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Haemophilia Homecare:

A Qualitative Evaluation Study of the Be Involved Infusion Program

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Abstract

Introduction: In Canada, haemophilia patients can receive healthcare through a limited number of specialized haemophilia treatment centres. Treatment of this X-linked bleeding disorder through self-infusion of factor replacement is common; however some individuals with haemophilia require additional infusion support from medical professionals. While provincially-funded outreach clinics and telehealth are available, pharmaceutical companies that supply factor have developed novel home infusion programs wherein registered nurses assist/manage factor administration in the patients' homes.

Aim: The current qualitative evaluation explored the real-world effectiveness and impact of the Be Involved (Pfizer Canada) home infusion service, from provider, program end-user, and needs analysis perspectives.

Methods: Qualitative interviews with patients and caregivers who had used Be Involved (n=7) and Be Involved staff (n=8) provided important insights and recommendations for program improvement initiatives. Also included were needs assessments of potential end-users (n=11) as a means to making program adjustments.

Results: The inductively derived findings revealed Be Involved as a highly valued, though key specialized service providing significant assistance to a small number of haemophilia patients. Augmenting traditional services, the program was endorsed as easing the burden of haemophilia care, while the Be Involved nurses were affirmed as highly effective and critical to the program's success. A lack of program promotion and awareness was evident – limiting uptake, amid communication and systems delivery challenges.

Conclusions: The current evaluation findings inform our recommendations for, and brief discussion of, the need for stronger promotional strategies and improved communication lines to increase the reach and efficiencies of the Be Involved program.

Introduction

Predominantly diagnosed in males, haemophilia A and B are rare, X-linked genetic bleeding disorders that affect approximately 3,200 Canadians [1]. Caused by a clotting factor deficiency (type A: factor VIII, type B: factor IX), both types of haemophilia are characterized by spontaneous or trauma-related bleeding into joints and soft tissue [2]. Standard treatment for haemophilia includes factor replacement therapy administered via intravenous (IV) infusion on-demand (in response to a bleed) or prophylactically (to prevent bleeds) [3]. Although a majority of Canadian-based individuals with haemophilia

(IWH) self-infuse at home [4] some require assistance from medical professionals, primarily nurses.

While most Canadian haemophilia patients are supported through Haemophilia Treatment Centers (HTC), those who live in remote/rural areas can experience significant challenges accessing specialist care locally [1,5]. The need to travel long distances amid transportation and financial constraints, along with disabilities/functional limitations impeding mobility, pose additional barriers to accessing HTCs. To optimize care, provincially-funded mobile outreach clinics, telehealth, and financial aid programs have been established [5].

Additionally, pharmaceutical companies that supply factor in Canada offer homecare infusion programs for IWH. These services are offered to those IWH being treated with the specific pharmaceutical brand of factor and typically include a haemophilia nurse who assists with or manages factor administration in the patients' home. One such program, Be Involved, is a patient support program for IWH funded by Pfizer Canada and administered by Shoppers Drug Mart, Specialty Health Network Inc. Shoppers Drug Mart is a Canadian health, beauty, and convenience retailer and patient assistance service organization that provides and resources Be Involved nurses. This program comprises four services that aim to help individuals with all aspects of their haemophilia management including a home infusion service, Be Supported, wherein specific Pfizer product infusion assistance, factor management, education, and support from registered nurses is provided.

Formal evaluation of the Be Involved services, specifically the homecare infusion component is integral to making effectual program adjustments. Currently, most haemophilia care research focusses on self-management, transitional care programs, and adherence outcomes, particularly in adolescents [2, 6-8]. For example, one study addressing homecare infusion services as part of the collective "Haemophilia Community" looked at men's perceptions of management through a resilience framework [9]. The current study offers a qualitative evaluation of the Be Supported service, forthwith referred to as 'Be Involved', drawing on the experiences of health care providers, program end-users, and a needs analysis conducted with potential program users as a means to inform program adjustments.

Methods

Data Collection

Following University of British Columbia Behavioural Research Ethics Board approval, three cohorts of participants were recruited: 1) Be Involved Patients and Caregivers (BIP/C), 2) Be Involved Staff (BIS), and 3) Needs Assessment Participants (NAP).

Inclusion criteria and recruitment methods for each cohort are outlined in **Table 1**.

