

Sexual health in hemophilia: Identifying and responding to healthcare providers' needs

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Introduction

- The topics of sexual health and sexuality have received growing attention in the hemophilia community over the past few years.
- Research suggests that the majority of people with hemophilia (PWH) experience a high degree of satisfaction with all aspects of sexual intimacy,¹ but there are unique physical and psychosocial aspects of hemophilia that may have a negative impact on the sexual lives of PWH.
- Little is known about whether these needs are being addressed in the hemophilia treatment centre (HTC) setting.

Objective

- The objective of this needs assessment was to ascertain, understand and address Canadian hemophilia healthcare providers' (HCPs') practices, comfort levels and knowledge needs discussing sexual health with patients.

Materials and methods

- The needs assessment was undertaken by the Canadian Hemophilia Experiences, Results and Opportunities (HERO) National Advisory Board, with assistance from SCRIPT.
- A 34-question survey was used to collect data from HCPs (hematologists, nurses, physiotherapists and social workers) who work at HTCs in Canada.
- Invitations distributed through HCP associations to reach the desired audiences:
 - Association of Hemophilia Clinic Directors of Canada (AHCDC)
 - Canadian Physiotherapists in Hemophilia Care (CPHC)
 - Canadian Association of Nurses in Hemophilia Care (CANHC)
 - Canadian Social Workers in Hemophilia Care (CSWHC)
- The survey was administered between September and October 2014 using both Survey Monkey (online survey software) and paper copies of the survey.
- A total of 152 individuals were invited to participate.

- HCPs' comfort levels discussing sexual health with young patients and/or parents were similar, 16% were completely comfortable, 42% were somewhat comfortable, 29% were somewhat uncomfortable, 10% were completely uncomfortable, and 3% were unsure.

HCPs' roles and responsibilities for sexual health

- Respondents' views on which member of the hemophilia care team should be responsible for discussions of sexual health with adult patients and young patients varied: the most popular answer for both adults and young patients was whichever member the patient is comfortable with (78% and 66%, respectively). For adults, the physiotherapist and nurse were chosen by 44% of respondents, the physician by 41%, social worker 33%, and 7% other (health psychologist). For young people, 63% of respondents indicated the physician, 55% the nurse, 50% the physiotherapist, 45% the social worker and 5% other (pediatrician, OB/GYN, health psychologist).

Previous training and educational needs

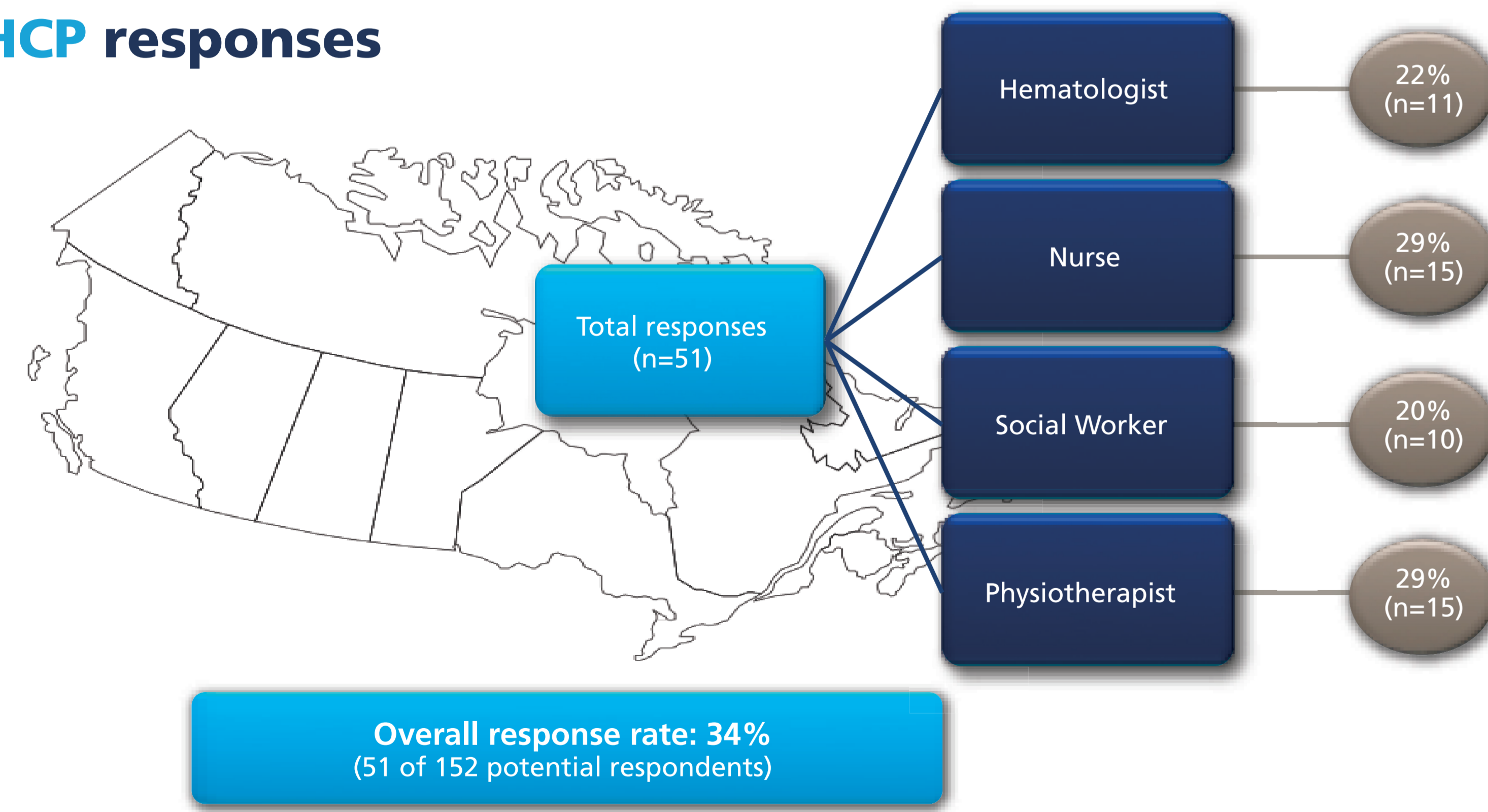
- 15% of respondents indicated they had been provided with training, and 30% had been provided with educational materials related to discussing sexual health with patients, whereas 59% had received neither training nor educational materials.
- 81% of respondents felt that training or educational materials would increase the likelihood of more discussions with patients with hemophilia about sexual health, 19% did not.

