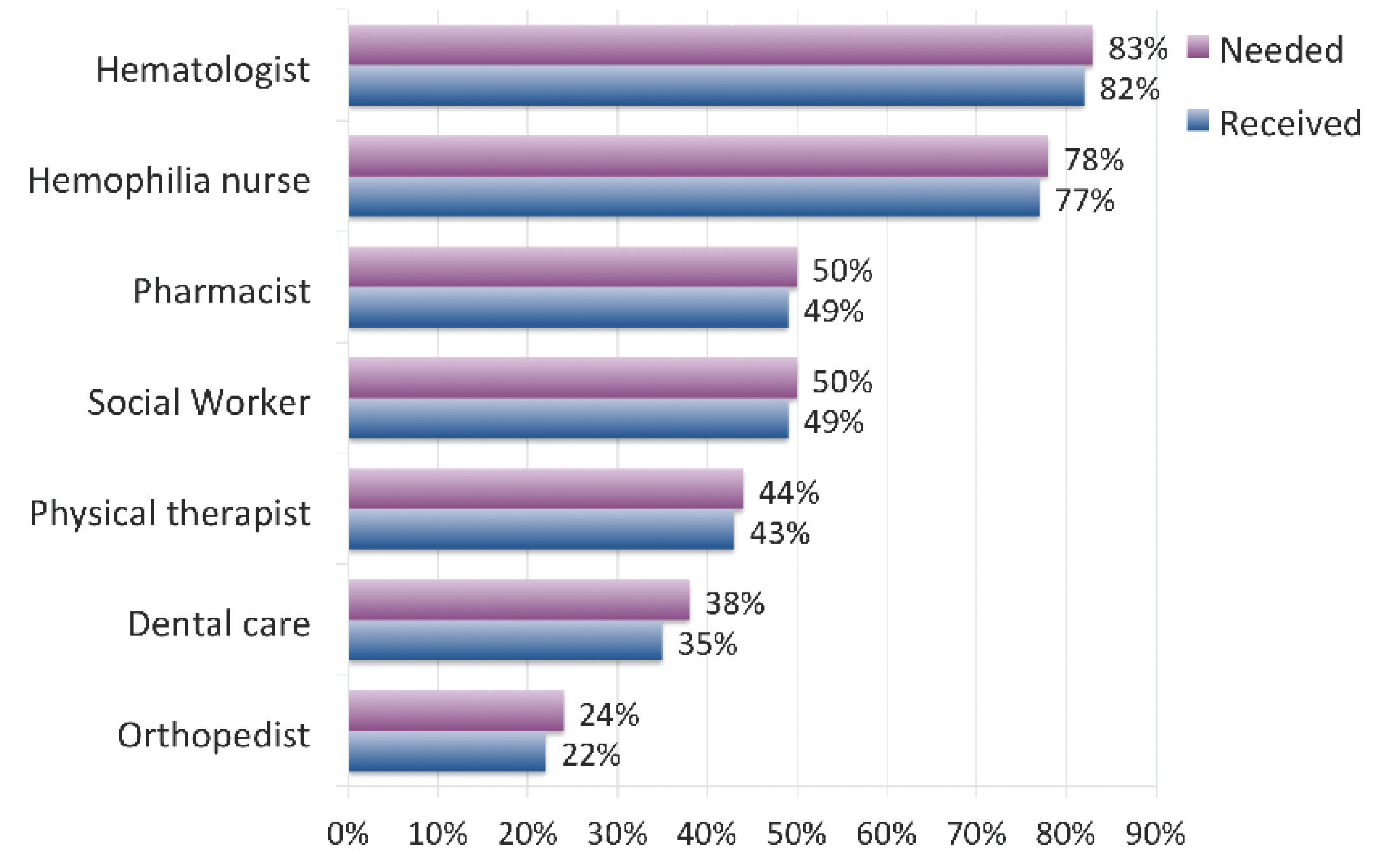
Results

There were 4004 questionnaires returned to the third party for analysis (16.5% response rate).
Analyses of the data included one-way frequencies, cross-tabulations and regression analysis using Stata v 12.

