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MEDIA & COMMUNICATION STUDIES | RESEARCH ARTICLE

Usefulness of rights based written narratives on sexual and reproductive health among HIV-infected women in Western Maharashtra, India

Shrinivas Darak^{1*}, Trupti Darak¹, Vinay Kulkarni¹ and Sanjeevani Kulkarni¹

Abstract: Narrative communication is emerging as an effective form of health communication in the research being carried out globally. This exploratory study assessed perceived usefulness of a book of seven narratives on different issues related to sexual and reproductive health among HIV-infected couples. Sixteen in-depth interviews and 174 structured interviews were conducted among HIV-infected women to understand the usefulness of such narratives and differences in knowledge and attitude respectively. Thematic analysis and descriptive statistics were used to analyze the data. The written narratives were perceived to be useful by HIV-infected women. They positively affected the self-efficacy beliefs of women, improved acceptance of the partner, helped them cope with the disease and in making more informed decisions as well as contributing to decreased misconceptions. The narratives were simultaneously perceived as “too emotional”, discouraging women to engage with the text. The knowledge and attitude about sexual and reproductive health (SRH) does not seem to be statistically significantly different among women who read the book compared to those who did not read it. In diseases such as HIV, which can lead to biographical disruption, this research shows that there is need for health communication that supports people in accepting and emotionally coping with the disease.

ABOUT THE AUTHOR

Shrinivas Darak has received training in Medicine, Anthropology and Demography and his research includes quantitative and qualitative methods incorporating disciplinary perspectives from clinical epidemiology, Public Health, Anthropology and Demography. His area of research has been gender, sexuality, reproductive health and HIV/AIDS with topical focus on strengthening research utilization to inform practices and policies. He is senior researcher at Prayas Health Group. With his other colleagues, his recent research includes understanding the impact of HIV/AIDS on reproductive lives of HIV-infected women in India, building evidence on effective social behavior change communication strategies regarding mother and child health and sexual and reproductive health of youth in India. Developing health communication material is one of the strength areas of Prayas Health Group.

PUBLIC INTEREST STATEMENT

Stories are powerful tools for making sense of our lived experiences. The research reported in this article aims at understanding whether or not health educational material written in the form of stories is useful to HIV infected women in India. The stories are based on previous research on the same population, focusing on sexual reproductive issues and upholding the rights of women to make choices in their lives. In a highly stigmatized disease such as HIV, there are limited opportunities for women to interact with each other and learn about their struggle. Reading about the stories of women who are in a similar situation and the extraordinary capabilities with which they confront the difficult circumstances regarding their reproductive lives provides the reader with the strength to cope with her own illness and make more informed decisions.

Subjects: Interpersonal Communication; Writing & Composition; Communication Theory; Health Communication

Keywords: written narrative communication; HIV/AIDS; India; sexual and reproductive health; transportation-imagery model

1. Introduction

Health communication is at the core of addressing any public health issue (Rimal & Lapinski, 2009). Health communication is broadly defined as “the study and use of communication strategies to inform and influence individual decisions that enhance health.” (Centers for Disease Control & Prevention, 2011). It has played a pivotal role in the combat of HIV (Tomori et al., 2014) by informing people about the risks, persuading them to adopt healthier behaviors and by addressing norms through which social identities and values are shared (Storey et al., 2014). It is a dynamic process with active involvement of the message receivers in processing and adopting the health message. Therefore an effective health communication strategy takes into account the ability of receivers to engage with the information and process it.

Narrative communication is emerging as an effective form of health communication in the research being carried out globally (Dragoman et al., 2014). It has been recommended as one of the evidence based effective strategies for health communication (Kreuter et al., 2014). A narrative is defined as “... any cohesive and coherent story with an identifiable beginning, middle, and end that provides information about scene, characters, and conflict; raises unanswered questions or unresolved conflict; and provides resolution” (Hinyard & Kreuter, 2007; Kreuter et al., 2007). It has been particularly argued to be more effective in impacting social norms (Moran, Murphy, Frank, & Baezconde-Garbanati, 2013). In contrast to the traditional model of health communication such as the elaboration likelihood model (Withers & Wertheim, 2004), which requires high ability of the message receiver to process the information, narrative communication is believed to follow the transportation-imagery model (Green & Brock, 2000) in which the person who is reading the narrative is ‘transported’ into the narrative world making it more likely that the reader will accept the propositions in the story. This phenomenon is argued to make narrative communication more effective.

Some recent studies have assessed the usefulness of narrative communication in cancer prevention and care (Baezconde-Garbanati et al., 2014; McGregor et al., 2015), cessation of smoking (Cherrington et al., 2015), management of hypertension (Cohn, 2011; Houston et al., 2011) and diabetes (Goddu, Raffel, & Peek, 2015). However, to our knowledge there is no study assessing the usefulness of narrative communication among HIV-infected people.

In this study the usefulness of written narratives about sexual and reproductive health was assessed among HIV-infected women from Western Maharashtra, India.

