

ORIGINAL ARTICLE

Clinical haemophilia

Sexual issues in people with haemophilia: Awareness and strategies for overcoming communication barriers

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Abstract

Introduction: The Haemophilia Experiences, Results and Opportunities (HERO) Study identified sexual health as an important psychosocial issue affecting people with haemophilia (PWH) worldwide. However, sexual health is inadequately addressed at haemophilia treatment centres (HTCs), because PWH and healthcare professionals (HCPs) experience barriers to broaching the subject. There is a clear need for HCP training to support communication in this area and improve comprehensive care.

Aim: The Sexual Health: Strategies for Effective Communication pilot programme was trialled in Canada to assess HCP readiness and ability to discuss sexual health issues with PWH and test communication tools to facilitate these conversations.

Methods: The pilot programme consisted of two 3-h sessions attended by seven HCPs from Calgary's Alberta Children's and Foothills Hospitals. The sessions included lectures and case scenarios and explained the check-in-affirm-clarify-answer and head-heart-body tools designed by the Centre for Sexuality to aid communication. The pilot was evaluated through discussions and an online questionnaire.

Results: The pilot was well received by all HCP participants. Questionnaire data showed improvements in participants' knowledge, skills and comfort level in conducting sexual health discussions. Greatest improvements were noted in knowledge (100% 'good' or 'excellent' after the pilot, compared with 29% beforehand). Importantly, 86% felt that the material presented would be applicable in clinical practice.

Conclusion: The Canadian pilot demonstrated the effectiveness of the proposed educational programme. The underlying principles could be adapted to similar programmes for other HTCs to facilitate sexual health discussions.

KEYWORDS

adult learning, communication techniques around sexual health in haemophilia, haemophilia and sexual health, professional practice, sexual health in haemophilia, sexuality and disability

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1 | INTRODUCTION

Sexual health of people with haemophilia (PWH) can be influenced by several physical, social and psychological aspects, which may cause numerous issues with intimacy.^{1–5} Arthropathy and iliopsoas bleeding may affect the ability to have sex, and fatigue, low testosterone and pain may discourage PWH from trying to engage in sexual activities.^{1,2} Furthermore, mental health and 'feeling different' to others may affect the relationship between PWH and their partners.^{2,5} Finally, in the older haemophilia population, co-infection with HCV or HIV plays a key role in sexual health and communication for PWH. Such infections may cause decreased sexual desire and increased sexual dysfunction, and there may be a fear of disclosure as well as transmitting these viruses to partners.¹

The Haemophilia Experiences, Results and Opportunities (HERO) Study, conducted worldwide during 2011–2012, explored key psychosocial issues affecting PWH, including sexual relationships.⁶ Of the 675 adult respondents, 53% reported that haemophilia negatively impacted the quality of their sex lives, yet only 28% discussed their concerns with a healthcare professional (HCP).^{6,7} Indeed, addressing sexual health issues of PWH represents a clear unmet need with regards to comprehensive haemophilia care.³ A Californian survey of 20 adult PWH aged > 18 years revealed that 30% did not have adequate information regarding sexual activity in the context of haemophilia.³ Furthermore, 63% of respondents wanted to receive more information on this issue at their haemophilia treatment centre (HTC), and 20% wanted to receive this information directly from HCPs at the HTC.³

Sexual health is inadequately addressed at HTC visits, with both patients and HCPs experiencing barriers to broaching the subject.^{2–4} Many PWH fear their HCP will be uncomfortable discussing their sexual health concerns and, as such, refrain from initiating these conversations.² The role of the HCP clearly extends beyond joint health, to ensure that comprehensive care is being offered to PWH.⁸ Training and education are essential to enable HCPs and the multidisciplinary team at the HTC to address and help resolve issues related to sexuality.⁴ In addition, 19% of 104 Canadian PWH surveyed in a mixed methods study reported no knowledge whatsoever of sexual activity in the context of haemophilia.⁸