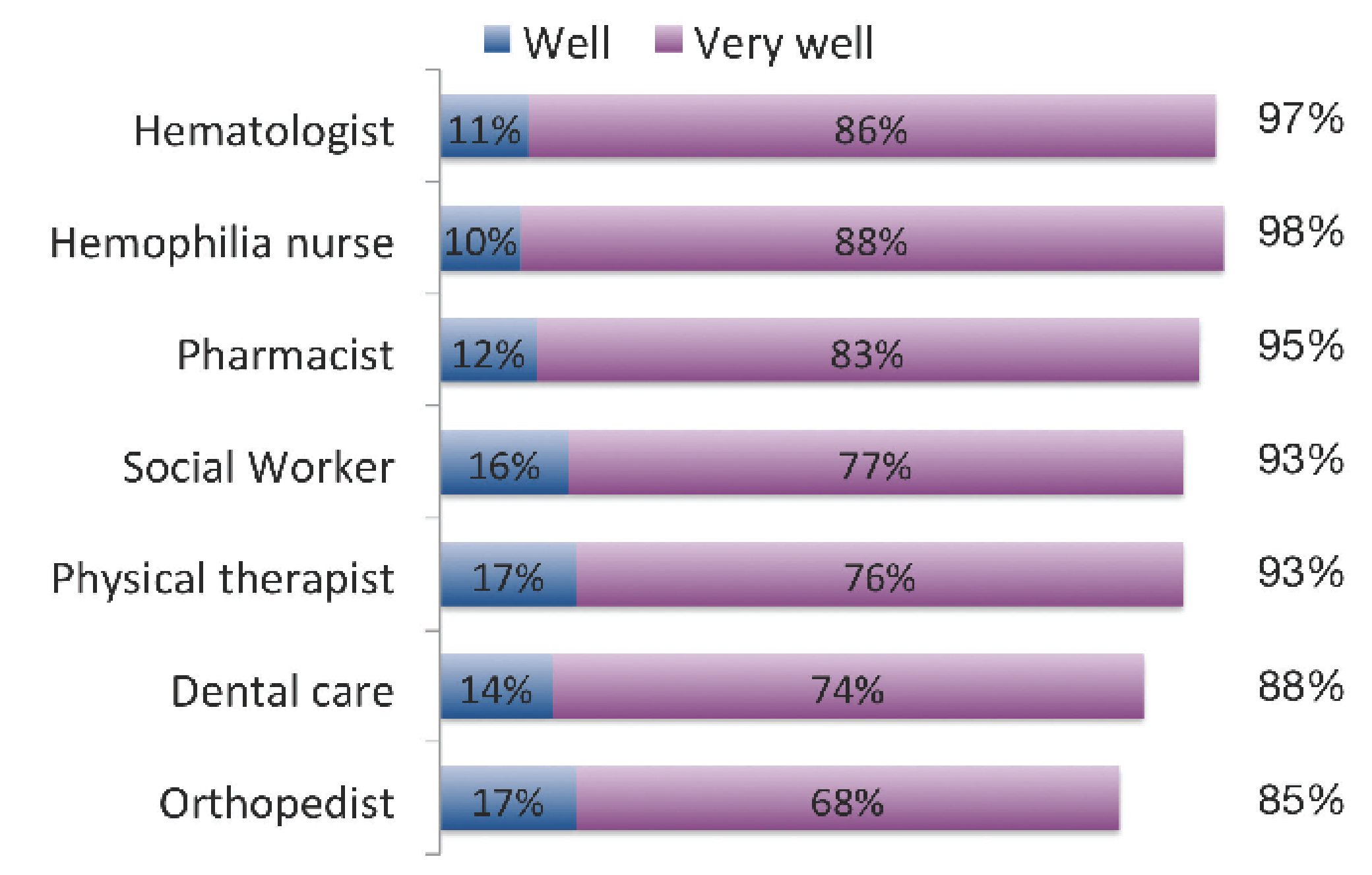
Representativeness of the Sample. 4,004 respondents of 24,308 surveyed population (16.5% response rate)

Demographic Characteristics	% of Survey Respondents	% of Hemophilia Data Set Population
Sex		
Males	73%	69%
Age		
25+ years	50%	37%
Race/Ethnicity		
Non-White	25%	29%
Disease Type		
Severe Hemophilia A&B	34%	26%
Von Willebrand Disease – Type 1	16%	34%

