

FROM VIH-TAVIE™ TO TAVIE-WOMAN™: DEVELOPMENT OF A WEB-BASED VIRTUAL NURSING INTERVENTION TO MEET THE SPECIFIC NEEDS OF WOMEN LIVING WITH HIV

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Abstract

The web-based virtual nursing intervention VIH-TAVIE™ was designed to help people living with HIV (PLWH) adhere to their antiretroviral treatment (ART). The content of the intervention is generic and gender neutral. However, it is recognised that women living with HIV (WLWH) experience their condition in a unique way and face gender-specific challenges regarding ART intake. Consequently, it seemed appropriate to adapt VIH-TAVIE™ specifically for women. The purpose of this paper is to present the qualitative results of an evaluative study of VIH-TAVIE™ that describe the experience of six WLWH who received the web-based computer-delivered intervention and to present the content and specificities of an offshoot intervention under development, TAVIE-Woman™. The following themes emerged from the content analysis of interviews with the WLWH about : 1) presence of actual nurse on site to facilitate transition to virtual mode; 2) virtual nurse humanises experience of computer-delivered intervention; 3) learners' appreciation of medium and content; and 4) perceived benefits following participation in the intervention. To adapt VIH-TAVIE™ for women, discussions were also held with a healthcare team in a mother-child university hospital centre. The gender-specific content added to TAVIE-Woman™ included digital storytelling of HIV-positive women, various topics about changing ARV medication during pregnancy, neonatal ART prophylaxis, disclosure to children, adapting to life

with HIV, selecting a birth-control method, and social support. Ultimately, the purpose of TAVIE-Woman™ is to support WLWH by offering them 24/7 access to tailored education and reliable quality information.

Keywords: HIV; women; medication adherence; web-based intervention; nursing

Introduction

The growing tide of people living with one or more chronic diseases and the challenges inherent in preventing and managing these health conditions bear witness to an urgent need for innovation to broaden the supply of care and services. In this age of giant advances in the field of information and communication technologies in health (i.e., eHealth), researchers in Montreal developed a concept of virtual nursing interventions and a computer platform called TAVIE™ (for Traitement, Assistance Virtuelle Infirmière et Enseignement - literally treatment, virtual nursing assistance and teaching). TAVIE interventions consist of online interactive sessions facilitated by a virtual nurse that engages the user in a process of self-management skill building. TAVIE™ has spawned a host of web-based interventions aimed at meeting the needs of client groups living with a health problem that is very often chronic (e.g., HIV, kidney failure, coronary heart disease, cancer, epilepsy, Parkinson's disease) and requires continuous personalised monitoring.

The first such intervention, VIH-TAVIE™, was designed to help people living with HIV (PLWH) adhere to their antiretroviral treatment (ART).¹⁻⁵ VIH-TAVIE™ consisted of four online sessions facilitated by a virtual nurse offering educational support. The virtual nurse is not an avatar but an actual nurse who interacts asynchronously with users via short pre-recorded video clips. The clips are triggered by complex algorithms based on user profile and input. The intended effect is for users to have the impression of interacting with a nurse in real time. Different camera angles and shots are used to enliven and humanise these asynchronous interactions.

The content of VIH-TAVIE™ is suited to both men and women living with HIV, that is, it is generic and gender neutral. However, it is recognised that women living with HIV (WLWH) face gender-specific challenges, most notably when it comes to planning and monitoring pregnancy in order to reduce the risk of HIV transmission from mother to child. Consequently, it seemed appropriate to adapt VIH-TAVIE™ specifically for women.

WLWH experience their chronic condition in a unique way. In a literature review, Carter et al.⁶ found that the challenges faced by PLWH differed by gender, including with regard to treatment access and maintenance. More specifically, research has shown that women were more likely than men to be less adherent to their ARV regimen, to interrupt treatment, and to experience more adverse effects.^{7,8} During pregnancy, adherence to ART is critical to prevent perinatal transmission of HIV. WLWH face many healthcare barriers that are heavily influenced by gender, including stigma and discrimination, violence, psychological distress, mental health and addiction issues, and lack of financial resources and social support. Female gender, the ability to bear children, and the possibility of perinatal transmission all contribute to the unique experience of women living with a stigmatising disease such as HIV infection.⁹ Many WLWH experience significant levels of stigma that can have a negative impact on their psychological well-being, their social networks, and their healthcare service utilisation.¹⁰ Several factors other than gender have also been found to be associated with suboptimal service utilisation, including low education level, insurance status, mistrust of the healthcare system, and weak trust in healthcare providers.¹¹

Supported by the Millennia2025 "Women and Innovation Foundation"¹² to demonstrate digital

solidarity among women in the field of eHealth, we undertook to develop TAVIE-Woman™, a virtual nursing intervention adapted to the unique reality of WLWH. The aim was to address the specific needs of WLWH regarding ART adherence and thus better promote their health and well-being.