1.1. Previous research on which the narratives are based

From 2008 to 2013, the authors carried out formative research, a life course study of reproductive career among (LCRC study) 622 ever-married HIV-infected women attending a HIV clinic in Western Maharashtra, India. The LCRC study was aimed at understanding the reproductive careers and fertility among HIV-infected Indian women and its implications for programs, policies and practices. The analysis of the data from the LCRC study revealed important gaps in provision of reproductive health services to HIV-infected women. In the LCRC study, the proportion of unwanted pregnancies conceived by the women after their knowledge of HIV was observed to be 51% whereas 50% of all these pregnancies were voluntarily terminated. Women who did not know that HIV transmission to the baby can be prevented were more likely to report unwanted pregnancy and induced abortion (Darak, Hutter, Kulkarni, Kulkarni, & Janssen, 2015a, 2015b; Darak et al., 2015). These findings were in line with studies from Sub-Saharan Africa, Europe and the United States that reported higher rates of unwanted pregnancies and induced abortion among HIV-infected women compared to HIV uninfected women (Ammassari et al., 2013; Bui, Gammeltoft, Nguyen, & Rasch, 2010; Kaida et al., 2011),

Table 1. Main themes presented in the stories

Story	Main theme	Plot	Excerpts from the book
1	Men and woman can choose permanent methods of contraception when they have completed their desired family size to avoid unintended pregnancies. We compare the permanent methods of contraception for men and women and encourage men to participate	This is a story of Manda and her husband Subhash where both are HIV-infected. Subhash is very caring and understanding. They have two children and don't want to have another child. They are using condom inconsistently and safe period method for contraception. Meanwhile Manda becomes pregnant twice and had to abort these unwanted pregnancies. So after a second abortion, the doctor refers them to a counsellor. They both go to the counsellor. The counsellor explains to them how safe period method is not reliable and informs them of various other contraceptive methods, including permanent methods of contraception	The counsellor said, "If you are completely certain that you do not wish to have any more children, operation is the best option. It could be a sterilization operation of either the woman or the man, but I would say a man's vasectomy operation is comparatively easier, saves time, and is also less troublesome" Manda was about to say something, but Subhash was already smiling at her. He said, "Alright then, I will undergo the operation, not Manda. I have no objections to having the operation done on myself. You see Manda, you have already borne the hardship of childbirths, now I should take on the responsibility of the operation." Now turning to the counsellor with a broad smile, he said, "Should I not, what do you say?" Manda realized once again how understanding her husband was
2	The importance of knowing about the timing of HIV diagnosis and disease progression and why does it matter when considering becoming pregnant	This is a story of recently married couple, Hawwa and her husband Hameed who was diagnosed with HIV and TB one year after their marriage. He is taking medicines for both HIV and TB. After testing, Hawwa finds that she is also HIV-infected. Her in-laws and neighbors taunt her for not being pregnant yet. She also wants to have a child but gets very disappointed as the counsellor asks them to use a condom every time they have sex to prevent cross infection. She decides to discuss her desire to have a child with her doctor. After confirming that Hawwa's CD4 levels are fine, he sends both of them to a counsellor to discuss pregnancy planning. The counsellor explains how they can have a natural pregnancy with maximum protection	Hawwa and Hameed were overjoyed. When they were diagnosed with HIV, they had doubts of being able to live at all, but now, they were going to have a sweet little baby. With it, life would hold a whole new meaning and would become so livable. These thoughts lifted up their spirits. The doctor had shouted at Hawwa last time; that was forgotten. Hawwa reasoned that the doctor was angry because Hameed had just started recovering, and they were already thinking of taking on this huge responsibility upon themselves. Hawwa was satisfied. She was being so thoughtful, having carefully thought of the future, and spoken with the counsellor. Hameed said to her, "It's good that we did not stop using the condom on any day we liked. We are being responsible, and careful ... One should be responsible at all times"
3	Different contraceptive choices for HIV-infected women	This story is about Sulabha and Suryakant. They both are HIV-infected. Sulbha undergoes repeated abortions as Suryakant never uses a condom under the influence of alcohol. He doesn't listen to her. She is doing everything on her own: earning their livelihood, bringing up their children, even going to doctors for getting abortions done. She changes her doctor each time because she is too ashamed to go to the same doctor again for abortion. Whatever she earns is spent on such expenses. This time she goes to an abortion center in some dark alley. She was not even anaesthetized and it was very painful. Seeing her condition, her doctor, who is treating her for her HIV, gets angry (concerned) and asks her to bring her husband to the clinic. She also wants to avoid another such situation in her already dreary life. So somehow she manages to take Suryakant to the clinic. This story is about efforts to deal with a non-supporting partner and what women can do in this situation	Suryakant seemed even more inattentive, lost, and perhaps helpless. Sulabha did not say a word in reply. The doctor resumed after a pause of observation, "You have two children. You must actually think of a permanent solution, a sterilization operation" This too was often talked about. Sulabha knew that the doctor would now say that male sterilization was easier and more advantageous, and would insist on Suryakant getting it done. Her husband, now afraid of the doctor, would look to her for help. Finally, after this drama played out, the operation, whether hers or his, would be postponed yet again. In the meanwhile, her abortions would go on! This was her stark reality. She continued playing the stupid woman in her efforts to find a way out. She asked, "The operation is going to be done, sooner or later, but if it is not done soon, what can I do to avoid this from happening again?" Perhaps by now the doctor realized why she was asking such questions, because he shut his eyes for a second and shook his head. Sulabha shook her head involuntarily. She looked at her husband's blank face, and smiled to herself, amused and amazed by this completely ignorant and disinterested man. Now she looked expectantly at the doctor" You are right," said the doctor, and pulled out a chart which showed various methods of contraception. He placed the chart before them, in fact, just in front of her

(Continued)

Table 1. (Continued)