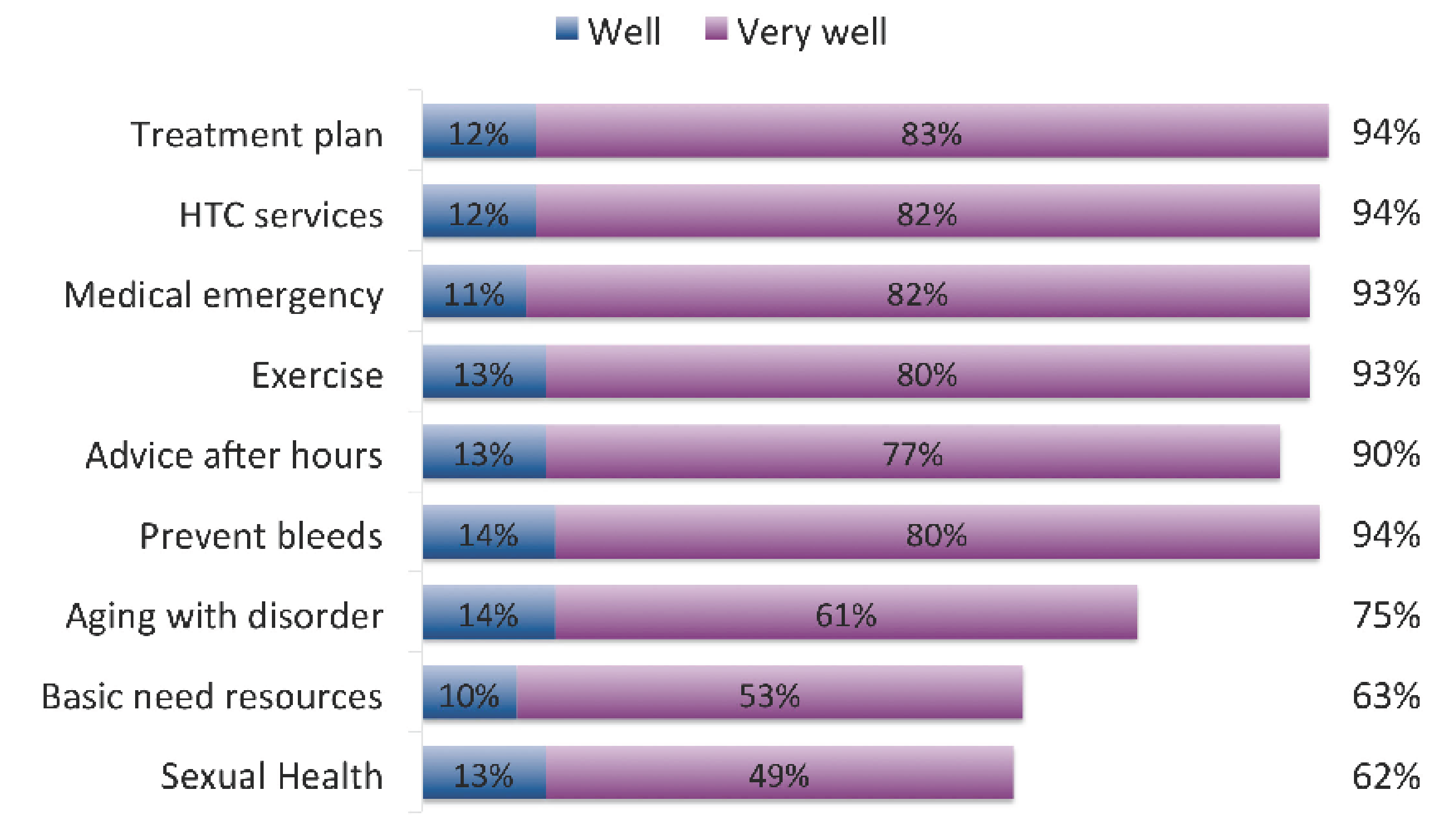
Perception of HTC Services—Services needed, received.



