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INTRODUCTION

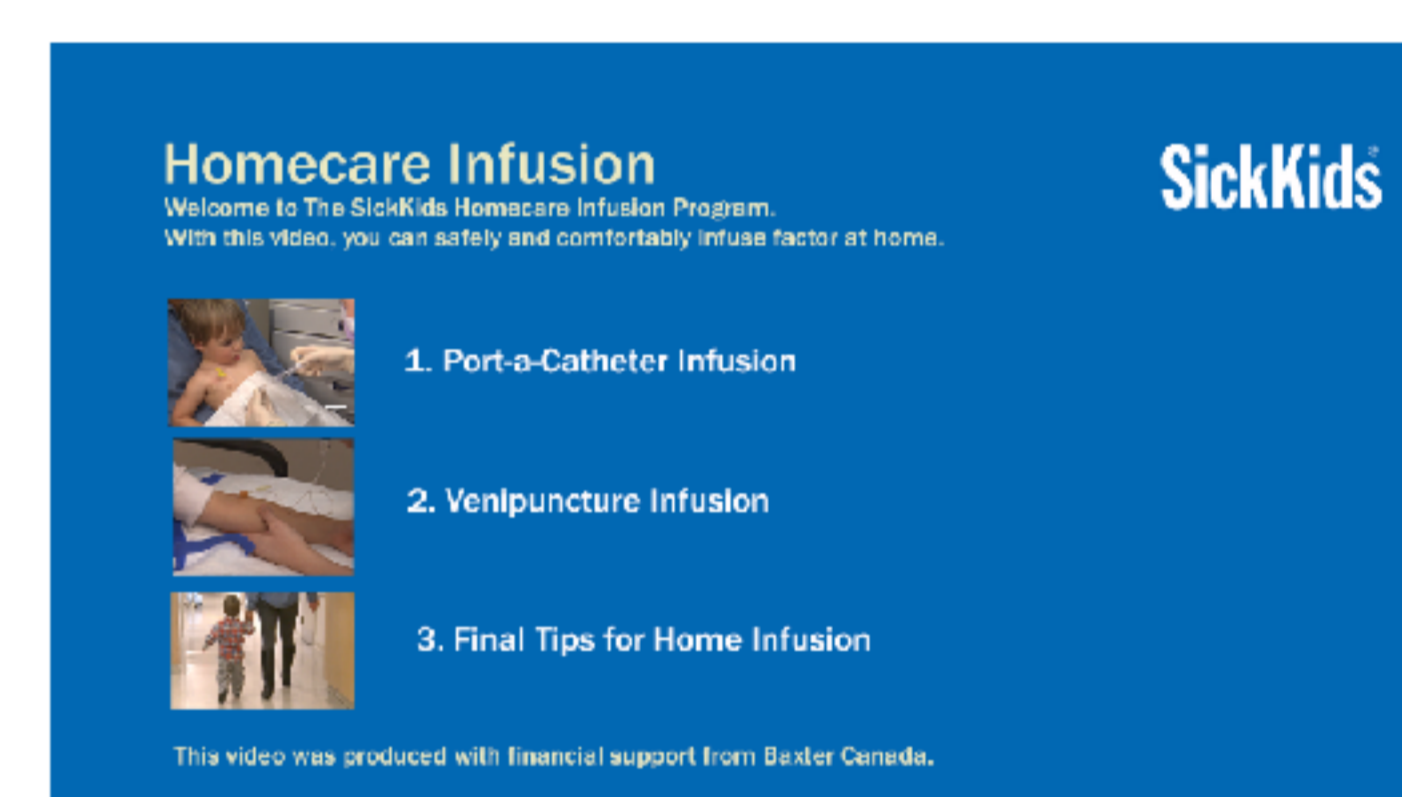
- In the 1970's, patients with hemophilia and their families needed to travel to the hospital to receive clotting factor treatments.
- The delay in treatment would lead to negative outcomes resulting in joint damage.
- A superior solution to promptly treating bleeds was required. Thus, factor administration in the home setting was initiated.
- Homecare infusion programs were developed to teach technical components of infusion including factor reconstitution, infusion preparation and venipuncture/CVL care and access.
- These programs further evolved when prophylaxis became the standard of care. The program became more comprehensive, including a focus on the patients' and families' knowledge of their diagnosis, disease trajectory and their ability to identify and assess severity of bleeds and then treat them.
- Empowering patients and families to administer factor at home greatly improves their quality of life.