Story	Main theme	Plot	Excerpts from the book
4	Right to know the HIV status of one's sexual partner and responsibility towards protecting one's sexual partner	This is a story of Sandhya and Sambhaji. Sandhya is an unmarried girl staying with her brother and sister-in-law who doesn't care much for her. She is lonely. She loves Sambhaji who comes to her workplace for electrical fittings. Sambhaji is HIV-infected but he doesn't disclose his status to Sandhya. He is very dominating and irritable but he loves her very much. He is the only ray of hope for Sandhya. Sexual intimacy grows in their relationship. But every time Sambhaji uses condom. However, one day he doesn't use condom and then without explaining her anything, he brings her to a clinic to meet a counsellor. Counsellor discloses Sambhaji's HIV status to her. She gets shocked. This story is about her coming to terms with this situation and dealing with the dilemma of what next?	She stood still when her heart posed this question. Tears were flowing down her face. She sobbed bitterly. Taking out a handkerchief from her bag, she wiped her tears. Images flooded her mind. Different facets of her personality jostled for space. She knew she was not selfish, but she had never thought of herself as entirely selfless either. One needs to be true to oneself, she knew. She lived by her convictions, and thought of herself as a woman of integrity. She had been deceived by this man. She had on her part, though, loved him. She was now faced with the choice of being selfless and forgiving him, or thinking about her own peace of mind and being just to herself. She had to weigh the love claimed by Sambhaji against his behaviour. At last, her mind gave its verdict, clear and loud I strongly feel that I should forgive him because I love him. I would readily marry him irrespective of any HIV or even a life-threatening cancer. He didn't tell me because I would refuse to marry him if I knew, and for the same reason he may accept his folly but that would be equally wrong! If he wants to win my love, shouldn't he first love me? And to love is to accept the rights of each other. To love is to be true and not hurt the person you love. If you truly love someone, you simply cannot lie to them
5	Dealing with widowhood at a younger age. Widowhood does not deny an HIV-infected woman's choices regarding relationships	This is a story of a woman, Jayashree who becomes widow aged less than 20. She was married when studying in high school. It was decided that after marriage she would stay with her parents until completing her education. After one and half months of marriage, she returns to live with her parents to continue her studies. Seven to eight months later, the shocking news of her husband's death comes. At the time of the funeral, she comes to know that he had AIDS. Then, without telling anyone at home, she gets tested for HIV and finds that she too is HIV-infected. Dhananjay, nephew of her aunt's husband, visits her frequently. They like each other. After a few months, his feelings become clearer to Jayashree. Dhananjay wants to marry her. She confronts a dilemma of whether or not to disclose her status to him. She wonders if she has any right to feel attracted towards anyone now. To resolve this dilemma, she speaks to a counsellor on a telephone helpline	A woman who seemed to be an elderly lady came on the line. The lady spoke in a gentle, compassionate voice, "Do you have any questions on your mind?" She listened very patiently to Jayashree's story. Then, she said, "First and foremost, you must take very good care of your health and if needed you must take medicines diligently. There are very good medicines nowadays, and they will help you maintain a good quality of life. You will live well, do not think of death, my dear. There is no problem if you remarry. If you wish to have a child, there would be no great problem. But communication between partners is crucial. Be honest with your friend. You need to tell him. He may go away forever, but you still cannot keep him in the dark. Why should you expect that he will say no and go away? Love can conquer the fear of HIV. And regardless of this matter with your friend, always remember that although you have HIV, you are still a human being! You have the same emotions as any other human being, don't you? That's why I do not see anything wrong in you feeling affection for this friend of yours, and you too should not be angry with yourself for having feelings for him"
6	Having a baby in the context of HIV discordance in a couple	This is a story of a discordant (one partner is HIV positive and other is HIV negative) couple Chittarupa and her husband Sharad. During her surgery for appendicitis, Chittarupa comes to know that she is HIV-infected. As per doctor's advice Sharad also gets himself tested for HIV and finds that test is negative for HIV. Chittarupa becomes very sad after hearing about her HIV but Sharad supports her a lot. He tries in every way to cheer up Chittarupa and make her feel optimistic. Despite the HIV, their married life is happy. After four years, Chittarupa's CD4 count drops and the doctor prescribes her anti-retroviral lifelong treatment to control her HIV infection. Their parents often ask them about having a child, but Sharad always tells them that he and Chittarupa don't yet want one. But when Chittarupa sees Sharad happily engrossed playing with a daughter of their old friend, she realizes that Sharad is fond of children. She talks with her doctor about this issue and asks him how they can have a child without incurring the risk of transmitting HIV infection to Sharad	Like a small child in an elocution competition who forgets her speech, Chittarupa stammered, but managed to speak her mind. "Sharad should not get HIV at any cost", she said. "If we keep using a condom, how will I get pregnant? Or should we just give up the desire to have our own baby?" "You do not need to be so worried," said the doctor. "It is not very difficult. There's no need to have intercourse without a condom. We could use artificial insemination where the sperms will be directly introduced in your uterus. And that will be all that is required for you to conceive" The doctor was a little amused at her unnecessary vexation" If you had asked me, I would have told you the same thing," said Sharad Chittarupa still had one question though, "The baby will not get HIV, right?" "We need to take precautions to prevent HIV transmission to the baby," the doctor told her. "You are already on medication, so there is not much more we need to do in your case" The doctor had very promptly and easily clarified her doubts about the pregnancy, as easily as she would solve geometry problems in school! Chittarupa had always been an optimistic person, and soon realized that she was worrying unnecessarily

Table 1. (Continued)