Results

Demographics

A total of 51 individuals responded to the survey for a response rate of 33.6%.

HCP responses

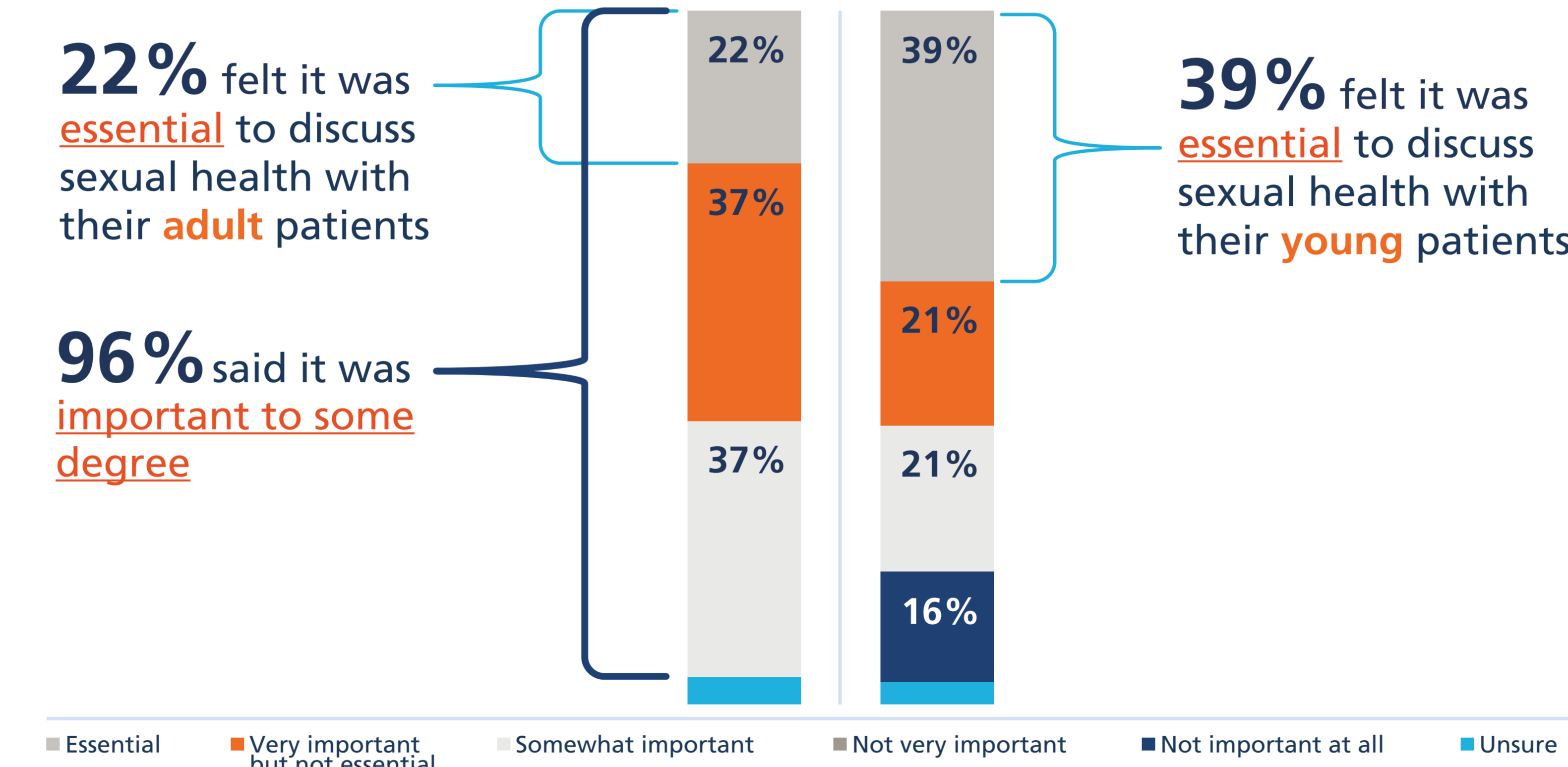


Number of years treating PWH varied:

