

Columbia Center for New Media Teaching and Learning

Seminar #683

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Chairs: Ryan Kelsey, Frank Moretti

Rapporteur: Ruth Palmer

Triangle Initiative Interventions in HIV Prevention and Treatment: A Progress Report

Speakers: Dr. Robert Remien of the HIV Center for Clinical and Behavioral Studies, Dr. Louisa Gilbert of the Columbia School of Social Work's Social Intervention Group, and Jessica Rowe, CCNMTL Triangle Initiative Senior Program Specialist

Summary: Drs. Remien and Gilbert presented two projects that use custom-developed multimedia interventions to support HIV treatment adherence and safer-sex behaviors, in South Africa and in New York respectively.

The Presentation

Seminar Co-chair Ryan Kelsey began the meeting by explaining that both of the projects being presented were developed in partnership with CCNMTL's Triangle Initiative, a strategic effort to develop digital tools to facilitate university work at the crossroads of community outreach, education, and research.

Dr. Remien then introduced Masivukeni (which means "Let's Wake Up!" in Xhosa), a pilot project funded by NIMH, and developed in partnership with CCNMTL over the last two years. Dr. Remien began by explaining that the development of antiretroviral drugs (ARVs) around 1996-97 has turned HIV, once a terminal illness, into a chronic one—but only if the drug regimen is strictly followed. The regimen is complex, often involving multiple pills taken at specific hours, and missing even a few pills can have severe ramifications for a patient's health. Getting patients to adhere to the regimen is especially challenging in sub-Saharan Africa, where infection is widespread but severely stigmatized. The goal of Masivukeni was to develop a laptop-based tool that lay counselors in South African clinics could use to conduct a behavioral intervention to increase HIV treatment adherence.

Dr. Remien explained that a behavioral intervention involves systematic education and training to modify health-related behaviors, in this case, adherence to the drug regimen. Encouraging behavior change is extremely complex, so when developing an intervention it is vital to take into account a patient's information, knowledge, and behaviors, as well as their self-regulatory processes, such as mood and motivations. You must also consider social factors, such as stigma surrounding disclosure of one's HIV status, and a patient's personal support network.

He explained that this particular pilot project grew out of a previous NIMH project, “SMART Couples,” which, in its involvement of the patient’s partner, was the first adherence-related intervention not focused solely on the individual. His team transferred the same idea to South Africa in the form of a treatment “buddy,” a person chosen by the patient to support him or her during treatment and, hopefully, to encourage adherence in the long-term.

One of the challenges for Dr. Remien and his team was to develop a tool that could be used by non-professional counselors. Availability of counselors varies at different South African clinics, and in the past counseling has not been standardized; Dr. Remien’s team hoped to develop a tool that would be easy to implement and flexible enough for use in different contexts, but that would also help standardize the counseling procedures. They wanted a tool that would not only walk the counselor and patient through the intervention using clear language, but that would also track and monitor the steps and the patient’s progress. They involved all key stakeholders in the development of the intervention, to make it as user-friendly and effective as possible in the South African clinical context.

CCNMTL Program Manager Jessica Rowe next demonstrated Masivukeni. She began by showing the screen a counselor initially sees, which provides a map of numbered activities. Many of the steps are intended to guide the counselor through subsequent stages of the intervention: these are text-based, each with objectives, instructions, and suggested times for how long they should take. But there are also several interactive activities for the patient, buddy, and counselor to do together on the screen.

Ms. Rowe demonstrated the “island activity,” explaining that the idea for the island was suggested by South African clinic workers as a metaphor that would resonate with patients. The activity shows a person standing on a small island, surrounded by water. At the top of the screen, the patient can manipulate several bars: one to raise and lower the person’s viral load; another to raise and lower the cd4 count; a third to indicate greater and lesser adherence to the ARVs. As the viral load is increased, the water rises to slowly engulf the patient; as the cd4 count lowers, the person begins to sink underwater, and to become skinny and pale. If you increase the level of adherence, however, the patient moves to higher ground, visibly demonstrating the value of consistently taking the pills as prescribed.

Ms. Rowe noted that in South Africa the ARVs are generic, and the pills change frequently, as does the precise regimen, which can get very confusing. CCNMTL and Dr. Remien, therefore, developed an activity that lets patients practice the regimen. The patients choose from images of different pills and drag them into a little cup, indicating how many and at what time they are supposed to take them.

One of the core goals of the intervention is to help patients develop problem-solving skills. First, the patient and buddy learn problem solving steps in a text-based discussion with the counselor; then they watch a video of two friends working through an issue, such as coping with long waits to access treatment in the clinic. The clinicians had advised Dr. Remien’s team that this would be more effective than a video of one person’s testimonial,

and they had been very pleased when they saw the results. Another activity lets patients choose from various problems that might negatively affect their treatment (such as distance from the clinic, drinking too much alcohol, fear of clinic staff, etc.), and then to make a plan for navigating those issues.

Here Dr. Remien reiterated that this had been a pilot study, intended to determine the feasibility of delivering these laptop-based interventions in a busy clinic; how acceptable the method would be among clinicians, health providers and patients; and how effective the intervention appeared to be. The pilot study included a randomized controlled trial of 65 patients, two-thirds of whom were women.