The purpose of this paper is twofold: to present the qualitative results of an evaluative study of VIH-TAVIE™ that describe the experience of six WLWH who received the VIH-TAVIE™ intervention and to describe the content and specifics of TAVIE-Woman™.

Methods

The VIH-TAVIE's study was approved by the Institutional Review Board (IRB) of the Centre Hospitalier de l'Université de Montréal (#08-106). The exploratory qualitative evaluation of VIH-TAVIE™⁴ was part of a wider quantitative quasi-experimental study aimed at comparing the effectiveness of two types of follow-up, traditional and virtual (i.e., VIH-TAVIE™), in promoting ART adherence among 179 HIV patients.⁵ Traditional follow-up consisted of meetings with health care professionals over a period of 3 to 4 months. Personalised health advice was given on these occasions and covered medication, side effects, and other problems encountered. In virtual follow-up, four VIH-TAVIE sessions, each 20-30 minutes duration, were offered over an eight week period. The qualitative study was performed to understand how 26 PLWH who completed all four online VIH-TAVIE™ sessions⁴ experienced the experimental intervention.

In this study, individual semi-structured interviews were conducted with participants to invite them to share their thoughts and feelings regarding VIH-TAVIE™. Each interview was recorded with consent and transcribed verbatim. First, a manual content analysis of the transcripts was performed regarding the experience of these 26 participants. Each interview was coded by a principal coder. Codes were then validated by another person well acquainted with the project. Differences and disagreements between the two were settled by consensus. Next, a secondary content data analysis was undertaken as part of the VIH-TAVIE™ primary qualitative research stream with a more narrow focus on the experience of the six women (out of the 26 participants) who took part in VIH-TAVIE™. An interview guide was used to ensure all topics of interest were covered, including use/appropriation of

technology, relevance of intervention (e.g., drug intake support), possible improvements to the intervention, and interaction with the virtual nurse.

Because VIH-TAVIE™ is intended to help build self-management skills useful to all PLWH, both men and women, we transferred a large part of its content to TAVIE-Woman™. To create gender-specific content (such as case stories), discussions were held in a mother-child university hospital centre with the team of a multidisciplinary clinic (i.e. obstetrician-gynaecologists, paediatricians, nurses, a social worker and pharmacists) dedicated to the care of WLWH and their children. WLWH were followed by obstetrician-gynaecologists in the context of either their obstetric or gynaecological care, while the children were followed for their HIV care by a paediatrician specialised in infectious diseases.

Various questions guided the discussions, including: “In your practice, what are the challenges facing women who are on ART or who plan to start ART (for example, with respect to pregnancy planning, during pregnancy and after delivery)?” Different techniques and methods were then used to tailor the TAVIE-Woman™ intervention, such as digital storytelling (verbal accounts or testimonies) of three WLWH who shared their experience of ART, case stories (illustrated narratives) and fact sheets. The filming of three videos (i.e. digital storytelling) of these WLWH was done as part of the TAVIE-Woman™ development. These WLWH were videotaped sharing their experience of being a WLWH who takes ART, facing challenging, overcoming difficulties and envisioning what access to the TAVIE-Woman™ intervention might mean for them. We expected that the use of these videos could be a means to create positive connections with other WLWH who would participate in the TAVIE-Woman™ intervention.

Results

The results are presented in two sections. First, the experiences of six women who took part in VIH-TAVIE™. Second, gender-specific content of the TAVIE-Woman™ intervention. The accounts of three WLWH who participated in the development of TAVIE-Woman™ (i.e. digital storytelling) are summarised.

The sample consisted of six women who completed all four VIH-TAVIE™ sessions. Their median age was

50 years (range of 33–66) and five of the six (83%) had completed high school. Half reported annual income below CAD\$15,000. The median number of years since HIV diagnosis was 10 and the median number of years on ART was 7. (Table 1)

Table 1. Demographics of the six study participants (median and range are given for age, years of HIV infection and years on ART).