- 26% of respondents had provided care for 16 to 30 years.
- 45% had provided care for 6 to 15 years.
- 29% had provided care for 0 to 5 years.

13% of respondents treated adults only, 36% pediatric/adolescents only and 51% treated both adult and pediatric patients.

Importance of sexual health

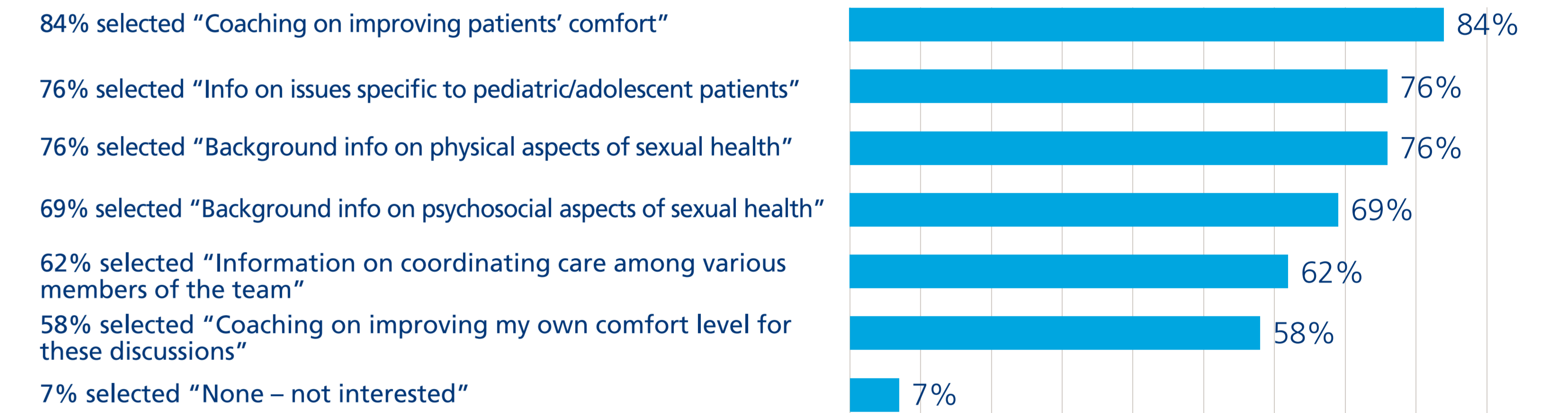


- When it comes to how often HCPs discuss psychosocial and emotional aspects of sexual health with adult patients, 22% of respondents reported they do not engage in these discussions but know other members of the HTC team do, 26% do not and do not know if other members of the team do, 4% discuss sexual health 50% to 80% of the time, 7% discuss it 20% to 50% of the time, and 41% discuss sexual health less than 20% of the time.
- With young PWH, 11% of respondents do not engage in discussions about psychosocial and emotional aspects of sexual health, but indicated that other members of the team do, 39% do not engage in these discussions or know if other members of the HTC do, 6% were unsure, 5% engage in these discussions over 80% of the time, 6% discuss sexual health 50% to 80% of the time, and 33% less than 20% of the time.

Comfort levels of HCPs and patients

- When it comes to HCPs' comfort discussing elements of sexual health with adult patients and/or their sexual partners in the clinical setting, 15% indicated they were completely comfortable, 37% were somewhat comfortable, 33% were somewhat uncomfortable, 11% were completely uncomfortable and 4% were unsure.

Training topics of interest to HCPs



Barriers

- HCPs perceived the following barriers to discussing and assessing sexual health as part of their practice: issues relating to parents of young patients, disclosures/confidentiality, reluctance to leave the room; HCPs' general comfort levels discussing sexual health; patients' comfort levels and lack of time during appointments.

Conclusions

Sexual health is not routinely discussed with all patients by HCPs at HTCs. Training and the availability of educational materials are lacking among Canadian HCPs, but may improve comfort levels and the likelihood of these discussions.

Next steps

These findings will be used to develop a pilot training program about sexual health to enhance the capacity of HCPs in HTCs in Canada to engage PWH in discussions and to provide care related to sexual health.

Reference: 1. Cassis F, Forsyth A, Gregory M, Lorio A. Qualitative and quantitative assessment of sexual intimacy in people with haemophilia in the HERO study. *Haemophilia* 2012;18(3):143.

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