Story	Main theme	Plot	Excerpts from the book
7	Women are disadvantaged not only because of their HIV status, but also because they are women	<p>This is a story of two women friends, Vaishali and Sunanda who meet each other after a long period. Vaishali is working in a laboratory in the same hospital where Sunanda's husband is admitted for HIV- related illness. A few days back, Vaishali also comes to know about her own HIV infection. In the story, Sunanda and Vaishali's husband are HIV negative. Vaishali is ill-treated by her husband and now after knowing about her HIV, the situation is even worst. He doesn't care about her anymore. He doesn't touch her due to fear of transmission</p> <p>Sunanda is also in the same situation though she is not HIV-infected. Her husband harasses her a lot. Initially he didn't disclose his status to Sunanda. Even while getting her tested for HIV, he doesn't tell her for what she is being tested. After a lot of insistence from Sunanda, he takes her to his doctor and then the doctor disclosed his HIV status to her</p>	<p>Vaishali kept talking. "He has in fact decided to desert me and my son. He will probably leave town. The other day I overheard him on the phone. I was shocked to hear him speaking to someone about me having HIV and he being negative. He was telling someone on the phone that I had cheated him. He was speaking very softly and lovingly. I asked him who was on the line, but he said it was none of my business. Till that day, he had not dared to talk to me like that"</p> <p>Sunanda said, "It is true that HIV has made you bear all this, but in my case, I cannot say a word to my husband. On the contrary, I have to hear him say that I should take on the disease if I love him!"</p> <p>For a while no one said anything. Then, Sunanda rose and arranged the pleats of her saree. "Let's go back. My husband is perhaps already crying hoarse that I have run away"</p> <p>"Okay. I will come with you to meet him"</p> <p>"Oh no, don't"</p> <p>"Come on, let's have some fun"</p> <p>Both friends walked hand in hand</p>

with 55–65% induced abortion (Abdala, Kershaw, Krasnoselskikh, & Kozlov, 2011; Decker et al., 2013; Liang, Meyers, Zeng, & Gui, 2013; Loutfy et al., 2012; Schwartz et al., 2012).

In order to take the findings of the LCRC study to the study participants and to address the issue of high rates of unwanted pregnancies and induced abortions, seven written narratives were crafted and compiled in the form of a book. While the findings of the LCRC study were used to derive the central themes of the stories, the narratives went beyond the findings and dealt with several other issues which are inherently associated with being HIV-infected, including disclosure of HIV status within a couple, betrayal in a relationship, etc. Our previous research and other studies clearly suggest that these issues are important part of the illness narratives of HIV-infected people (Darak & Kulkarni, 2002; Laws, 2016). The theme of each story, the plot and the excerpt from the story is given in the Table 1. The unifying thread across all these stories was that they gave importance to HIV-infected women's right to decide about their sexual and reproductive lives, while considering the socio-cultural complexities and the difficulties in realizing their rights. Narrative format of communication (stories) was deemed most appropriate to address these complexities while technical information on different issues (contraceptive methods, fertility options for HIV discordant couples, etc.) was given at the end of each story. This technical information provided at the end of each story in the form of boxes and flow-charts was believed to make the text complete and provide women with a ready reference about different contraceptive and fertility choices they have.

This study assessed the usefulness of written narrative health material about sexual and reproductive health given in the form of a book containing seven stories to HIV-infected women from Western Maharashtra, India who had participated in the LCRC study. The book was prepared in Marathi, which is the official language of Maharashtra state and is spoken by the majority of the people in the state and by the participants of LCRC study. The book was authored by a team of three people; the first author who wrote these stories is a health professional working in the field of HIV/AIDS for more than 25 years and has created several health communication materials in different formats such as books, booklets, narratives, flipcharts, films etc. The second author, who mainly prepared the illustrations, is trained in medicine and has extensively worked in the field of health communication, training of village health workers, grass root activists and different community groups on effective health communication. The last author is a researcher and principal investigator of the LCRC study who, on the basis of the findings of the LCRC study, provided the issues on which the narratives should be written. All three authors worked together towards the creation of these

narratives. The book has 50 pages. Each story had two illustrations, which were intended to reflect the ethos of the story rather than being informative. The text on each page was given in two columns with large font size to make the reading comfortable, as the majority of the intended readership had moderate reading skills.

The usefulness of narrative communication was assessed using the extended transportation-imagery model presented by van Laer, de Ruyter, Visconti, & Wetzels (2014), which provides an evidence-based list of antecedents of storytellers and story-receivers. For example, storytellers must have *Identifiable characters* (story receivers understand the experience of the character by knowing and feeling the world in the same way), *Imaginable plot* (the story plot and the temporal sequence of events that happen to the character create a mental imagery in the mind of the story receiver) and *Verisimilitude* (stories that are believed to be grounded in real characters and events that actually happened). The antecedents for story-receivers are *Familiarity* (degree to which the story-receiver has prior knowledge or personal experience with the story topic), *Attention* (the story-receiver's degree of focused concentration), *Transportability* (the story-receiver's propensity to be transported, which functions independently of any particular story and is related to empathic abilities). Some other demographic antecedents such as *age*, *gender* and *education* have also been identified as factors contributing to the process of transportation.

2. Methods

2.1. Setting

This study was conducted at a specialized HIV clinic in Maharashtra, India run by a non-governmental (NGO), non-commercial organization currently providing care to approximately 3,000 People Living with HIV (PLHIV).

2.2. Participants

The current study was conducted among HIV-infected women attending the study clinic, who had participated in the LCRC study and who were given the book to read. Women, who were not willing to or unable to provide written consent, were not willing to participate for any reason and who reported that they cannot read, were excluded from the study. Participants for qualitative study were recruited from the group of women who were enrolled in the LCRC study and who had received the book at least a month before the interview for this study. Women were purposively selected for the qualitative study to get maximum variations in the experiences. All women were contacted at the time of their routine visit to the clinic.

Total 258 women who visited the clinic during May 2015 to November 2015 were assessed for eligibility for participation. Out of 237 women who were eligible, 174 women were enrolled in the study after written informed consent.

Of the 174 women who had received the book and were interviewed in the study, 83 (47.7%) women had read all its stories, 60 (34.5%) had read a few narratives, 15 (8.6%) had glanced through the book and 16 (9.2%) had not read it at all.