Results showed significant improvements in self-reported adherence and knowledge of treatment, and declines in psychiatric distress among patients. Patients said they found the activities visually engaging and that they learned things they had never understood before. Treatment buddies reported that they learned a lot about how to help their partners, as well as useful information about their own health, while counselors appreciated the road map the tool provided, and felt it advanced their counseling capacities, including their ability to identify and refer patients to mental health counseling. The clinic providers said they wanted to adopt the tool as their standard counseling technique; they appreciated that it forced the counselors to spend as much time as they should with each patient. Dr. Remien concluded his presentation by noting that even South African policymakers, initially skeptical, now seem encouraging; they realize it is critical that they improve their HIV counseling.

Next, Ryan Kelsey introduced the day's second presenter, Dr. Louisa Gilbert of Columbia School of Social Work's Social Intervention Group. Dr. Gilbert explained that she and principal investigator Dr. Nabila El-Bassel of SIG had partnered with CCNMTL to develop and test a multimedia version of the WORTH intervention, an HIV/IPV (Intimate Partner Violence) prevention intervention designed for drug-involved women who are under community supervision (meaning they are on probation or parole, or enrolled in an alternative-to-incarceration program). She explained that there was a growing number of women in this demographic who are at risk of HIV and/or IPV, so WORTH was developed to meet this need.

WORTH is focused on empowering participants and, like Masivukeni, is based on social-cognitive behavioral change theories. In its traditional, non-multimedia version it was found effective for use with prisoners at Rikers. The goal of the current project, which is funded by the National Institute for Drug Abuse (NIDA), is to develop a multimedia version of WORTH and compare its effectiveness to traditional WORTH.

Dr. Gilbert explained that the core elements of WORTH are: raising awareness of the risks of IPV and HIV; improving problem-solving skills; helping participants negotiate skills for safer relationships; conducting IPV screening, brief interventions and referrals to services; enhancing participants' social support networks; identifying unmet service needs and referrals; and personal goal setting for future prevention.

Here CCNMTL Director Frank Moretti intervened to ask if participants were active drug users. Dr. Gilbert confirmed that they were: to participate they must have tested positive for illegal substances within the previous 90 days. Most are users of crack-cocaine or marijuana. She went on to explain that they had developed the multimedia tool in hopes that the interactive, visual format would promote attention and retention, because in addition to following a supervisor's steps on a Smartboard, each participant would be working on an individual pc to complete activities and volunteer answers to questions anonymously.

Dr. Gilbert said the other key enhancement in the multimedia version of WORTH is the incorporation of fictionalized virtual role models. These are introduced at the beginning of the intervention (which involves four sessions, meeting once a week for a month), and woven throughout. These characters model behaviors and positive norms, and participants seem to identify strongly with them. The characters were carefully developed in consultation with the community workers so they would be as identifiable as possible for participants. It seems to be more effective to have these characters model the behaviors than to have a supervisor do so.

However, Dr. Gilbert explained, in addition to the potential advantages of the multimedia version, there were some potential drawbacks: would it impede group dynamics or weaken the relationships between participants? Would less savvy computer users be left behind? They were also concerned that technical difficulties could interfere with the intervention.

Next, Ms. Rowe demonstrated the multimedia version of WORTH. She explained that it involved two facilitators using a Smart board, and up to nine participants, each sitting in a semi-circle with a laptop. The computers are all online, and they talk to each other, so all participants move through the intervention in a coordinated way, controlled by the facilitators. The participants can respond to questions anonymously at various stages.

Ms. Rowe then showed a clip of Charlene, one of the four video characters, describing how personal troubles had led her to a drug habit, sex work, and HIV. Ms. Rowe explained that all of the characters describe their own relationship to HIV and IPV, but they also interact with one another, talk about problem solving, and model positive skills.

Another activity in the intervention is a myth/fact quiz game about HIV that participants respond to anonymously on their laptops; this is a way for all to participate without the shame of not knowing the correct answers. Another activity has individual participants create a risk map on which they place people in their lives who put them at risk of unsafe sex and violence; they also create a support map showing their proximity to supportive people in their lives. Another stage helps them learn about available services, eventually guiding them to websites and contact info, which they can print out and take with them at the end. The tool also includes an intimate partner violence survey, which assesses their risk level.

At the intervention's end participants get a detailed safety plan, complete with risk assessments and goal setting. The supervisor receives a log detailing how much time was spent on each activity, and how participants are progressing, including what goals they have set.

Dr. Gilbert concluded by explaining that they are still in the middle of the trial; to date they have enrolled 185 women and they hope to include 210 more, with a goal of completion by May 2013. After that, they hope to take the multimedia intervention into different environments. There are also a number of pieces of multimedia WORTH that can be built out for other projects. For example, they have found that women are more likely to disclose partner violence to a computer than to another person, so they plan to do a pilot study to look at computerized pilot IPV screening of women under Drug Court supervision.

