Feedback-guided Development for Patient Education Animation: HIV Transmission via Breastfeeding

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Abstract

This project uses animation to communicate the risk of HIV transmission via breastfeeding to mothers living with HIV in Canada. Current guidelines do not recommend breastfeeding for HIV+ mothers because there is always some level of risk. Knowledge of mother-to-child transmission is poor, and the cultural pressure to breastfeed has complex implications. It was essential that the science of transmission risk be conveyed in a clear and culturally sensitive manner. To accomplish this, we adopted a user-testing approach and sought feedback from members of the target audience throughout the development process.

Introduction

This project uses animation to communicate the risk of HIV transmission via breastfeeding to mothers living with HIV in Canada. Healthcare providers often do not openly discuss infant feeding options with this population, as current guidelines do not recommend breastfeeding for HIV+ mothers. In Canada, the majority of this population are women who have emigrated from countries in Africa or are of Indigenous descent. Knowledge of mother-to-child transmission is poor compared to that of HIV transmission in general. Moreover, for many in the target audience, cultural pressure to breastfeed is entwined with the risk of disclosure and stigmatization. It was essential that the science of transmission and the level of risk be conveyed clearly and in a culturally sensitive manner, to allow women to make appropriate, informed decisions about whether or not to breastfeed. To accomplish this, we adopted a user-testing approach and sought feedback from members of the target audience throughout the development process.

Figure 1. Bakery metaphor used to explain the difference between cell-associated and cell-free HIV. Sketches show the evolution of this visual device, from a factory metaphor.

Materials & Methods

Pre-production

The main concepts identified as integral to understanding the risk of transmission via breastfeeding were:

- the difference between cell-associated and cell-free virus,
- how blood and breastmilk are connected,
- why cell-associated virus is present in breastmilk,
- how transmission risk accumulates over time, and
- the fact that the risk of transmission can never be zero

Our initial approach to explaining these concepts through visual narrative was based on research in the literature (such as studies on the experiences of women living with HIV with infant feeding in Canada, the US and the UK)^{4,5,6}, interviews with key local healthcare providers and researchers working on infant feeding and HIV health and communication, and an analysis of the visual language used to describe HIV in art produced by members of the HIV community.

Figure 2. Evolution of character design and perspective.

Script, animatic, and visual asset production

Throughout development, the script, animatic, and character designs were presented for feedback to members of the target audience, healthcare providers, and representatives from Canadian HIV organizations in an iterative design process. These check-ins took the form of focus groups, presentations with discussion, and circulation of materials via e-mail. At each round of feedback the script, animatic, and visual assets were revised, and sent for further comment.

Results

Ongoing collaboration with the target audience helped us develop an animation with a wide diversity of characters, culturally sensitive metaphors, and nuanced descriptions of risk. What follow are three notable examples where target audience feedback led to significant changes in approach.

Bakery Metaphor

A conventional factory metaphor, designed as an overlay (Fig.1), was initially used to describe the difference between cell-free and cell-associated virus. However, feedback identified the factory metaphor as having connotations of hard labor, industrialization, and colonization. To avoid these stigmatizing connotations, the metaphor was changed to that of an automated bakery.

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Figure 3. Visualizations of increased risk over time were replaced with visualizations of facts, such as the number of immune cells in breastmilk, and the implications of such facts for overall risk.

Character Design

Initial designs featured a Kenyan mother, passing her knowledge to the audience in first person. Feedback cited discomfort, finding that focusing on women of one type of background (African) implicitly placed blame on this community. Accordingly, the narrative focus was more widely distributed, using sequences which featured multiple women. Several other characters were also designed to represent a diverse population of mothers living with HIV. (Fig. 2)

Visualization of Risk

Initial visualizations used relatable icons, such as milk bottles, to convey how risk of HIV transmission increases over time. Focus groups revealed confusion, and a strong bias to interpret information in order to support what women wanted to hear, rather than the fact of unavoidable risk—for example, one respondent expressed relief that she could breastfeed her baby as long as she did not do so for too long. This visualization was deemed to be potentially misleading. Facts such as the number of immune cells in breast milk, and that the risk of transmission cannot be 0%, are instead relied upon to relate the significance of the risk. (Fig. 3)

Discussion & Conclusions

User-testing approaches are necessary when creating patient education animations. Population needs, background, and context have a dramatic impact on patient understanding, and cannot be understood properly without user testing and direct feedback. Doing so helps prevent insensitive concepts and easily misinterpreted information, and thus is key to effective patient education animation.

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