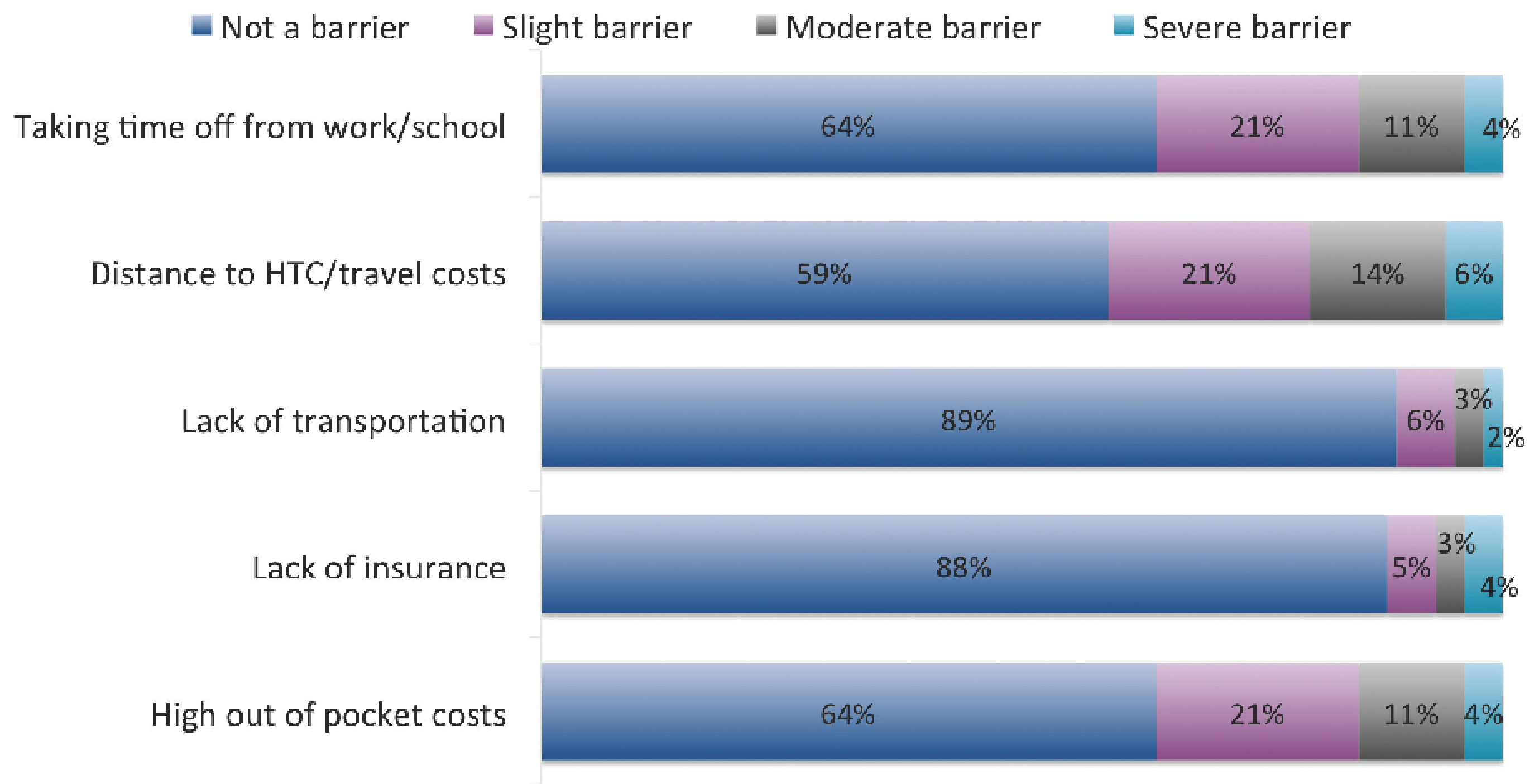
Perception of HTC Services—How well services met needs.



