

What do Canadian men with hemophilia need to know to facilitate optimal disease self-management? A mixed methods approach

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Introduction

Approximately 3000 Canadian adults with hemophilia actively manage this chronic disease through self infusion at home with support from a Hemophilia Treatment Centre (HTC), of which there are 24 across the country.¹ Self management places responsibility on individuals to be knowledgeable about the disease, treatment approaches and their rationale, and possible complications and prevention strategies². To date, only 2 studies that assess individuals' knowledge levels and understanding of hemophilia have been published, and no Canadian data on this topic exist^{3,4}. The availability of such data could lead to better educational strategies and optimal disease management.

Objectives

To determine what individuals with hemophilia know and would like to know about their disease and its treatment from the perspectives of physicians, allied healthcare professionals working in hemophilia (nurses, physiotherapists, social workers), and Canadian men with hemophilia, to facilitate optimal disease self-management.

Methods

Two phase, mixed methods design:

Phase 1 Qualitative: 3 focus groups and 2 interviews (13 participants) were conducted with physicians and allied healthcare providers in the field of hemophilia (nurses, physiotherapists, social workers) to identify from their perspective knowledge required for disease management by men with hemophilia;

Participants were asked: "What do you think is important for men living with hemophilia to know about the disease and its treatment?" Probes: What types of information do patients seek from the HTC? Is there information patients find difficult to understand or retain? What are the best ways of sharing information with patients?

Phase 2 Quantitative: Data from phase 1 were used to develop a survey which was disseminated to adult males with hemophilia at 3 HTCs across Canada. Self reported current knowledge levels and knowledge seeking were measured.

Results

In phase 1, healthcare providers identified the following areas of knowledge that they considered to be important for individuals to possess:

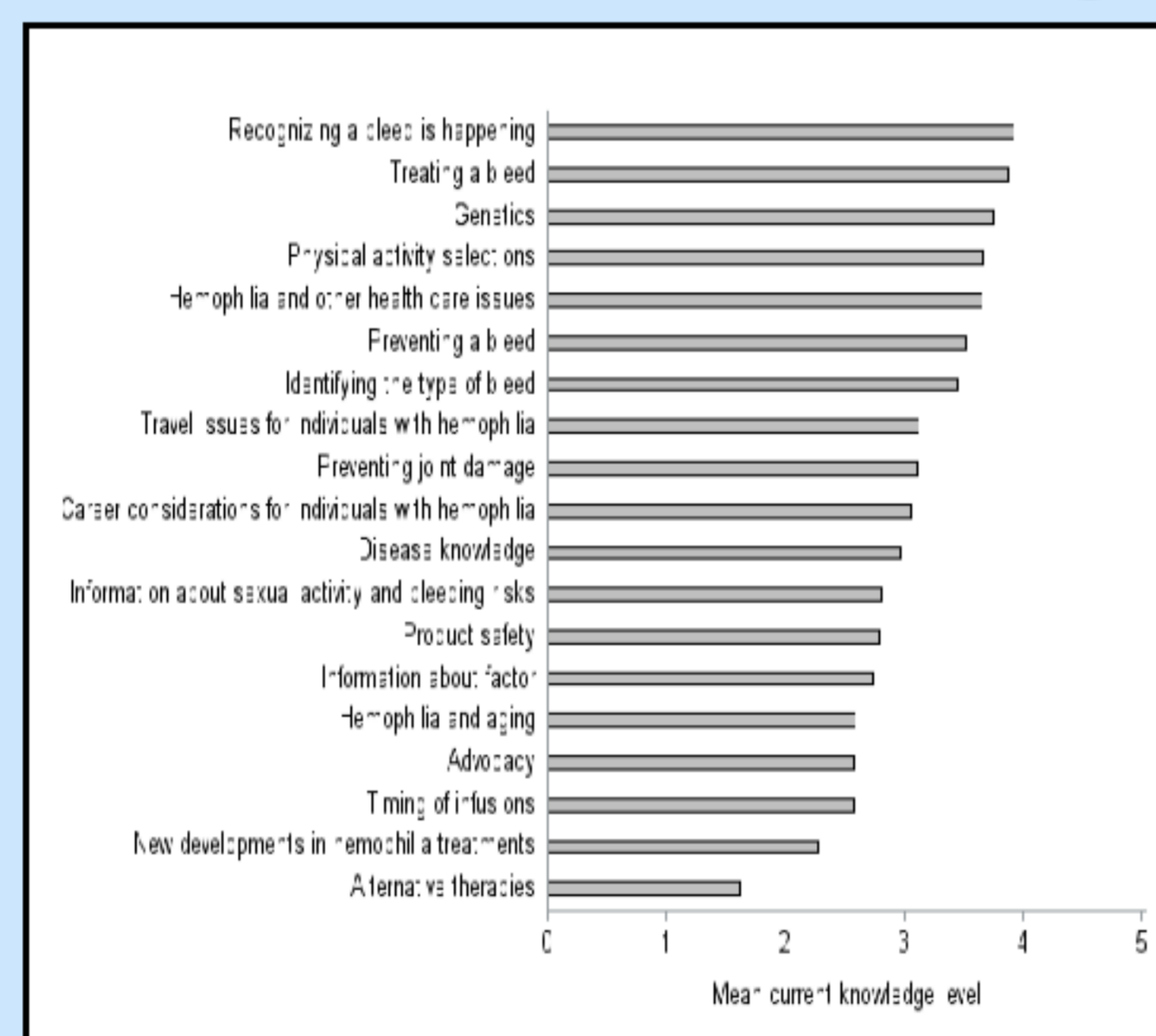
- Recognizing that a bleed is happening
- Treating a bleed
- Disease knowledge
- Travel issues
- Information about factor
- Preventing a bleed
- Hemophilia and aging
- Identifying the type of bleed
- Product safety
- Alternative therapies
- Genetics
- Sexual activity / bleeding risks
- Timing of infusions
- Hemophilia / other health care issues
- Physical activity
- Career considerations
- Advocacy
- New treatment developments
- Preventing joint damage