2.3. Data collection and analysis

This exploratory study applied a mixed methods approach, using both qualitative as well as quantitative research techniques. The usefulness of the book was assessed through qualitative in-depth interviews conducted by a trained interviewer. In research with HIV-infected participants, fear of disclosure of their HIV status to other participants is always their concern. To protect personal identity, establish good rapport and allow women to freely express their opinions and perceptions, in-depth interview as a tool was considered appropriate. An in-depth interview guide was prepared to help the interviewer probe issues stemming from reading the book, barriers and facilitators for

reading, feelings after reading the narratives and their perceived usefulness (i.e. the extent to which the stories were helpful and in what way), and impressions about specific components of the book (language, pictures, style, size). Interviews were audio-recorded after obtaining written consent from the women and were later transcribed verbatim.

Quantitative interviews were conducted by a trained interviewer using a structured questionnaire to assess the knowledge and attitude among women regarding different Sexual and Reproductive Health (SRH) issues. Statements were made by the interviewer and women were asked if they agreed with the statement.

Data were analyzed in R 3.2.1 package for both qualitative and quantitative data. R is open source data analysis software. Qualitative data collected through in-depth interviews were transcribed. The data were then imported into the “RQDA” software (R-Qualitative Data Analysis) (Huang, 2014). RQDA is a package within R software that is designed for conducting qualitative data analysis. The coding was done by assigning a combination of deductive as well as inductive codes. Using the codes and the code categories, quotations were retrieved to analyze the underlining concepts and constructs. Selected quotations used in this article were translated into English by the first author. Descriptive comparison using chi-square test was done to assess the difference in knowledge and attitude among women who had read the book and those who had not.

2.4. Ethical Considerations

The study protocol, consent forms, and data collection tools were reviewed and approved by an Institutional Ethics Committee for Research (IECR) of the NGO. The ethics committee is registered with the government agency (registration number: ECR/146/Indt/MH/2014). Informed written consents were obtained from the women. The information collected during the interviews was kept confidential among the study team. Counselling support was available to women when required.

3. Results

The minimum age was 25 years and the maximum was 50 years. The median age was 38.5 years. The majority of women (78.2%) who participated in this study had above primary level education (>7 years of education). Women were almost equally distributed in the socioeconomic categories with upper class, middle class and lower class representing 36.5, 30.0 and 33.5% respectively. Most were residing in urban areas (68.4%). Almost 50% of the women were not currently married.

In-depth interviews were conducted among 16 HIV-infected women. The profile of the women who participated in the qualitative study is given in Table 2.

4. Usefulness of narratives (qualitative results)

In the qualitative interviews women reported different aspects on which they found the book useful. Although the stories in the book were centered around sexual and reproductive health issues, their perceived usefulness was not limited to SRH issues alone. The stories were perceived to be empowering as well as informative. The usefulness of these narratives is summarized in Figure 1.

4.1. Improved self-efficacy

After reading stories from this book I wrote my own story. I had written an article about my feelings about this book after reading it. I will share it with you when I come next time to the clinic. (38 years, 10 years of education, rural, married woman who read the complete book)

Table 2. Profile of HIV-infected women who provided qualitative in-depth interviews

Project ID	Age	Education	Marital Status	Contraception	Occupation	Place	Read book
IDI_001	45	15	Married	Menopause	Working	Urban	Didn't read the book
IDI_002	30	9	Married	Temporary	Not working	Rural	Read 1-2 stories
IDI_003	37	7	Widow	NA ^d	Working	Rural	Read whole book ^a
IDI_004	37	12	Widow	NA	Not Working	Rural	Read whole book
IDI_005	41	9	Married	Permanent	Not Working	Urban	Read 1-2 stories
IDI_006	23	10	Married	Temporary	Not Working	Rural	Read few stories
IDI_007	30	10	Married	Permanent	Working	Urban	Read whole book
IDI_008	35	9	Married	Permanent	Not working	Urban	Read few stories
IDI_009	40	15	Married	Permanent	Not working	Urban	Read whole book
IDI_010	40	17	Widow	NA	Working	Urban	Read few stories
IDI_011	36	17	Married	Temporary	Working	Urban	Read few stories
IDI_012	33	7	Remarried	Temporary	Working	Urban	Read few stories
IDI_013	32	9	Widow	NA	Working	Rural	Read few stories
IDI_014	32	12	Married	Temporary	Working	Rural	Read whole book ^c
IDI_015	37	18 ^b	Married	Temporary	Working	Urban	Read whole book ^c
IDI_016	28	10	Married	Permanent	Not working	Urban	Read 2-3 stories ^e

^aRead whole book 2-3 times.

^bParticipant has a ME and is currently pursuing a PhD.

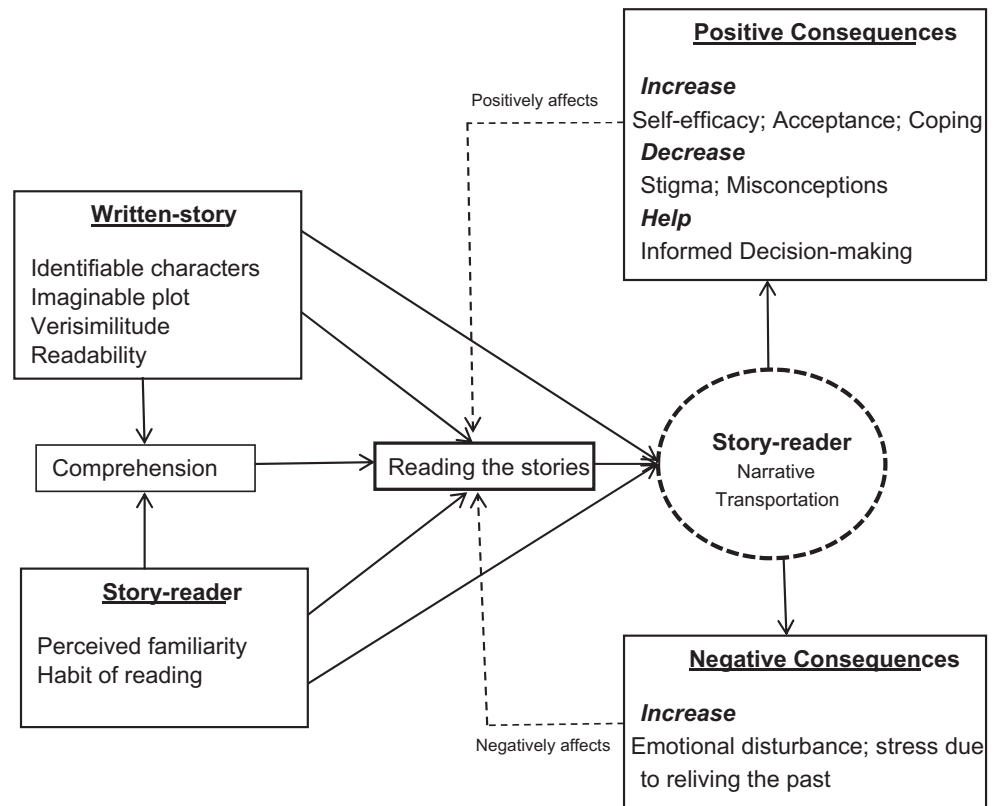
^cRead book after being introduced to the current study.