Discussion

Briana Ferrigno, CCNMTL Communications and Marketing Manager, asked Dr. Remien how they collected feedback from patients and others about Masivukeni. He explained that an independent assessment had been done that included interviews and surveys, and that his team had also conducted informal discussions and focus groups. CCNMTL Executive Director Frank Moretti asked if the medication has gotten any simpler over time. Dr. Remien replied that it has – but less so in South Africa, where most patients take generic drugs, usually on a two a day regimen. The pills do change every once in a while, which further complicates adherence issues.

Ann McCann Oakley of the Columbia School of Social Work asked Dr. Gilbert to explain how many sessions were involved in the WORTH intervention. She responded that they do four group sessions over one month, with follow-up assessments at 3, 6, and 12 months. Mark Phillipson, CCNMTL Senior Program Specialist, asked Dr. Gilbert how they were defining multimedia; the incorporation of virtual role models seems like more than just an additional medium—perhaps it is a whole new mode or approach? Dr. Gilbert agreed, acknowledging that they used “multimedia” in a very broad sense to refer to the use of the computers to deliver the intervention, as opposed to a paper manual.

CCNMTL Programmer Analyst Eddie Rubeiz said he would be curious to know what a multimedia WORTH facilitator learns from administering the program about what aspects of it work and which do not; do they have a method for capturing this? Dr. Gilbert responded that facilitators fill out a form at the end of each session about how it went. She added that one advantage of traditional WORTH is that supervisors have greater flexibility to make adjustments should anything come up. A computer-based program is more linear, with less leeway for improvisation.

Maurice Matiz, CCNMTL Vice Executive Director, noted that the physical space and technical requirements for administering multimedia WORTH sounded imperative for its success, to which Dr. Gilbert responded that yes, the configuration of the seats and

computers had turned out to be extremely important for involving all members, and that these constraints could prove problematic in different contexts. Ms. Rowe volunteered that in South Africa they found that the counselors, patients, and buddies were not using the computers in the way designers had envisioned. Rather than the counselors monopolizing and reading off the computer, only occasionally showing it to the patient, all had huddled around it. This led the team to change some of the language, and redesign some aspects of the program. Dr. Remien noted that as much as the digital tools can do, the human intervention element is still vital to their success; it is the interplay between the multimedia tools and human interaction that brings them to life.

Ryan Kelsey asked both presenters if these tools have affected how they think about their research or teaching. Dr. Remien responded that it has transformed the development of interventions and expanded his thinking about what is possible; at his Center they want to teach all investigators about the possibility of using digital tools. He added that Masivukeni had also been used as a teaching tool in some classes, including one on Global Interventions in Health Care, and another on Women, Children and AIDS. Dr. Gilbert added that Ms. Rowe had presented Masivukeni in her HIV course at the School of Social Work, and it was very effective as a teaching case study.

Dr. Remien noted that it was also a good tool for teaching about the importance of cultural understanding in the development of interventions. For example, the risk mapping done in WORTH was totally alien to South African patients, who do not envision their social networks the same way. Clinicians helped his team understand that a more familiar metaphor would be a tree, with the patient's support network branching out around them—so they built a graphic of a tree.

Dr. Gilbert said that in terms of her research, this work has changed her thinking about scalability: the development of these tools requires a significant initial investment, but they are easily disseminated to other environments. They have a better uptake rate than manual-based programs, they empower lay facilitators, and they are great for standardizing the steps. Dr. Moretti interjected that these were exactly the arguments that were made several years ago when they were trying to get the project funded, so it is gratifying to hear they are playing out according to plan.

Ann McCann Oakley asked Dr. Gilbert if the WORTH participants in this study were court mandated. Dr. Gilbert replied that they were not, they had been recruited when exiting probation sites and at Bronx Community Court, which sees about 12,000 clients a year. Ann asked if the computers were connected via a local network, to which Ms. Rowe responded that no, they were just online, which was part of why synching them was a challenge. Dr. Moretti asked how hard it was to train facilitators, to which Dr. Gilbert replied that aside from a few minor crises it had not been difficult. Dr. Remien added that a nice side-effect of implementing these tools had been watching the lay counselors take pride in learning new skills.

Ryan Kelsey asked the presenters what CCNMTL could do better in the future. Eddie Rubeiz volunteered that they need to train facilitators to better troubleshoot technical

issues as they arise. Dr. Gilbert added that they still needed to analyze the administrative log and the audio tapes of the interventions to see what was really working what was not. Dr. Remien noted that they found the logs especially helpful for finding out where counselors are skipping steps and where they are spending the most time.

Dr. Moretti asked Dr. Gilbert what she was learning from the study about criminalization; she responded that it is tremendously stigmatizing. Many of their participants are involved in petty theft or sex work to support their drug habits, so this is something the fictional role models discuss at length.

CCNMTL Creative Director Liz Day asked both presenters if participants stay in touch with one another after the interventions. Dr. Remien said anecdotal data indicates that all treatment buddies stayed engaged for at least the year. Dr. Gilbert said their participants sometimes exchange contact information, suggesting they have bonded in the process. She noted that she believes this is one sign of a successful intervention.

Ryan Kelsey concluded the meeting by thanking the presenters.