[Insert **Table 1.**
Recruitment
Method and
Inclusion
Criteria here]

All participants provided written consent and demographic information, ahead of completing an individual semi-structured telephone interview. Interview questions and prompts to elicit participants' views and experiences of Be Involved were open ended, including "what works particularly well in the program?", and, "what could be improved in the program?". The interviews lasted between 20-60 minutes, were digitally recorded, transcribed verbatim, and checked for accuracy. To ensure confidentiality, all potentially identifying information was removed, including participant, hospital or clinic names, and geographic locations. Each participant was offered a \$50 Chapters/Indigo gift card to acknowledge their time and contribution to the study (2 participants declined).

Sample

Twenty-six participants took part in the study; 7 BIP/C, 8 BIS, and 11 NAP. BIP/C ages ranged from 30 to 84 years [Mean = 46.5]; BIS, 34 to 68 years [Mean = 52], and NAP, 27 to 69 years [Mean = 42]. The BIP/C cohort included both IWH (n=5) and caregivers (spouse n=1; parent n=1) who had utilized Be Involved. IWH rated their need for care assistance as low to moderate, although many reported the need for infusion-related support as their primary linkage to Be Involved. The BIS cohort included registered nurses who worked for Be Involved (n=4) providing home infusion support, and other clinic-based nurses (nurse coordinators (n=3) and a nurse practitioner (n=1)) who referred patients and caregivers to the Be Involved program. Within Canada all nurses have passed a standardized examination and are registered with their governing provincial regulatory body. BIS participants had a wide range of experience with treating haemophilia patients,

both in terms of years and number of patients treated. The NAP cohort included IWH (n=9) and caregivers (parent n=2) that had not used Be Involved. Please see **Table 2** for detailed demographics.

[Insert **Table 2.**
Cohort
Demographics
here]

Data Analysis

Uploaded to NVivo 11, the triangulated data were analyzed separately in each cohort and compared, and coded using descriptive labels (i.e., challenges, benefits, knowledge). Hard copies of the coded data were read and notes were made to summarize excerpts and refine coding labels amid inductively deriving preliminary themes. Coding was iterative beginning with broad data fractures and allocating segments on the basis of recurring ideas and narratives within the data. Preliminary themes emerged, including Daily Challenges, Successful Outcomes, Program Benefits, Program Challenges, and Homecare Suggestions. Along with discussions between the first and second authors to drive consensus about the findings and decide on illustrative quotes, the aforementioned analytic processes ensured rigor in the development of the thematic findings ensuring that the results were grounded in the participants' interview data.

Findings

Providing Key Specialized Services

Overall, BIS and BIP/C participants strongly endorsed Be Involved as an excellent program; "improving the quality of life for families and individuals". Participants shared an array of reasons for accessing the program, including post-surgical care, caregiver respite, and long-term support for those requiring ongoing care. BIP/Cs were satisfied with the care they, or those they cared for, received through the program, with most (n=6, 86%) rating the program a 5 (scale of 1 to 5; 5 indicating highest level of satisfaction). Participants suggested that those who had mild and/or moderate haemophilia, youth, and rural patients

benefited most. While many rural patients used emergency rooms for prophylactic treatment, one BIS explained the difficulties and barriers around accessing care in highlighting how the program helped to ease demands on these emergency rooms, as well as HTC's and other health care providers;

Well rural, as much as the capability, of the ERs in smaller centres is not, I mean, training can occur as well, but as the ER becomes [...] much busier, it's difficult for those small centres to provide the best care. You know, they might not have a hematologist, they might not be able to reach the hematologist on call.

Recounting that the social, financial, and health-related burdens of haemophilia care were amplified by lost productivity, paid worktime and risk to job-security, BIP/C and BIS described how Be Involved helped offset these challenges. A BIS participant explained;

When I looked at it six years ago, I used to say, "Oh my God, I wish I had it [Be Involved] when I was working." I have seen parents struggle to get their kids down there twice a week, or once a week, I've seen mothers and fathers lose jobs over it. Now I go in and the parents aren't losing their jobs, the kiddy is far more settled because he is in his home. The gentlemen, the adults, they can still work from home and I kind of scoot in and scoot out between what they're doing with work. I think the service and the program; that above anything else has really improved the quality of life of the families, and of the individual.