Providers also emphasized the roles of rapport, timing and context in successful knowledge sharing, and the impact of time restrictions in busy clinic settings. They recommended individualizing education according to personal needs and learning styles, but acknowledged the difficulty in assessing individuals' knowledge needs and gaps.

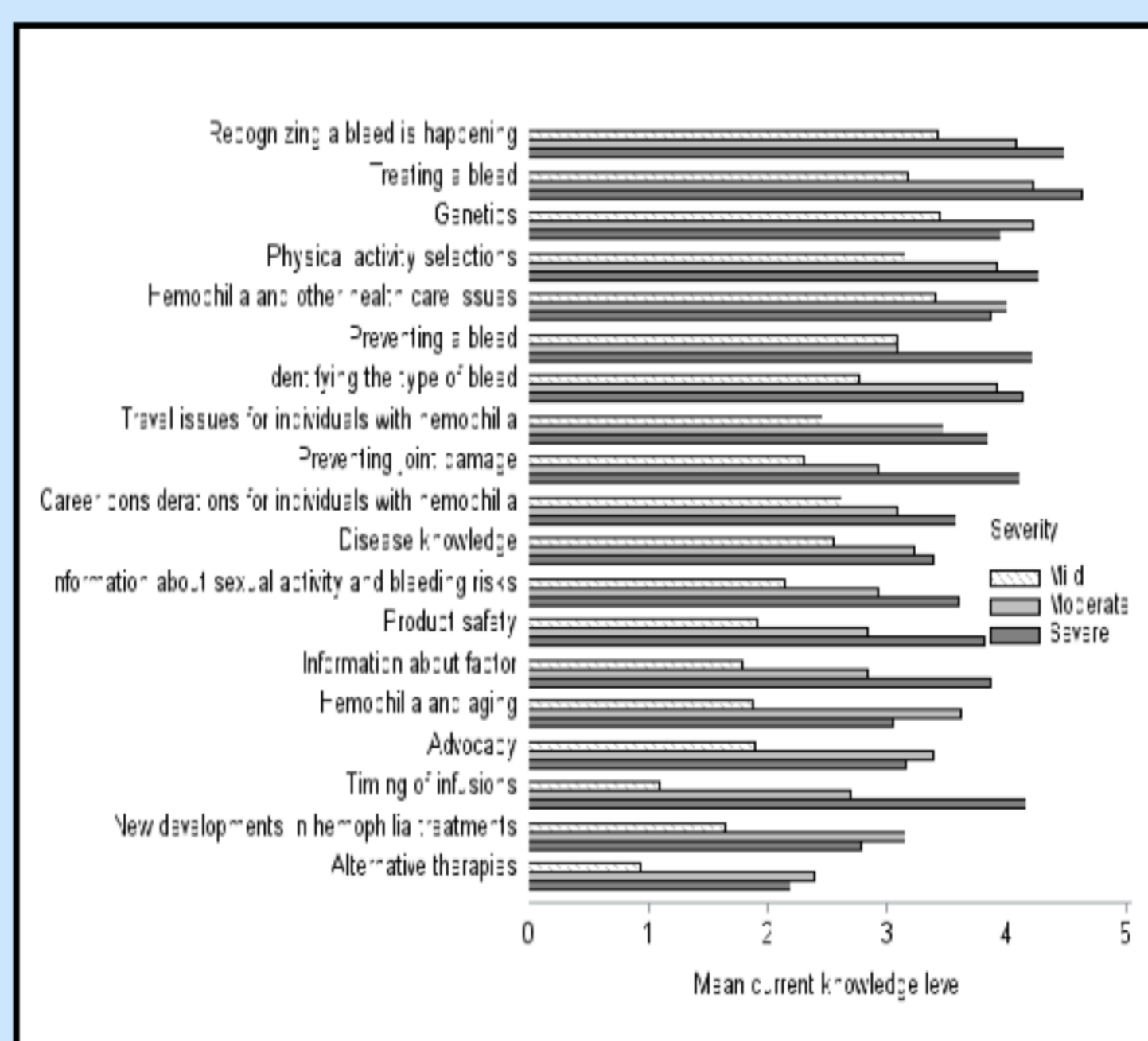
In phase 2, the 19 knowledge areas identified by healthcare providers were used to develop the survey:

- 104 / 280 (37%) responded to the survey
- 75% of respondents had Hemophilia A, 25% of respondents had Hemophilia B
- 48.5% had mild hemophilia, 12.5% had moderate hemophilia and 39% had severe hemophilia

Mean current knowledge levels were calculated:

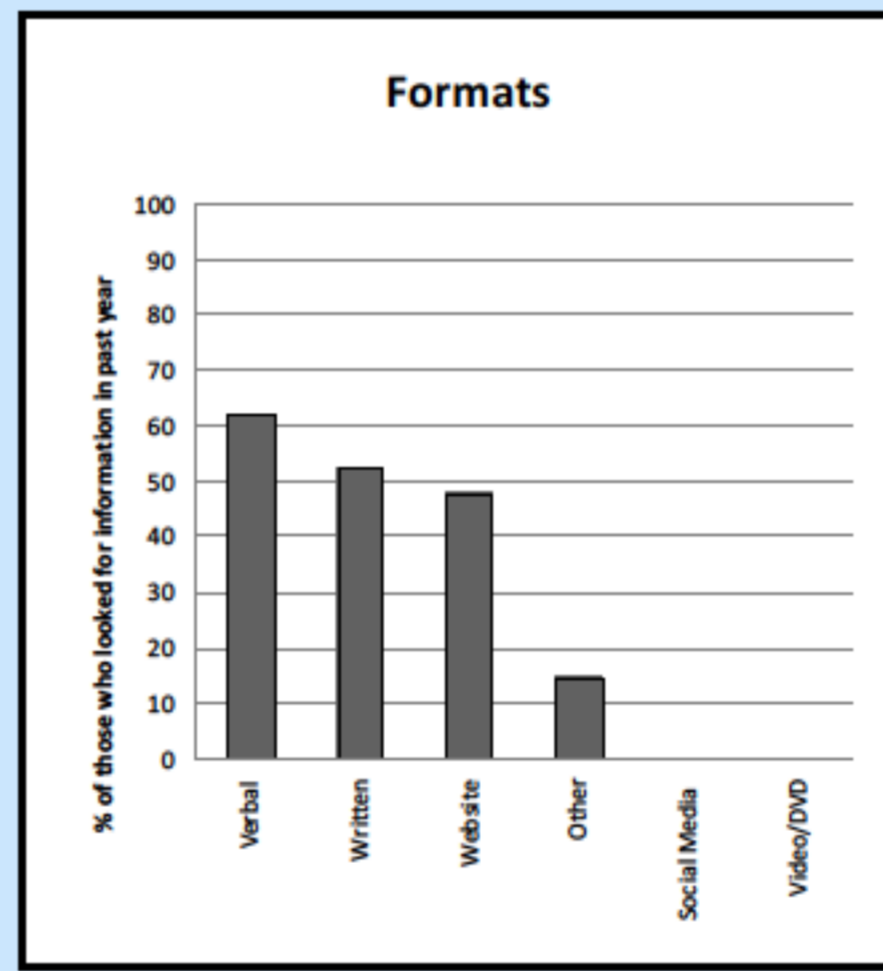
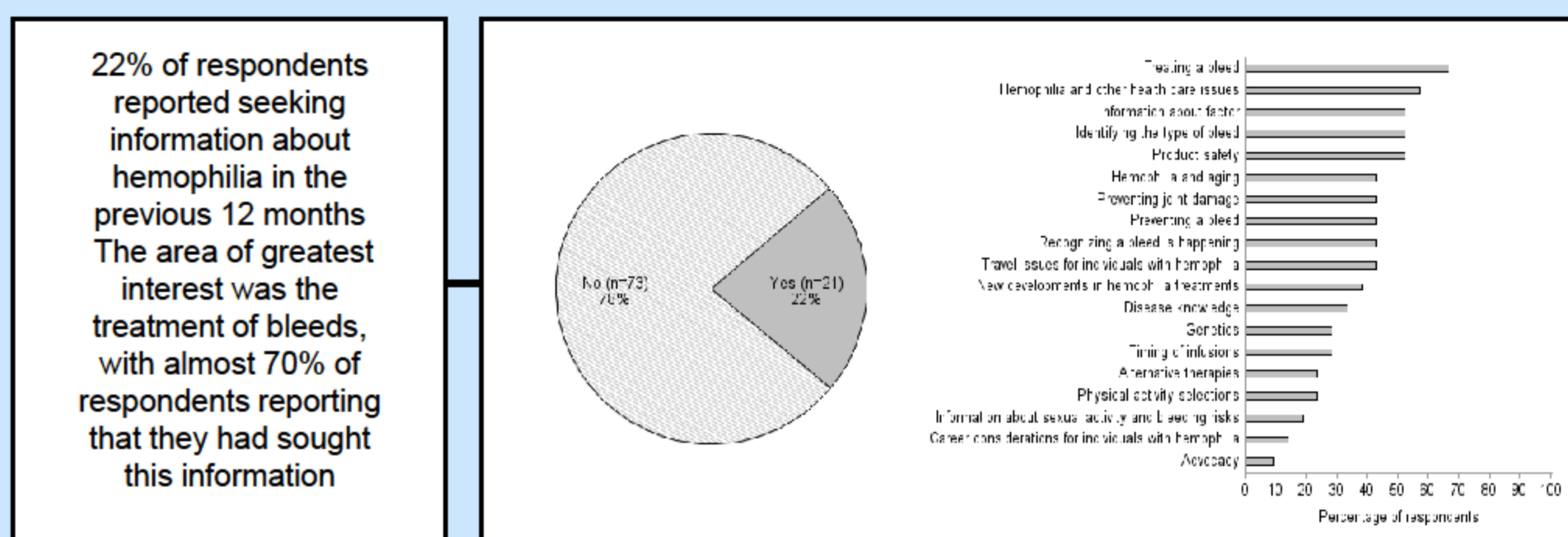


Respondents reported the highest levels of knowledge in the areas of recognizing and treating a bleed, followed by knowledge of the genetics of hemophilia, physical activity selections and knowledge of hemophilia and other health care issues.