Furthermore, focus groups of 13 Canadian HCPs (nurses, physicians and physiotherapists) identified sexual activity as an important topic to be discussed with PWH; however, more could be done to improve education on this topic.⁹ Insights from Canadian participants in the HERO Study data support the sexual health needs of PWH: 50% of Canadian PWH ($n = 9$) reported haemophilia negatively affected their sex lives and only one person with haemophilia talked to their doctor or clinical team about sexual intimacy.¹⁰ The importance of this issue was recognised by the HERO Canadian National Advisory Board in 2013 and since then a Canadian sexual health initiative has been adopted, supported by a sexual health needs assessment across adult and paediatric HCPs in Canada (conducted in September 2014) and a survey of Canadian physiotherapists (conducted in 2013; results shared in 2014 and 2015).

The results from the Canadian survey showed that only 33% of physiotherapists assessed sexual health as part of physical examinations at least some of the time. Key barriers to sexual health discussions were the comfort level of HCPs and patients, as well as lack of knowledge of this issue. Lack of space, privacy and time during appointments, as well as poor collaboration and communication among the entire HCP team, were also identified as barriers. In total, 59% of the physiotherapists surveyed had not received any training on how to conduct sexual health discussions and 81% of HCPs would respond positively to receiving training on this topic, which they believed would support these conversations with PWH. Almost all (99%) of social workers surveyed and 88% of registered nurses reported that further training would help sexual health discussions.

Here we discuss a pilot programme titled, Sexual Health: Strategies for Effective Communication, inspired by the data from the Canadian physiotherapist survey. This programme was designed to help HCPs learn ways to communicate more effectively about sexual health with PWH and was trialled in Calgary, Canada. The pilot programme was conducted in two parts: the first part highlighted the importance of sexual health to PWH and tested a training and education methodology to address the sexual health unmet needs in haemophilia, while the second part was a checkpoint to assess the impact of the tools presented during the first part and how HCP practice changed. The objectives of the programme were to highlight the importance of sexual health for PWH and to help HCPs learn ways to communicate more effectively around sensitive issues pertaining to sexual health.

2 | METHODOLOGY

The pilot workshop comprised two 3-h sessions conducted in October 2016 and February 2017, respectively. The training focused on sexual health, sexuality and issues that HCPs might face when talking about these subjects with patients. The workshop was conducted by one of the authors (B.V.T.), a sexual health expert from the Centre for Sexuality, Calgary, Canada, and participants included seven experienced HCPs (registered nurses, social workers, physiotherapists, haematologists) working in the paediatric and adult haemophilia clinics from Calgary's Alberta Children's and Foothills Hospitals.

Both sessions consisted of a combination of lectures and case scenarios that related specifically to sexual issues in haemophilia (see **Appendix 1** for example case scenarios used in the pilot). Part 1 highlighted the importance of sexual health to PWH and explained two tools designed by the Centre for Sexuality to help HCPs communicate about this issue with PWH: the check-in-affirm-clarify-answer communication model and the head-heart-body model. Part 2 asked what topics arose in the clinic since the first session.

2.1 | Communication model and decision-making tool

During part 1 of the pilot, the check-in-affirm-clarify-answer communication model was presented to HCPs as a framework for