Age, in years	50 (33-66)
Native country	
Canada	4
Other	2
Marital status	
Single	2
Divorced/Widowed	4
Sexual orientation	
Heterosexual	3
Homosexual	1
Bisexual	1
Transsexual	1
With children -	
Yes	3
Number of children (min-max)	1-3
Highest educational level	
High school	5
College	1
Annual income, in CAD	
<\$15,000	3
\$15,000–\$24,999	2
\$25,000–\$34,999	1
Employment status	
Employed	2
Retired/Volunteer	1
Unemployment insurance	3
Living arrangements	
Alone	3
With partner, family, friend	2
Other (housing)	1
Years of HIV infection	10.2 (5.6–25.8)
Years on ART	7.2 (3.8–21.8)

Content analysis yielded four major themes that described the experience of a virtual nursing intervention in support of ART adherence. These themes and their corresponding subthemes are presented below.

Presence of actual nurse on site to facilitate transition to virtual mode

Having an actual nurse on site during the sessions was reassuring as women could turn to that person when in doubt:

“If I didn’t understand something, there was always someone next to me to answer my questions, no matter how trivial. And she always answered my questions, uh... with a nice smile on her face and, well... that reassured me. I felt reassured. As if I’d known the person for a long time.” (Woman #2)

Virtual nurse humanises experience of computer-delivered intervention

For women, computers can be an impersonal tool. However, in the case of VIH-TAVIE, the participants highlighted the human dimension of the intervention:

“You don’t feel labelled as much, like, you feel more... respected in the sense that... a computer, well, it’s just so impersonal.” (Woman #1)

“Uh, a computer is alright, I mean, a computer is not a human being, but, uh, I still had the impression of having a human being in front of me.” (Woman #3)

Learners’ appreciation of medium and content

The women appreciated the quality of the teaching delivered by the virtual nurse. They also pointed out the usefulness of fact sheets they could print out to be used as reference material during and after the intervention. The sheets reassured the participants and were useful in managing side effects, among other things.

“I don’t know what I’d do without them [fact sheets]. I’d probably be over at my doctor’s all the time asking: “What do I do about feeling tired all the time? What do I do about my lack of appetite?” Instead, with all the fact sheets, I can get by on my own [...] I took all of the sheets so I can help myself. And, uh, these tools have been a great help. I mean, I was very happy to have them because, see, I’m still using them today.” (Woman #4)

One woman expressed her appreciation of the novelty of dealing with medication through a computer-delivered intervention accessible from home. Another woman stated that she appreciated the fact she was free to navigate the sessions on her own.

Perceived benefits following participation in the virtual nursing intervention

Women identified many benefits following their participation in the intervention. The WLWH reported using strategies proposed by the virtual nurse to manage side effects and to adopt a positive attitude toward medication:

“It’s like I’m taking vitamins now. In my mind, uh, they’re no longer drugs. In my mind, they’re drugs, you know, there are ways, you know, that’s the positive

thing it brought me, it’s having a different perception of taking medication and integrating it, uh... it doesn’t have to be a big deal. There are possibilities, it opened up, uh... opportunities in my line of thought to see things differently.” (Woman #1)

They learned to integrate medication intake in their routine and gained awareness of the importance of respecting certain conditions to ensure regular medication intake by (e.g., taking medication with food). One woman stated that, before VIH-TAVIE™, she drank 2-3 beers a day and failed to take her medication methodically. After her participation in VIH-TAVIE™, something changed: She reduced her alcohol consumption and began taking her medication regularly.

Completing the virtual nursing intervention gave the women confidence, reassured them, and encouraged them to continue with their ART. Acceptance of the disease and not feeling alone were other emotional benefits reported. The women used various terms and expressions to qualify their experience: “reassuring”, “seeing the light”, “heartening”, “felt welcomed”, and “trust”. They were moved to see that researchers took an interest in their situation by setting up projects such as VIH-TAVIE™:

Uh, confidence, having strong confidence. Knowing you’re not alone. Knowing there are a lot of people helping you anonymously (...). It’s like, sometimes, you think that because you’re HIV positive, you’re alone. No. Not true. You’re never... Anyway, as far as I’m concerned, I’m, I’m very grateful towards (name of hospital). (Woman #2)

From VIH-TAVIE™ to TAVIE-Woman™: content adapted specifically for women

The VIH-TAVIE™ intervention consists of four sessions and contains short video clips (n=120), narratives (n=16) and consolidation tools (e.g., logbook of adverse effects, 60 PDF files). This content is generic and gender neutral. The TAVIE-Woman™ intervention is based on the whole of this content plus more clinical content, accessible in print (fact sheets) and audio-visual mode, specific to women.