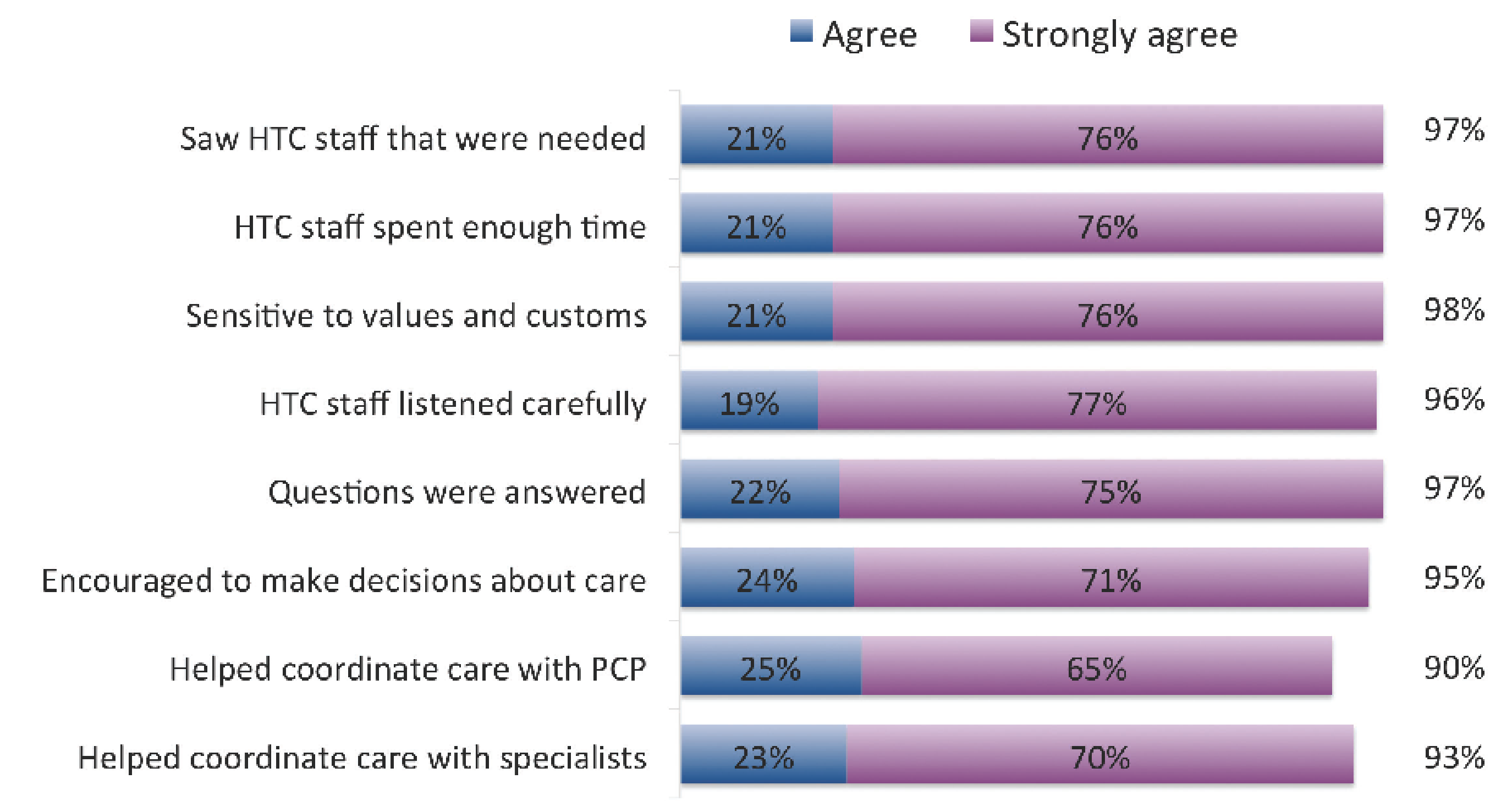
Perception of Information Needs



Perception of Barriers to Care



Perception of Delivery of Care



Conclusions

The results from this national survey showed that patients highly rated the services and information provided by the HTCs and reported few barriers to care. Specifically:

- Less than 3% of respondents reported they needed services and information and did not receive it across a wide range of categories.
- 70%-80% rated the services and information as meeting their needs "well" or "very well."
- 90%-97% of respondents "agreed" or "strongly agreed" they were receiving tailored, culturally sensitive care, and that HTC staff listened, and spent enough time with patients.
- There were few barriers to receiving care, with only a small proportion of respondents citing moderate or severe barriers related to time, distance from the HTC, or insurance costs. Further analysis revealed that where barriers/problems existed, they were two to three times more prevalent among minorities.

The principal limitation to the survey is the low response rate. Those returning the surveys may be those most connected to the HTC and thus, may be more supportive of its efforts. Over-represented respondents included males, those with severe hemophilia and older patients. Minorities, women and younger patients were under represented. The sample was limited to active HTC patients and the results cannot be generalized to all patients with bleeding disorders.

The focus of this survey was to collect national, aggregate data to provide insight into areas where further improvement efforts might be directed. Comparisons to determine inter-regional or HTC differences require further analyses. Additional information needs to be collected for areas in which respondents indicated that information did not meet their needs and include: aging with the disorder, basic needs resources, dietary advice and sexual health. Further evaluation of gaps in services to the under-represented populations of minorities and women needs is required to develop strategies to improve their care.

Acknowledgements

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our vision. *To advance and improve the care of individuals affected by bleeding and thrombotic disorders.*
our mission. *To provide stewardship of a secure national database, adherent to all privacy guidelines, which will be used to support clinical outcomes analysis, research, advocacy and public health reporting in the hemostasis and thrombosis community.*
our values. *Improving clinical outcomes and care, facilitating continuity of care, fostering collaboration, maintaining confidentiality, conserving resources through a common infrastructure.*

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