For BIP/C, the Be Involved program clearly addressed important needs, particularly for patients requiring intermittent infusion after acute injuries or post-surgery, those caring for young IWH, or for patients no longer able to self-infuse. Additionally, both caregiver parents within the NAP cohort saw benefit in having a nurse help manage their children's haemophilia. By contrast, most NAPs who were IWH positioned themselves as highly independent in their management of haemophilia and did not anticipate needing homecare infusion services like Be Involved;

I'd have to be a real mess compared to what I am now. Yeah, let me just knock on wood here. I'd have to be in a totally different living state because I'm extremely independent. I wouldn't have any foreseeable need for homecare or help.

In essence, most IWH in the NAP cohort linked homecare infusion services to 'other' health and disability issues. These participants also discussed family members as being their primary social supports, and as one NAP described, his relationship with the HTC was strong and longstanding, negating need for home infusion services;

I don't think I've had an issue where I've had to have a nurse come to my house and help administer Factor. [...] I can talk to a hematologist within minutes usually, if I need to.

That the IWH in the NAP cohort distanced themselves from needing homecare services likely reflected their independence and preference for self-management and perhaps mastery, amid their established connections to health care services. That said, the positive feedback from BIP/Cs and BIS highlighted the Be Involved program as specialized and beneficial to a small group of patients and/or their caregivers under specific circumstances.

The centrality of nurses

Be Involved nurses were highlighted as pivotal to overall user experience and featured prominently in how BIP/Cs rated the program. A majority of BIP/Cs affirmed that their interactions with the Be Involved nurses were positive, describing them as quick, knowledgeable, friendly, accommodating, helpful, and experienced. As one BIP/C stated;

I believe the personality – it's the hugest thing all the time, right? Especially the nurses – they are always working with the people – one by one, you know I mean all the time and it's – if you have a good nurse, it's a good experience, right?

The Be Involved nurses played an integral role in aligning patient-provider needs and priorities through a patient-centric homecare model. This involved getting to know patients and developing rapport, while also demonstrating haemophilia-specific knowledge to patients and/or caregivers to facilitate trust and openness. A BIS participant elaborated;

I think it's really, really important that you give them a little bit of your background, so they know that there's just someone - the person that's coming out is not someone that has no knowledge of haemophilia. I mean, most nurses have good peripheral skills, I.V. skills, but I think they want to know that I know what I'm doing with haemophilia. So, that puts their minds at ease.

Indeed, the level of the nurses' knowledge was critical to patient satisfaction, and a lack of haemophilia-specific knowledge had a negative impact on the patient experience, with one former BIP/C quitting the program, in explaining, "[I] wouldn't say he was very knowledgeable about haemophilia, no. And administering it ... I was less than comfortable about it."

NAPs also echoed the integral role of nurses in homecare infusion services. Underpinned by comprehensive training in haemophilia care, credentialed skilled nurses were endorsed as critical to the credibility and uptake of these services, especially given the lack of familiarity with haemophilia among many healthcare providers;

Just [the nurses] knowing they're gonna be dealing with Haemophilia. It's not fair - someone to come to your house and know nothing, really about anything, you know?[...] Because a lot of people know nothing about Haemophilia, so if someone shows up at your house and you're struggling, it would be a little too much I think.

In addition to direct patient care, nurses were key to establishing system efficiencies. For example, challenges were seen with patient intake/questions wherein the different time zones and office hours challenged communication and reporting lines between the Be Involved nurses, their line managers, and the referral staff. These systems-related issues could undermine patient care, and demanded additional effort from the nurses to bridge the multiple stakeholders. As one BIS highlighted;

Because we work out of our home, I have a manager who lives in [name of province], my manager is in [name of another province], the girl who handles everything else is in [name of city]. So, that's a big time difference, so if it's

something that I know is not going to happen because of the time difference, a lot of us will deal with it ourselves and then just do the paper trail.

Lack of program awareness and support

Many participants highlighted a general lack of awareness and/or understanding of haemophilia homecare infusion services; and more specifically the Be Involved program. For some BIS participants employed by multiple pharmaceutical companies, Be Involved was experienced as one of many homecare infusion programs wherein some confusion could arise in defining and differentiating the Be Involved brand from other pharmaceutical-sponsored programs. Related to this, some BIS participants described little interaction or communication around the program specifics. BIS participants also noted the pivotal role clinic-based nurses had in raising awareness of and referrals to the Be Involved program. Indeed, champions for Be Involved, (i.e., clinic-based nurses) were critical to the program's visibility and patient recruitment as a Be Involved nurse elaborated:

I think there's got to be a constant drumbeat with the clinic nurses, with the nurse coordinators, to make sure that this is always foremost in their mind that there is a homecare program for their patients. Cause it starts there, because the nurse coordinator is the one that's looking at the whole family holistically, and if she looks at them and says, "Oh my God, this family's not going to survive this, let's get homecare in there," it usually does not come from the doctor.