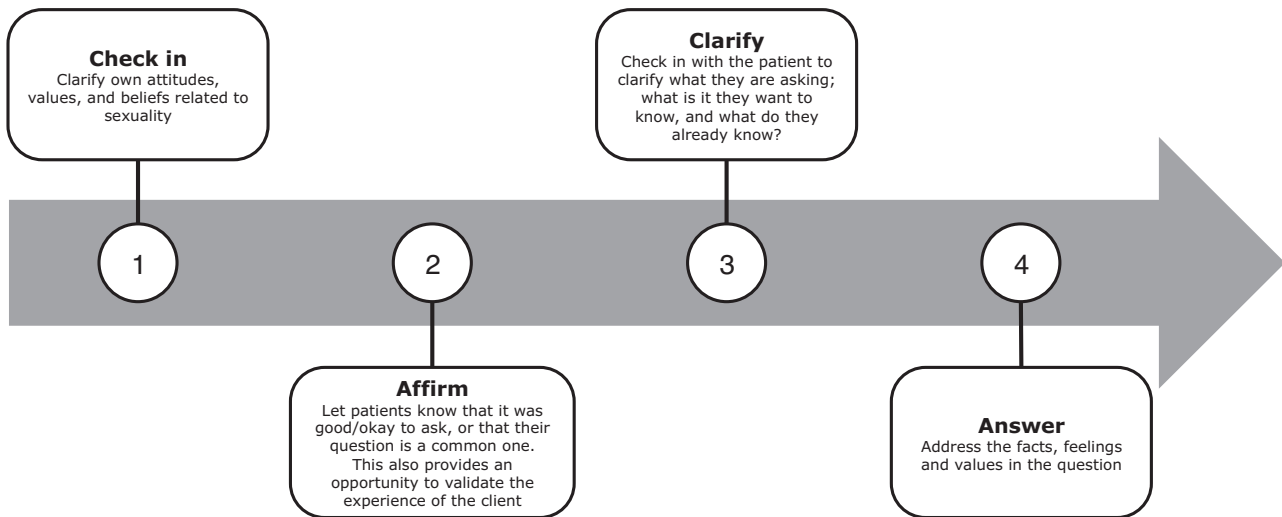


FIGURE 1 Check-in-affirm-clarify-answer communication model

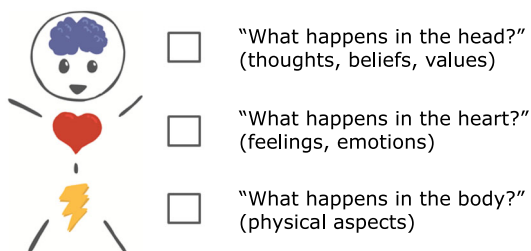


FIGURE 2 The head-heart-body decision-making tool

sexual health discussions (see Figure 1). This model first suggests HCPs check in with patients by clarifying their own beliefs about sexuality, before affirming the importance of these discussions and validating the feelings and experiences of the patient. Clarifying patients' questions is important to ensure the issue is well understood before providing answers. The importance of body language, facial expressions and tone of voice to support the conversation was also emphasised.

The head-heart-body decision-making tool was also described during part 1 of the pilot (Figure 2). This tool provides a holistic approach to understanding how haemophilia affects patients' sexuality. HCPs were advised to structure their conversations according to this tool, by working from the head down – first considering the patient's thoughts, beliefs and values before progressing to the heart to discuss their feelings and emotions. Only after these topics have been covered should HCPs move on to discussing the physical aspects of sexuality. The HCPs practised using this tool by working in groups to role play example adult and paediatric (teenage) patient case scenarios that were written by one of the authors (G.B., specialist physiotherapist) and formatted for use by another author (B.V.T., sexual health expert).

2.2 | Patient case scenario 1

The patient is a 35-year-old man with severe Factor VIII deficiency and multiple joint arthropathy. He is attending an appointment today

accompanied by his wife, to discuss options for pain control. He is visibly and verbally frustrated by his ongoing issues with pain and is suffering from sleep deprivation, depression, and anger over the impact on his life and marriage. The pain has significantly limited his libido. His wife is equally upset, tearful, and vocalises how guilty she feels for getting upset about her dissatisfaction with their sex life because she knows that the reason is that her husband is in pain.

2.3 | Patient case scenario 2

The patient is 16 years old with severe Factor IX deficiency. He is openly gay and in a relationship for the first time. He has never had sex, and although the relationship is not yet sexual, it is becoming serious and he is wondering if he should tell his boyfriend that he has haemophilia. He wants to have sex with his boyfriend but is afraid that disclosing the truth about his bleeding disorder might result in a break-up.