THE SICKKIDS HOMECARE PROGRAM

| Homecare Patients at SickKids | # Using Method & (Median Age) | |
|---------------------------------|-------------------------------|-----------------|
| | Venipuncture | Port-A-Catheter |
| Hemophilia A (n = 79) | | |
| Severe (n = 61) | 47 (12yr) | 14 (6.5yr) |
| Severe + Inhibitor (n = 9) | 1 (7yr) | 8 (6yr) |
| Moderate (n = 9) | 9 (11yr) | 0 |
| Hemophilia B (n = 16) | | |
| Severe (n = 12) | 7 (13yr) | 5 (3yr) |
| Moderate (n = 4) | 4 (16yr) | 0 |
| VWD (n = 9) | | |
| Type 2N (n = 1) | 1 (15yr) | 0 |
| Type 3 (n = 8) | 8 (8yr) | 0 |
| FVII Deficiency (n = 4) | 2 (8yr) | 2 (6.5yr) |
| FXIII Deficiency (n = 2) | 2 (15yr) | 0 |

Evolving the Program

- "The SickKids Homecare Infusion Resource" video was developed to facilitate patients/families learning of homecare.
- Using this, patients can learn essential concepts of homecare prior to attending in-hospital teaching sessions and review when necessary at home prior to coming to teaching sessions.



Challenges

- Teaching and certifying patients on this program is challenging due to limited nursing time, resource availability and language barriers. Families learning homecare is also challenging due to the time commitments for them.
- On average to complete the existing home infusion program, it takes 6 to 10 weeks. This is dependent on the learning styles of the patient/family as well as the number of infusions being performed per week.

Existing Program

STEPS FOR HOMECARE CERTIFICATION:

- Patient/Family complete a pre and post knowledge questionnaire to ensure a foundation of knowledge has been built prior to being in the home setting.
- Teaching is based on standardized certification checklists.
- Once all areas of learning have been met, a verbal contract is completed and homecare is commenced.
- Patient/Family are asked to complete a questionnaire within one month of program completion. The questionnaire provides feedback on the program. *It was found that numerous patients/families requested a video to assist with the learning process.*
- Yearly renewal of certification.

Statements from Patients/Families Regarding the Video

- "This video will be tremendously helpful for other families learning treatment at home. I know if we had this video, we would have learned the many steps that much faster, with more confidence. Not being able to practice/visualize without wasting products was the biggest road block in our process."
Father of patient with severe hemophilia.
- "This video was great. Definitely made the learning experience easier and quicker!"
Mother of patient with severe hemophilia.
- "This is amazing! This is going to help me so much!"
Patient with severe FXIII deficiency.
- "The video helped me review all the steps I was taught while in clinic. I used it as a refresher and it definitely made me feel more prepared and confident."
Mother of patient with Type 3 von Willebrand Disease.

SUMMARY & CONCLUSIONS

- The video:
 - Assists the learning process through demonstrating port-a-catheter or venipuncture access, factor reconstitution and administration and bleed detection and management.
 - Expedites the learning process and lessens the burden on healthcare resources while enhancing patients' and families' understanding of how to recognize bleeds and effectively deliver factor replacement therapy resulting in optimized quality of life.
- The impact of the video:
 - Patients/Families have reduced their clinic visits and have come better prepared for teaching sessions.

ACKNOWLEDGEMENTS

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