^dNot applicable for women who were not sexually active.

The women in this study often expressed the feeling that after reading the narratives “you get the strength to deal with the disease” or “your confidence increases to confront the challenges”. This shows that the book has some impact at the level of these women’s self-efficacy beliefs.

Because of the narrative format of communication, women seemed to identify themselves with the situation and characters in the stories, deriving inspiration from them.

Figure 1. Usefulness of narratives among HIV-infected women.



You know what I think, after reading the experiences of the women in these stories, by comparing what happened in their life (and) what happened in my life ... how (positively) they are living with HIV, how strongly and courageously they face all the problems, gives me inspiration to live like them. It gives me confidence that I can also do anything. (32 years old, 9 years of education, rural, widow, read most of the stories)

4.2. Increased acceptance of partner

The role of the partner is emphasized in all the stories. There is a range of support that women in these stories have received from their partners. The point that ‘it is not important to delve on how the husband got the infection, but it is important to jointly see how they both can lead a good life’ is also stressed in most of the stories. This stance taken in these stories was to encourage women to objectively assess their relationship with husbands and try to find some positive solutions for themselves. The importance of open discussion about sexuality between the couple is also highlighted in the stories.

It appeared that women could relate to this stance and mentioned that after reading the stories they were able to forgive their husbands for giving them this infection and making their life miserable. For many women this was the most significant impact of the book as previously they could not take these thoughts off their mind.

After reading this book I realized that my husband is a very good person. I realized that having trust in a relationship is a very important thing and everything depends on this trust. Before reading this book I used to think “how miserable my life is now, how beautiful it was before HIV ... Who is responsible for it?” Unknowingly I used to blame (tochayache) my husband for that. But after reading this book I removed such thoughts from my mind. (37 years, 18 years of education and pursuing her PhD, urban, married woman who read the complete book)

Women who were currently not in any relationships also felt that the book could help couples accept each other.

This book will provide people with the courage to accept this disease. My husband was HIV negative. He (divorced me and) got married to another woman. But I think after reading the stories from this book, partners will be able to accept each other along with their HIV status. (44 years, 12 years of education, urban, divorced woman who read the complete book)

4.3. Improved coping: Knowing I am not alone

Reading the stories of many women in a similar situation made them realize that they were not alone and that there were many women who had confronted similar challenges, positively dealing with the circumstances. This appeared to constitute a relief and helped them cope better.

I think this book is very good and perfect. At least I found it very interesting to read. I used to think only about myself, that why this (HIV) happened to me. But after reading this book I came to know that there are many such people who are suffering from this disease, and I am not alone and probably I am in much better position. (30 years, 10 years of education, urban, married woman who read the complete book)

5. Reduced misconceptions

The women included in the study were in different stages of their reproductive lives. Women who had completed their desired family size said that they did not look at the information provided in the book (at the end of each story) but were more interested in reading the experiences of other women. Some women who read the information mentioned that it could be very useful.

This book will help to clear the misunderstandings people have—for example, widows infected with HIV should not marry or HIV-infected woman should not have a pregnancy, etc. These stories can help to get information about different contraceptives, how to use them—as people only know about condoms and don't know about other contraceptive methods. The information that they can have a child in spite of having HIV is very important for those HIV-infected couples who want to have one. (35 years, 15 years of education, urban, married woman who read the complete book)

6. Firmness in decision

This book was prepared from a rights-based perspective and the stories covered the spectrum of contraceptive and fertility options that the women have. The overall purpose was that of enabling women to understand and exercise their rights and responsibilities regarding sexual and reproductive health issues. The narratives seemed to have helped women make more informed decisions. For example, a woman in this study mentioned that this book helped her to firmly decide not to have a baby.

This book helped me to be firm in my decision. Even before reading the narratives, I didn't want to have a baby. But sometimes I used to think that I should have my own baby. But after reading stories from this book about couples who wanted to have a baby and their worries regarding their children, my husband and I made a firm decision of not having our own child. (41 years, 14 years of education, urban, married woman who read the complete book)

7. Other effects

7.1. Narrative communication increased the ease of reading and improved comprehension

Women said that because the information is provided in the form of stories, it increased the interest in reading and also improved understanding.

For the first time I read such a big book. When I started reading it, I got more involved. I was curious to know what the next story is about, what are the experiences of other women. Because it is in the form of a story, you don't feel bored while reading, in fact that makes it easy to understand. (32 years, 12 years of education, rural woman who is married and read the complete book)

Women felt that some people might not be comfortable talking of sexual and reproductive issues in person and, in such situation, having these things written in the form of stories could be beneficial.