2.4 | Evaluation of success

Evaluation was carried out through open discussions and an online questionnaire. An open discussion was conducted after the first session to evaluate success. Participants completed a questionnaire at the start of the first session and 6 months after each session in order to assess how their perceptions of communicating sexual health issues to PWH had changed as a result of the training.

3 | RESULTS

3.1 | Open discussion feedback

Overall, comments from participants were positive and the training imparted was reported to be helpful to all participants and their teams.

Following the training, participants reported being more aware of their own values about sexuality, understood how their values can influence their approach to discussing sexuality with PWH, and felt more at ease talking about relevant sexual health topics. Some quotes from the discussions during the pilot include: "...it forces a clinician to think about his/her approach to discussing sexuality with clients"; "if you feel awkward about the conversation, it will be awkward"; "use the analogy of a first-year medical student taking a history – practice makes perfect, which highlights the importance of role playing".

Attending the pilot as a multidisciplinary team will upskill all HCPs to engage in sexual health discussions with PWH if the scenario arises. However, it was noted that in some HTC it might not be practical logistically for the entire team to be trained together. Importantly, the tools trialled during the pilot were considered useful and would be particularly helpful in discussions with patients during transition from childhood to adolescence. Indeed, one HCP who used the resources in clinic found their transitioning PWH was receptive to discussions on sexual intimacy; however, their mother was not. Engaging in such discussions with transitioning PWH needs to be carefully considered to respect both the adolescent's and parents' wishes, and a direct and personal approach with respect to the adolescent may be best. The participants recommended this training to other HCPs and felt they would benefit from further training themselves to continue to build on and improve both their own comfort level and that of their patients.

3.2 | Pilot formal feedback

Results of an online questionnaire assessing the success of the pilot programme are shown in Figure 3. Improvement was noted in all aspects assessed, with greatest increases in 'good' and 'excellent' scores seen in the aspect relating to knowledge of sexual health. In total, 100% of participants felt their knowledge was 'good' or 'excellent' after the pilot, compared with only 29% beforehand. After the pilot, the majority of participants understood what sexuality and sexual rights are, and 50% understood what sexual health is. Practical communication skills also improved, with 71% believing their skills were 'good' or 'excellent' after the pilot, compared with 43% beforehand. After the pilot, all participants reported being capable of preparing for a conversation about sexuality with PWH and 50% reported they were able to conduct these discussions and react appropriately. In total, 86% of participants reported their comfort levels were 'good' or 'excellent' after the pilot, compared with 29% beforehand, and two-thirds reported feeling more at ease talking about sexual health topics. Importantly, 86% reported that the material presented in the workshop would be applicable in clinical practice.

4 | DISCUSSION

The Sexual Health: Strategies for Effective Communication HCP pilot programme was well received by all seven HCP participants. The results and feedback from the HCPs were consistent in demonstrating