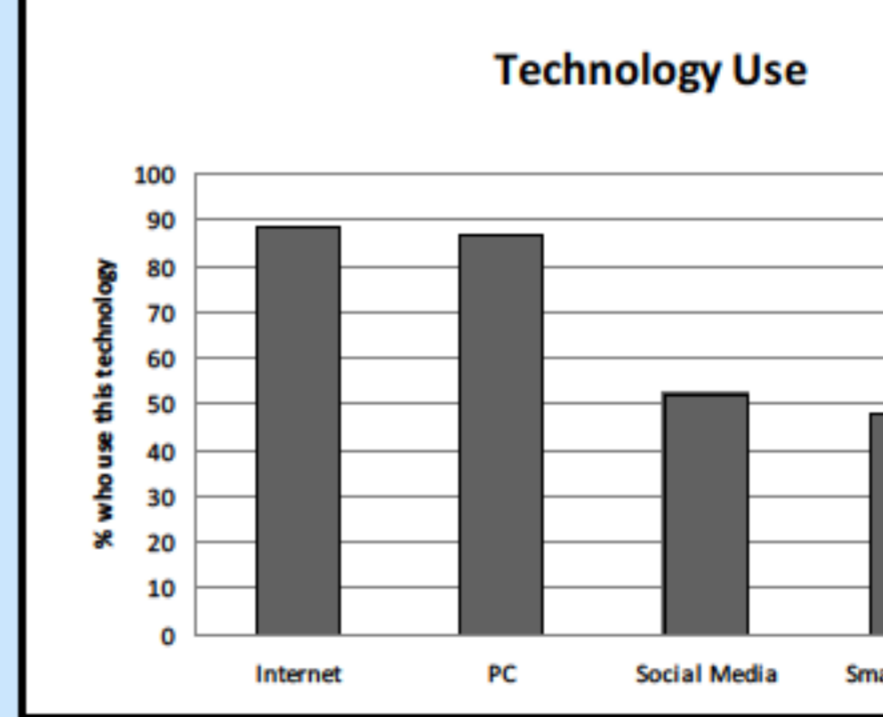
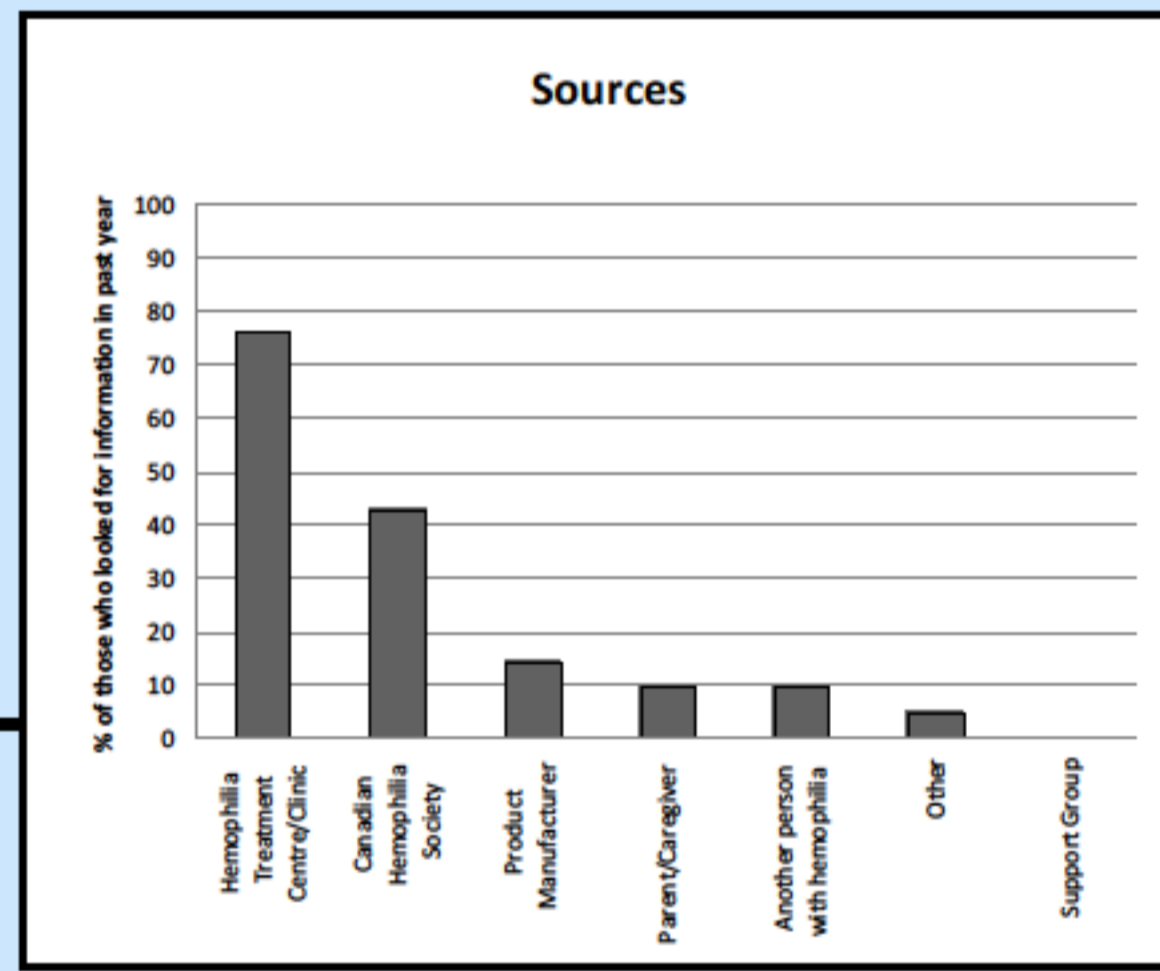
Current knowledge in all areas was positively correlated with an increased severity of hemophilia. This correlation was statistically significant for all areas of knowledge except genetics and the relationship between hemophilia and other health care issues.