It is easier to understand the information when it is provided through stories. If you just talk to people about it then I think no one is willing to listen. If you directly talk or ask them about these issues then people also feel shy (ashamed of) talking about it. But if you provide this information in the form of stories then people will read it. (40 years, 15 years of education, urban, widowed, who read a few stories in the book)

8. Negative aspect of narrative communication

The strength of narrative communication is its ability to connect with the reader. However, this could also be its limitation, especially in the context of HIV where narrating difficult life situations is an inherent part of the story. The stories are perceived as 'too emotional' and for some women it acted as a barrier for reading the stories.

I read few stories ... felt positive but also it was emotionally disturbing (traas zala). I had to make conscious efforts to step aside from this feeling. By disturbing I mean somewhere, from inside, it was hurting to know that people, including myself, have to face this trouble. After all, (... though there is support and medicines) at the end, the fact that there is no cure still remains ... Somewhere, in the back of your mind, this thought keeps on knocking every now and then. Even if you have coped with the situation, while reading about it (HIV) you are constantly reminded of this fact. (36 years, post-graduate, urban, married woman who read only a few stories in the book)

I knew that many women had participated in the (LCRC) study and their experiences were written in this book. I didn't dare to read it ... I felt scared ... when I came to the clinic I could make out from the faces of the other patients how difficult it must be for them to deal with it. When I myself face so much hardship ... the financial difficulties for taking the medicines ... I can only imagine what others must be going through, so I thought it is best not to read about it. (45 years, 15 years of education, urban, married woman who had not read the book at all)

9. Knowledge and attitude (quantitative results)

Most women had good knowledge about condom use and also about issues related to Antiretroviral Treatment (ART). Almost all women knew that condoms are the only device that can prevent sexually transmitted infections as well as pregnancy (93.1%), and condom use is essential even if one of the partners is using other contraceptives (93.7%). Most women also knew that ART, when taken regularly, can provide long healthy life (98.3%) and it can significantly reduce mother to child transmission (83.9%). These aspects (condom use and ART) are also regularly emphasized during counseling sessions provided at the clinic. However, the knowledge regarding other contraceptive methods was relatively lower compared to that of condom use. Sixty-eight percent of the women knew about emergency contraceptive pills that can be taken after unprotected sexual contact to avoid pregnancy; and approximately only half of the women knew about medical abortion (50.6%) and that the medical termination of pregnancy can be done (legally in India) until 20 weeks of pregnancy (53.4%). Very few women knew that oral contraceptive pills are not advised in combination

with some specific antiretroviral treatment (15.5%). While most women said that the decision to use contraception should be taken by the man and the woman together (97.7%), many of them also said that this decision should only be taken by a doctor (59.2%), indicating the dominant role of health care providers in contraceptive decision-making among HIV-infected couples. Most women knew that unsafe abortion can lead to severe health problems, including death of the woman (89.6%).

Descriptive comparison of knowledge and attitude-related questions among women who had read the book compared to those who did not is shown in Table 3. There seems to be moderate improvement in knowledge related to some aspects that were emphasized in the book, such as, for example, male sterilization (vasectomy) as consisting in a simpler procedure than female sterilization (tubectomy) (58.7 vs. 41.9%), the perceived need to use other contraceptives even when using condoms (28.0 vs. 12.9%), and health risks of unsafe abortion (91.6 vs. 80.6%). However, a statistically significant increase was observed in a change in attitude as regards avoidance of pregnancy as not only falling under women’s responsibility (48.3 vs. 25.8%; $p = 0.037$).

Table 3. Descriptive comparison of knowledge among women who read the book compared to those who did not read it

Sl. No.	Question	Read	Not read	p-value
		n = 143 (%)	n = 31 (%)	
<i>Knowledge related questions</i>				
1	If a couple doesn't want a child in the future then a man or a woman can choose a permanent contraceptive method	130 (90.9)	25 (80.6)	0.113
2	Vasectomy is simpler than tubectomy	84 (58.7)	13 (41.9)	0.131
3	In our country, medical termination of pregnancy can be done up to the 20th week of pregnancy	77 (53.8)	16 (51.6)	0.978
4	There are medicines to terminate pregnancy up to 9 weeks	72 (50.3)	16 (51.6)	1.000
5	There is a pill that can be taken after unprotected sex to avoid pregnancy	100 (69.9)	19 (61.3)	0.469
6	Unsafe abortion can lead to severe health problems in women, including death	131 (91.6)	25 (80.6)	0.098
7	When women are taking some specific ARV medicine, oral contraceptive pills are not advised	22 (15.4)	5 (16.1)	1.000
8	HIV-infected women should not use Cu-T	110 (76.9) ^a	22 (71.0)	0.638
9	If one of the partners is HIV-infected and the other is not, then the couple cannot have their own child without transmitting HIV to the other partner	67 (47.2) ^a	14 (45.2)	0.995
10	ART minimizes the possibility of mother to child transmission of HIV to a great extent	121 (84.6)	25 (80.6)	0.593
<i>Attitude-related questions</i>				
11	For HIV-infected people, the decision about appropriate contraceptive method can only be taken by the doctor	59 (41.3) ^a	12(38.7) ^a	0.952
12	As HIV-infected couples always need to use a condom, there being no need for them to use other contraceptive methods	40 (28.0) ^a	4 (12.9)	0.128
13	It is alright for anHIV-infected widow to enter into a physical relationship, at her choice	44 (30.8)	8 (25.8)	0.741
14	It is women's responsibility to avoid getting pregnant	69 (48.3) ^a	8 (25.8)	0.037

^aNumbers shown are for the option “disagree”.