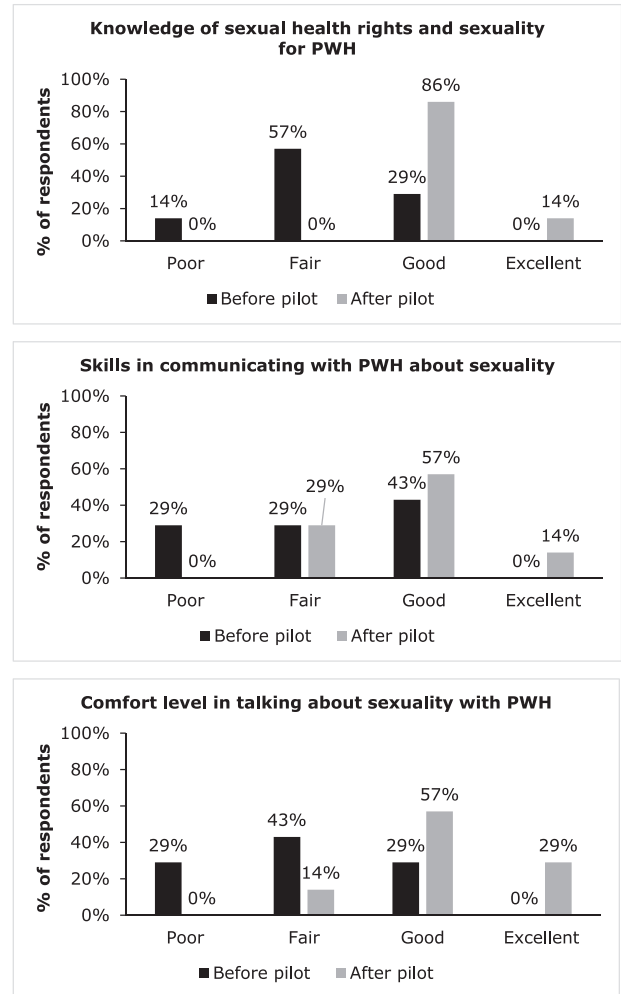


FIGURE 3 Results of pilot feedback (n = 7)

improvements in their knowledge, comfort and skills to conduct sexual health discussions with PWH, which is an interesting and reassuring result given that participants only attended two sessions in the pilot. Feedback from the programme noted the relevance of such training programmes and tools used, and highlighted the need for more training and educational materials focussed on sexual issues in haemophilia, in alignment with the findings of other studies.^{3,4,8}

The pilot programme included facilitated discussions focussed on sexual health/sexuality in combination with practical application of the check-in-affirm-clarify-answer model and the head-heart-body model, equipping participants with a new approach and skill set. The latter model provides a framework for sexual health discussions with PWH and ensures that thoughts and feelings are addressed before physical aspects of sexuality. There are numerous physician-patient communication tools, many of which are effective in promoting behaviour change among HCPs.¹¹ The Permission, Limited Information, Specific Suggestions, and Intensive Therapy (PLISSIT) counselling model provides structure to sexual health interventions offered by HCPs, with Level 1 (permission giving) most aligned with the head-heart-body model.² Level 2 of the PLISSIT model (knowledge



giving) may also be followed by HCPs to dispel myths versus facts and provide basic healthcare information, whereas advanced levels (Level 3, specific suggestions, and Level 4, intensive therapy) require more specialised knowledge and expertise.² Finding the right tools to support HCPs with facilitating difficult conversations in any field of medicine will optimise patient care.¹¹ Indeed, effective communication in the healthcare setting improves clinical outcomes and patient satisfaction, and reduces costs.^{12,13} Training should not be limited to one-off sessions; ongoing exercises and regularly practising techniques will reinforce key principles so they become part of routine clinical practice.^{2,11} In this way, individuals may be referred to a HCP who has received the right training, and who has the right tools and skills for speaking about sexual health issues with PWH. The HCP should then select the most appropriate tools and techniques learnt during training to individualise the approach to the specific circumstance and PWH.

This analysis is limited by the small sample size and the inclusion of participants who chose to take part in the pilot, and who are therefore likely to have a general interest and openness to sexual health issues (which may result in some sampling bias). Additionally, the pilot could have benefited from a longer follow-up to evaluate whether learnings were retained and incorporated into clinical practice.

The HERO data suggest that in patients with moderately severe haemophilia, the issues pertaining to sexual health in haemophilia are applicable worldwide and not just in Canada. In a quantitative analysis of HERO data ($n = 675$ adult PWH), of those answering questions on sexual relationships, haemophilia negatively affected the sex lives of 53% of PWH surveyed worldwide, and only 28% discussed their concerns with HCPs.^{6,7} A more recent assessment of data from both the HERO (global and US-only subgroups) and the B-HERO-S (US population with predominantly mild-moderate haemophilia) studies reported 53–74% of PWH felt that haemophilia or related conditions impacted the quality of their sex lives.¹⁴ The most common reason cited was previous experience with having a bleed (40%).¹⁴ Overall, 56% of US PWH sought advice from haemophilia HCPs.¹⁴

The communication approach used in the Canadian pilot programme could be adapted as necessary for similar training worldwide, applying the same principles and methodology to discussions with PWH across all haemophilia severities. Although methods of communication should be modified to take into consideration cultural differences, it is important to note that sexual health issues are universal and there is a need to break down communication barriers between HCPs and PWH.