The women who will participate in TAVIE-Woman™ will first be asked to create an account in order to connect to the intervention. They will then be able to view three digital stories told by WLWH describing their experience with ART medication and expressing their thoughts regarding the possibility of accessing the TAVIE-Woman™ intervention. These

videotaped digital stories were incorporated to help create a bond between the women sharing their life experience and the women who will participate in the intervention. Here is an excerpt from the digital stories told by the three women that shared their views on the prospect of the TAVIE-Woman™ project:

“TAVIE-Woman™ would be a very interesting project not only because it could help manage medication intake and side effects but also because in the world of HIV there isn’t much targeted directly at women. Me, I didn’t always see myself reflected in the literature because many of the things that interested me were directed at men who have sex with other men, so I was always having to adapt a little. Having a programme specifically for women, I think it’s important because we’re part of the population at risk, like anybody else [...] so it’s great to have something that speaks to us directly.” (Woman #1)

“The online version of the TAVIE-Woman™ project is very interesting for us, for all women living with HIV. It would help us a lot, especially at the start of a treatment. You tend to shop around left and right on the Internet. Or when you have to change treatment... It’s important to get help immediately, it pushes you to take care of yourself. At the same time, it helps you see that you’re not alone, someone’s there to support you to get on with your life and to get through the process.” (Woman #2)

“I think that a project such as TAVIE-Woman™ could be interesting. If I could ask a virtual nurse questions, that would be interesting, it would be great! I see my doctor once a month or every three months. Often, I have questions to ask. If I want her to answer them, I have to prepare a list. Because I’m like “timed.” I have 15 minutes with her and I have to make it fast. It would be interesting to have exchanges with someone online. It would not have to be complicated, though, because I’m not very good with computers. I’m pretty basic. It would have to be fast and easy.” (Woman #3)

Users will then view a video clip of the virtual nurse, where she provides an overview of the objectives of TAVIE-Woman™ and of the content of its sessions. Moreover, eight case stories of HIV-positive women are accessible in the form of illustrated narratives (i.e., voiceover to images) dealing with various themes such as: beginning ART and changing medication during pregnancy, neonatal antiretroviral prophylaxis, disclosure to children, adapting to life with HIV,

selecting a birth-control method, and social support. These case stories are based on real-life examples. The women who shared their stories serve as role models to influence and encourage the users of the TAVIE-Woman™ intervention to adhere to their medication regimen. These case stories are also available in a summarised version on printable fact sheets (PDF files). Two other animated clips concern how community groups can support WLWH and the role of obstetrician-gynaecologists in monitoring their health. Finally, five fact sheets taken with permission from the CATIE website,¹³ Canada’s source for HIV and hepatitis C information, cover the following: HIV diagnosis during pregnancy; HIV, women and pregnancy; pregnancy planning; and tools for HIV-positive women and their babies. These sheets are available as PDF files that can be downloaded and printed out.

Conclusions

The next phase of the project will consist of implementing the TAVIE-Woman™ intervention in two care settings in the Montreal area with the aim of promoting its adoption and encouraging WLWH and health professionals (physicians, pharmacists, nurses) to use the TAVIE-Woman™ in clinical HIV care. These two target groups will be invited to consult the four TAVIE-Woman™ sessions. The acceptability of the intervention will then be documented through discussion groups. Moreover, conditions that might facilitate or hinder the implementation process will be identified. Based on the Greenhalgh model of the determinants of the diffusion, dissemination and implementation of innovations (in our case, the TAVIE-Woman™ intervention), we will collect data on the following: characteristics of the TAVIE-Woman™ intervention (e.g., perceived benefits, accessibility, compatibility), user profile (e.g., needs, motivational level, skills), and receptiveness and disposition of settings towards TAVIE-Woman™ and other interventions.^{14,15} Consequently, it seems imperative that we examine the viewpoints of both WLWH and of professionals to ensure the TAVIE-Woman™ intervention meets the needs of women and fits in with and complements professional practices. Investigating the organisational perspective would be valuable to facilitate implementation efforts on multiple levels.

Too often, information on HIV and its treatment is poorly understood by patients, thus undermining their management of the condition. Furthermore, access to

information would also allow family and friends to gain a better understanding of the vagaries of the disease, allay some of the fears surrounding it, and demystify its risks and consequences. The TAVIE-Woman™ intervention was developed to support WLWH by offering them 24/7 access to tailored education and reliable quality information.

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Conflicts of interest. 360 Medlink holds a licensing option on the VIH-TAVIE™ and TAVIE-Woman™ interventions. 360Medlink is associated with José Côté (for VIH-TAVIE™ and TAVIE-Woman™) and with Geneviève Rouleau and Isabelle Boucoiran (for TAVIE-Woman™).

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