Moreover, BIS participants highlighted the lack of communication and absence of a digital presence (e.g., email communication, website, and social media) as key barriers for the referring HCPs. Linking to BIP/C participants, the visibility and recognition of Be Involved as a distinct program was lacking to the extent that some were unaware that they were enrolled in the program. One BIP/C participant remarked, "I don't recollect the title 'Be Involved', at all"; and while a few participants knew the program name, none recalled receiving any written information about the Be Involved program. As one BIP/C described, most were introduced to the concept of homecare services via a clinic nurse, with little additional detail;

Yeah, I'm not sure – they just told me it's going to be – I'm not sure that it was part of some kind of program, right? They just told me it's going to be the nurse from Shoppers.

Affirming the lack of awareness around homecare infusion options, when NAPs were asked, “What is your general experience with haemophilia programs or ‘out of hours’ services?”, one participant quipped: “out of hours’ services? I didn't know there was any?” This captured the sentiments of most NAPs; indeed, none were aware that haemophilia homecare infusion programs such as Be Involved existed. The reliance on HTC nurses referring patients to Be Involved was evident, as were the limitations imposed by the lack of direct advertising from Pfizer/Shoppers to potential program users.

Discussion

Taken together, the findings drawn from the current evaluation study reveal Be Involved infusion support as an integral, though specialized, component of some haemophilia patients' care. That said, the program's value and reach could be expanded as service users and providers clearly highlighted the significant benefits afforded by Be Involved and the centrality of trained nurses administering homecare. Given the vast Canadian geographies, as well as health and socioeconomic inequities affecting many haemophilia patients and their caregivers, there is much to be gained through efficiently run homecare infusion programs such as Be Involved. However, as the program currently stands, there are also adjustments that could be made including enhanced marketing and promotion, and streamlined referral/intake processes, in order to maximize the program's reach, uptake, and impact.

Specifically, the lack of Be Involved brand visibility that render the program invisible to many people – including potential referral nurses and some patient and caregiver groups who would significantly benefit from these services – should be addressed. This lack of visibility limits program uptake, and heightens referral/intake systems-related issues. Much benefit may be derived from the development, implementation and formal evaluation of distinct program branding and education materials, with multi-modal dissemination

pathways, including print and digital materials to reach all potential end-users and referral centers. Efforts to connect clinic and Be Involved nurses through shared online and in-person educational seminars could also be implemented to build collaboration, and reduce uncertainty surrounding patient referrals and treatment regimens. Further to this, it may be worthwhile to include contact numbers, as well as briefing information on Be Involved policies and services in promotional materials intended for patients and caregivers.

Significant challenges to current communication and referral processes potentially impacted the quality and continuity of patient care, and this finding highlights the need for more streamlined referral and intake processes in order to optimize uptake of the program. Currently, referrals are made by HTC nurse through a standardized form to the Be Involved program via a fax request. Once processed and approved, Be Involved contacts Shoppers Drug Mart, and a Be Involved nurse contacts the patient directly. An online booking system and digital educational materials may increase efficiencies and usability of the program, waylaying dependence of specific Be Involved nurses. Standardized referral processes and clear report lines within the same time zones are also recommended to enhance patient care, workflow, and employee efficiencies. Finally, there may be significant benefit for industry (Pfizer) to partner more directly with haemophilia treatment centers to develop 'holistic' resources 'in house' as a means of making out-of-hours services available to better address the needs of underserved haemophilia patients and caregivers. Given the centrality of nurse competence to the acceptability and effectiveness of Be Involved, there may also be important opportunities for ongoing peer specialist haemophilia training to aid nurse retention and increase the programs capacity and scale.