Methods to overcome barriers and optimise communication between HCPs and PWH would undoubtedly support discussions of a sensitive nature. Being empathetic and non-judgemental rather than sympathetic can help PWH to feel understood, as opposed to pitied. A good listener can also help to normalise issues raised and help PWH feel supported.² Furthermore, social skills to empower HCPs to initiate these conversations can be practised or even taught.²

In addition to managing these conversations sensitively and effectively, ongoing training for HCPs would help to provide practical guidance to PWH experiencing sexual issues. This could include suggesting alternative sexual positions to aid comfort and avoid bleeds.^{1,4,5}

Apart from anecdotal experiences and biomechanical considerations, there are few data to inform guidelines either in the general sense or for patients with particular target joints. However, the recent approach taken in the Activity Intensity Risk initiative through survey/consensus of 17 expert physiotherapists to evaluate range of risk and risk drivers of 101 physical activities could be extended to evaluate sexual positions.¹⁵

It is important to note that an increasing number of middle-aged PWH experience erectile dysfunction (ED).^{3,5} In addition to discussing the psychosocial issues related to sexuality, HCPs could also evaluate PWH for ED using a single question from the Massachusetts Male Aging Study: 'How often are you able to get and keep an erection good enough for sexual intercourse – always, usually, sometimes or never?'^{15,16} Of course this question should be broached in a sensitive and thoughtful manner, but a simple assessment would enable provision of additional support as necessary, including referring patients or prescribing medication.¹⁵ It is important to note that ED may also be an indicator of underlying vascular disease and should be investigated accordingly as part of the comprehensive care of PWH.

Adopting a holistic approach to patient management means that sexual health should not be differentiated from other aspects of haemophilia care. Indeed, the sexual health of PWH should be considered within the overall context of the individual and, as such, it should be the responsibility of HCPs to open discussions during consultation.^{1,8} The entire multidisciplinary team needs to take responsibility for addressing sexual issues in PWH and should therefore be provided with appropriate training. Such a holistic approach to care can be applied not only to haemophilia, but to other non-communicable chronic diseases.¹⁷

5 | CONCLUSIONS

Sexuality is intrinsic to human nature and is a significant factor in life. Its value is the same for PWH, yet complications may arise due to physical and psychosocial issues associated with this chronic condition.² Improved communication between PWH and HCPs is essential to overcome barriers and enable open discussions of sexual health that provide support to PWH. The Sexual Health: Strategies for Effective Communication HCP pilot programme demonstrated principles of training to facilitate sexual health discussions. HCP participants gained skills and knowledge to better conduct sensitive conversations in the HTC; from the guidance provided by the training programme, HCPs can then select the most appropriate tool to tailor their approach to each individual with haemophilia and their personal circumstances. Our pilot programme may be culturally adapted to other countries and clinics, which, building on the experiences and lessons learnt, may develop similar programmes of their own, applying the same communication principles.

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DISCLOSURES

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CONFLICTS OF INTEREST

Greig Blamey (G.B.) has received honoraria from Novo Nordisk and Shire, funding to attend congresses from Pfizer, consultancy fees from Novo Nordisk, and personal fees from Shire. Becky Van Tassel (B.V.T.) reports no conflicts of interest. Elizabeth Sagermann (E.S.) has acted as a paid consultant for Novo Nordisk on activities related to the HERO programme. Ann Marie Stain (A.M.S.) has acted as a paid consultant for Novo Nordisk on activities related to the HERO programme. Linda Waterhouse (L.W.) has acted as a paid consultant for Novo Nordisk Canada Inc. on the Canadian HERO National Advisory Board. Alfonso Iorio (A.I.) has received project-based funding via research or service agreements with Bayer, CSL, Grifols, Novo Nordisk, Octapharma, Pfizer, Roche, Sanofi, Sobi and Takeda.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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