10. Discussion

The rights-based written narratives about sexual and reproductive health issues were perceived to be useful by HIV-infected women. Though the narratives are centered on SRH issues, their usefulness seems to go beyond SRH. The narratives positively affected the self-efficacy beliefs of women, improved acceptance of the partner, helped them cope with the disease, helped in more informed decision-making and decreased misconceptions. On the negative side, the narratives were perceived as 'too emotional', discouraging some women to engage with the text. The knowledge and attitude about SRH does not seem to be statistically significantly different among women who read the book compared to those who did not read it.

Self-efficacy is an individual belief in one's capabilities to achieve something in a given circumstance. The concept, first proposed by Bandura (1977), is still considered an important construct while assessing the way people deal with different life situations. Bandura mentions different sources which can contribute (positively or negatively) towards people's belief in their self-efficacy. One of the sources mentioned is "Vicarious Experiences", which means that people can develop high or low self-efficacy by observing other people perform. If they see a person in a similar situation succeed, then that can increase their self-efficacy. In line with Bandura's explanation of "Vicarious Experiences", reading about how other women in the stories acted in a specific situation seems to have increased the self-efficacy beliefs of women in the study.

A positive HIV test result is not just a revelation that one is having a serious incurable health condition but also raises several questions that can significantly affect the social and psychological health of the individual. It can be a severely disruptive event affecting almost every aspect of life such as family, children and career; in other words, it can result in biographical disruption (Alexias, Savvakis, & Stratopoulou, 2016; Bury, 1982). In the Indian context, where approximately 90% of HIV-infected women are apparently monogamous and acquire HIV infection from their husbands (Gangakhedkar et al., 1997), for these women the most important stressors could be related to loss of trust and betrayal in the conjugal relationship. The findings of this research highlight that the women feel the need to talk about these issues, and a well-written narrative addressing these complexities would be beneficial in helping women cope with the disruptive impact of the disease.

A recent systematic review of interventions targeting sexual and reproductive health and rights outcomes of young people living with HIV from Sub-Saharan Africa showed limited number of evaluated interventions to strengthen SRH needs of HIV-infected people (Pretorius, Gibbs, Crankshaw, & Willan, 2015). The study also found that most of the interventions are based on cognitive behavior therapy and provided in the form of counseling and psychosocial support. Though counseling can greatly help HIV-infected individuals to adopt healthy behaviors and address many of their personal and interpersonal issues, it appears that there still remains a space for communication on issues (mostly unrelated to health) that people feel are important but inappropriate to discuss during counseling. Also, through one to one counseling, one might not learn about the experiences of others and how others have coped with similar challenges. Therefore, a book of narratives could be used to supplement the counseling process. Counsellors could motivate people to read the book, discussing their feelings and issues in the next counseling session. The way people react to these narratives might also provide better insights to the counsellor regarding the way they are coping with their disease and the specific stressors; in other words, such narratives would help the counsellor to understand peoples' own illness narratives and correct harmful narratives, if any. This therapeutic use of narratives will also enable counsellors to acquire narrative competence, which is the ability to understand and act on the stories and plight of others (Charon, 2001).

This exploratory study did not find statistically significant difference in the knowledge and attitude regarding SRH among women who read the book compared to those who did not, except that more women familiar with the narratives believed that avoiding pregnancy is not only women's, but also men's, responsibility. However, inclusion of a sample of relatively older women who had completed their desired family size (and hence not interested in the information) as well as a descriptive study design are the limitations for assessing the role of the book in improving knowledge.

This book was provided to ever-married women who had participated in the previous LCRC study, irrespective of their current marital status and need for contraceptives. Hence along with currently married women, the sample included women who had opted for a permanent method of contraception and women who currently did not have partner (widow or divorced). There was no perceived need for contraception in this group of women and hence the information related to contraception was not much useful to them. The findings of this exploratory study suggest that the narrative format motivates women towards acquiring a greater level of health literacy. Further studies among women who are in need of contraception and with a study design geared towards understanding the effectiveness of the book (for example, pre and post design where the baseline [pre-intervention] level of knowledge and practices are documented then the intervention is provided and effectiveness of that intervention is assessed after a reasonable period [post-intervention]) should be subsequently carried out.

11. Conclusion

With the rapid expansion of antiretroviral treatment (ART) in low and middle income countries, the communication strategies used in many programs providing care and support to HIV-infected people are by and large focused more on the medical aspect of the disease, such as adherence to antiretroviral treatment (ART), consistent use of condom etc., neglecting other important impacts of the illness on the lives of People Living with HIV (PLHIV). Health communication is often restricted for bringing the desired change in utilization of health services and adhering to prescribed treatment. This research shows that there is need for health communication that goes beyond communication on behavior change and supports people in coping with the disease.

One of the important roles of health communication material could also be that of making the choices of people more informed, which may or may not lead to change in their behavior. Specifically, as regards sexual and reproductive health, written narratives might have the benefit in conveying some intricate issues that women are not comfortable in discussing with the counsellor in person. Such material can also be used as a supplement to counseling to make the choice of women more informed. However, the short term and long term impact of such interventions and their generalizability needs further research.

The effectiveness of the written material depends a lot on how it is written (structure, language). Based on previous research on readability and comprehension (mostly of English language), there are several guidelines regarding the preparation of generally easy to read health material (for example *Simply Put: Guidelines for preparing easy-to-understand health material*, organized by the Center for Disease Control and Prevention (CDC), USA). However, guidelines specific to the Indian context regarding preparation of written narratives are frequently lacking. Although there have been some recent efforts in this direction (for example, a recent paper by Kreuter et al., 2014 that outlines some aspects of using narrative in public health practices), more efforts are needed to guide people to create effective narratives for addressing different public health issues, especially the ones that involve biographic disruption.

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