Limitations

Recruitment to the current study was challenging, especially as there was a relatively small number of Be Involved patients and caregivers from which to draw. The small BIP/C cohort (n=7) reflects the scale of the program, which at the time of the current study drew participants from only 38 eligible Be Involved patients and their caregivers across Canada. This was also the case with Be Involved nurse recruitment (n=4), as only 15 were employed in this capacity across Canada during the study. These recruitment challenges

highlight the limits of what can be reasonably claimed as a formative and preliminary program evaluation. While there were some concerns raised about the Be Involved nursing care expertise for IWH, we are also limited by the self-reported demographic data collected to fully explain those preliminary findings. Future research might usefully explore relationships between the provision of credentialed nursing care and IWH patient satisfaction (and outcomes) in evaluating the education needs of Be Involved nurses.

Conclusion

The well intentioned Be Involved program reflects the ever growing need to augment traditional point of care services to reduce the burden of this rare but chronic illness. While challenges prevail in highlighting and coordinating such 'home-care' services it is vital to the life quality of IWH and their caregivers that formal program evaluations guide adjustments to extend the reach of these important services.

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ER collected, analysed, and interpreted data, wrote and revised the manuscript. JO designed research study, oversaw data collection, analysed, and interpreted data, wrote and revised manuscript. YJ helped develop research study and logistics, contributed to the writing of the paper. CB designed research study, organized recruitment, and oversaw logistics.

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Table 1. Recruitment Method and Inclusion Criteria

Cohort	Recruitment Method	Inclusion Criteria
Be Involved Patients and Caregivers (BIP/C)	<ul style="list-style-type: none"> • Recruited from the Be Involved program via consent to receive information about participation in research studies • Contact details for potential participants who provided written consent were forwarded to the principal investigator and contacted by the research coordinator 	<u>Be Involved Patients</u> <ul style="list-style-type: none"> • IWH • 14 years or older • English speaking • Residing in Canada • Had used or were currently using Be Involved homecare infusion services <u>Caregivers</u> <ul style="list-style-type: none"> • Parents/guardians/partner caring for an IWH • 19 years or older • English speaking • Residing in Canada • Family member who had used or were currently using Be Involved homecare infusion services
Be Involved Staff (BIS)	<ul style="list-style-type: none"> • Recruited via email sent by the Be Involved Program Coordinator • Potential participants contacted the research coordinator by telephone or email and were screened for eligibility 	<ul style="list-style-type: none"> • 19 years or older • English speaking • Residing in Canada • Referring patients to the program or providing patient care to IWH through Be Involved
Needs Assessment Participants (NAP)	<ul style="list-style-type: none"> • Recruited through posters, flyers, and haemophilia association/society web advertisements • Potential participants contacted the research coordinator by telephone or email and were 	<ul style="list-style-type: none"> • 19 years or older • English speaking • Residing in Canada • IWH or their caregiver (parent/guardian/partner)

	screened for eligibility	• Had not used any Be Involved services
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Table 2. Cohort Demographics

BIP/C (n=7)	
Age (years)*	
Range	30 – 84
Mean	46.5
Participant role	
IWH	5
Caregivers	2
Education level	
Diploma or Certificate	1
Some College	1
Bachelor's Degree	3
Master's Degree	2
Haemophilia type (have or assist with)	
A (Factor VIII deficiency)	5
B (Factor IX deficiency)	2
Haemophilia category (have or assist with)	
Mild	1
Moderate	1
Severe	5

Treatment (use or assist with)	
Prophylaxis	3
On-demand	4
BIS (n= 8)	
Age (years)*	
Range	34 – 68
Mean	52
Years of Experience Treating Haemophilia patients	
<5	2
5-10	2
11-15	3
16-20	-
>20	1
Years with Be Involved**	
<5	5
>=5	1
Number of Patients worked with through Be Involved	
<5	3
5-10	3
>10	2
NAP (n=11)	
Age (years)	
Range	27 – 69
Mean	42
Participant role	
IWH	9
Caregivers	2
Education level	
High School	1
Diploma or Certificate	2
Some College	4
Bachelor's Degree	3
Master's Degree	1

Doctoral Degree	1
Haemophilia type (have or assist with)	
A (Factor VIII deficiency)	11
B (Factor IX deficiency)	-
Haemophilia category (have or assist with)	
Mild	1
Moderate	2
Severe	8
Treatment (use or assist with)	
Prophylaxis	8
On-demand	2
No treatment	1

*One participant did not respond

**Two participants did not respond

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