Knowledge seeking behaviour was measured:



• The majority of respondents obtained information verbally

• Written formats and websites were the next most frequently accessed sources



Respondents reported their technology use as follows: PC / internet (84%), social media(48%), smart phone (44%), tablet (26%).

Conclusions

Canadian men with hemophilia are well informed about the disease. Healthcare providers at HTCs play substantive roles in this, supporting and educating clients on their lifelong journeys with hemophilia. Survey respondents were knowledgeable in the areas identified as essential for good disease management by healthcare providers (recognition, identification and treatment of bleeds), and less knowledgeable in areas identified by providers as those in which knowledge transfer could be improved (sexual activity and hemophilia, aging and timing of infusions). Thus there was congruence between the results from each phase of the study.

The HTC was the preferred source of information for individuals, supporting the findings of a previous study⁴. The second most frequented source was the website of the Canadian Hemophilia Society, which is also the primary source of educational materials for healthcare providers, and is generally regarded as a trusted source of information on hemophilia within Canada and beyond.

The majority of respondents obtained information verbally or in written form, as would be expected given that the HTC was their primary source of information. However, respondents reported comfort levels with computers, the internet, social media and smart phone technologies suggests that these are potential sources of knowledge sharing for future consideration. These alternate sources of knowledge provision could also alleviate the issue of limited time for education during scheduled visits to HTCs, providing "the right information at the right time".

The majority of respondents in this study did not report looking for information on hemophilia in the previous 12 months. However almost all of these individuals did attend their HTC during that time, and it is possible that they obtained information that they needed in the course of their consultation. Thus these individuals may well have been recipients of knowledge over the past 12 months, although they may not have felt that they were engaging in "knowledge seeking" behaviour. Defining and quantifying knowledge seeking behaviour is difficult, and this may be partly responsible for the low rate of knowledge seeking reported. We therefore suggest that future research could involve healthcare providers and individuals with hemophilia in the development and evaluation of a knowledge assessment tool, which could better identify knowledge levels, gaps and knowledge seeking behaviour.

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